


# How Do Patients With Axial Spondyloarthritis Experience High-Intensity Exercise?

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**Objective.** In a few studies, high-intensity exercise has displayed beneficial effects on cardiovascular health among patients with rheumatic diseases, yet the high-intensity exercise mode is still not fully accepted among health care professionals. The aim of this study was to investigate experiences of high-intensity exercise among patients with axial spondyloarthritis.

**Methods.** Fourteen respondents who had participated in a high-intensity exercise program for 12 weeks were included in this qualitative study with individual semistructured, in-depth interviews. The respondents' median age was 53, ranging from 23 to 63 years old, and both men and women of different ethnicities were represented. Interviews were analyzed by qualitative content analysis, including both manifest content and interpretations of underlying latent meaning.

**Results.** The analysis resulted in five categories describing the respondents' experiences with high-intensity exercise: 1) high-intensity exercise as a challenge for both body and mind, 2) increased faith in one's own body, 3) changed attitude toward exercise, 4) taking charge of one's own health by challenging the disease, and 5) exercise in a social context.

**Conclusion.** Supervised high-intensity interval exercise was perceived as challenging for both body and mind but was also described as a positive experience, with rapid bodily effects that strengthened respondents' faith in their own bodies. The new experience seemed to have changed the respondents' attitude and motivation for exercise and made them start taking charge of their health by challenging the disease. Exercise in a social context, under professional leadership, enhanced exercise self-efficacy and helped the respondents to adhere to the exercise program.

## INTRODUCTION

Axial spondyloarthritis (axSpA) is a chronic inflammatory rheumatic disease, mainly affecting the spine and/or sacroiliac joints, and encompasses patients with both radiographic (ankylosis spondyloarthritis) and nonradiographic sacroiliitis (1,2). Patients with axSpA report or display chronic back pain (often with pronounced stiffness), physical limitations (3), fatigue (4), and decreased health-related quality of life (3). In addition, patients with axSpA have an increased risk of cardiovascular diseases, in which inflammation and traditional risk factors contribute to the elevated risk (5,6).

Combined pharmacological and nonpharmacological treatment modalities are recommended for optimal management of axSpA (7). Physiotherapy and exercise are considered through-

out the disease course (8). Traditionally, flexibility exercises have been emphasized to improve and maintain mobility (9), whereas aerobic exercises have not. Aerobic exercise has been shown to be effective in improving physical function, stiffness (10–12), and cardiovascular health (13,14) in patients with axSpA. However, only a minority of the patients engage in aerobic exercise at a high enough intensity to improve aerobic capacity (15–17). An explanation might be that aerobic exercise, especially at high intensity, has been viewed with skepticism by rheumatologists and physiotherapists because of the increased risk of flare-ups of the inflammatory arthritis disease (18,19).

Although high-intensity exercise is a rather new modality within the rheumatology field, there is growing evidence for its benefits (14,20). A recent randomized controlled study from our research group showed that high-intensity exercise improves

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### SIGNIFICANCE & INNOVATIONS

- High-intensity exercise was experienced as a physical and mental challenge but also as a manageable exercise mode to improve physical fitness and general health in patients with axial spondyloarthritis.
- Patients attributed their enhanced sense of efficacy to engage in high-intensity exercise to coaching from a knowledgeable physiotherapist.
- Group exercise with peers gave patients a social context that helped them adhere to the challenging exercise program.

cardiovascular health without exacerbating disease activity in patients with axSpA (20).

Qualitative studies report that patients with rheumatic diseases experience various degrees of benefits from exercise at a lower intensity (21-23). However, studies investigating patients' experiences with high-intensity exercise are lacking. One cross-sectional study of axSpA identified patients' motivation as being both the top barrier and top facilitator of high-intensity exercise (24). Because both personal interest in and the enjoyment of exercise appears to be important for patients' participation in an exercise program (22), an exploration of the patients' perspectives on high-intensity exercise was assumed to provide useful, in-depth understanding of patients' acceptance of this mode of exercise.

The aim was to investigate patients' experiences with high-intensity exercise. The resulting insight was expected to be valuable for health care professionals in guiding patients to exercise at a high-intensity level.

## PATIENTS AND METHODS

**Design.** A qualitative study with individual, semistructured, in-depth interviews was conducted to explore the respondents' perspectives. The data were subjected to qualitative content analysis with an inductive approach to illuminate the respondents' experiences with exercise at a high-intensity level (25,26). In such an approach, empirical data are analyzed in categories to develop general knowledge of the research questions posed.

**Respondents and recruitment.** The respondents were recruited from the outpatient rheumatology unit of the Sahlgrenska University Hospital in West Sweden. Eligible respondents were patients with axSpA who had previously participated in a 12-week high-intensity interval exercise program (20) and were able to speak and understand Swedish. The respondents were contacted by mail 3 months after completing the program with an invitation and description of the study; 14 of 16 eligible patients agreed to participate in the interviews. Each respondent signed an informed consent approved by the Regional Ethical Review Board in Gothenburg.

**Study sample.** A total of five women and nine men formed the study sample. The median age of the respondents was 53 years, and all respondents but one fulfilled Assessment of Spondyloarthritis International Society (ASAS) criteria for radiographic axSpA (27,28). Both native Swedes and immigrants were represented, and all respondents followed more than 80% of the prescribed exercise protocol (Table 1). Before entering the exercise program, none of the respondents performed any regular aerobic or strength exercise in excess of 1 h/wk, implying low to moderate fitness level. The adherence of the exercise protocol for the two patients who did not participate in the interviews was 75% (27 of 36 sessions) and 97% (34 of 36 sessions), respectively.

**Exercise program.** The exercise program included 40 minutes of high-intensity interval exercise on ergometric bicycles in bouts of 4 minutes at more than 90%-95% of maximal heart rate (HR<sub>max</sub>), followed by 3 minutes of active rest at more than 70% of HR<sub>max</sub>, repeated four times. HR<sub>max</sub> was determined at baseline and controlled by a pulse watch. The strength exercise was individually adapted and focused on large muscle groups (eight to ten repetitions and two to three sets over 20 minutes). The exercise sessions took place in a supervised hospital setting twice a week. Participants also performed one weekly aerobic exercise session of their own choosing lasting at least 40 minutes at more than 70% of HR<sub>max</sub> (controlled by a pulse watch). A physiotherapist with knowledge of both rheumatology and the exercise program supervised the exercise sessions in the hospital (20).

**Data collection.** All interviews were conducted at the Department of Physiotherapy at Sahlgrenska University Hospital in Gothenburg, Sweden, between September 2016 and June 2017. The interviewer (AB), who was not active in the exercise program, is a female physiotherapist with a long experience with

**Table 1.** Respondents characteristics (N = 14)

|   | Results           |
|---|-------------------|
| Age, median (minimum; maximum), y           | 53 (24; 63)       |
| Social status, n (%)                        |                   |
| Living with an adult                        | 14 (100)          |
| Ethnicity (Swedish born)                    | 11 (78.6)         |
| Education, n (%)                            |                   |
| 12 y  | 9 (64.3)          |
| University                                  | 5 (35.7)          |
| Exercise adherence, n (%)                   |                   |
| >80% exercise protocol                      | 14 (100)          |
| Disease activity, median (minimum; maximum) |                   |
| BASDAI                                      | 3.0 (1.05; 6.60)  |
| ASDAS                                       | 1.53 (0.84; 2.14) |
| Pharmacological, n (%)                      |                   |
| NSAID                                       | 3 (21.4)          |
| TNF inhibitor                               | 7 (50.0)          |

Abbreviation: ASDAS, Ankylosing Spondylitis Disease Activity Score; BASDAI, Bath Ankylosing Spondylitis Disease Index; NSAID, nonsteroidal anti-inflammatory drug; TNF, tumor necrosis factor.

**Box 1 Interview guide**

Could you please tell me what it was like to participate in this exercise study?

Could you please tell me how you experienced exercise at such a high intensity?

What might have facilitated exercise at this level?

What might have prevented exercise at this level?

rheumatology and rehabilitation of patients with different rheumatic diseases. The interviews followed an interview guide with open-ended questions covering respondents' experiences with the exercise program, high-intensity exercise, and barriers and facilitators for exercise at a high-intensity level (Box 1). One pilot interview was conducted to evaluate the interview guide. No revisions were made for the interview guide, and the pilot interview was included in the analysis. The interviews lasted from 40 to 90 minutes and were audiotaped and transcribed verbatim.

**Data analysis.** The transcribed interviews were analyzed using qualitative content analysis, which included description of the manifest's concrete content as well as deeper interpretations of its underlying latent meaning (26). All interviews were first read through several times to obtain a sense of the whole. The analysis was then performed in the steps described by Graneheim and Lundman (26): The text was developed into meaning units, condensed, and thereafter abstracted. The abstracted meaning units were formed into subcategories and categories by the first author (AB) and the last author (KM), a senior researcher with expert knowledge in qualitative research methods. By discussing back and forth between the whole and its parts, consensus was met. For further validation of the results, a panel of researchers with knowledge of qualitative methods was invited to discuss the results. All authors are physiotherapists with a long experience with rheumatology and are researchers within the field.

**RESULTS**

The analysis resulted in 5 main categories with 14 subcategories: 1) high-intensity exercise as a challenge for both body and mind, 2) increased faith in one's own body, 3) changed attitude toward exercise, 4) taking charge of one's own health by challenging the disease, and 5) exercise in a social context. The subcategories were supported by quotes. The number within parentheses after each quote in Table 2 refers to the specific respondent.

**1. High-intensity exercise as a challenge for body and mind.** *Mental and physical challenges.* The exercise program was described as being both physically and mentally challenging, testing the respondents' limits on physical exhaustion and increased pain. Although they felt proud of managing

exercise at such high intensity, they also experienced some resistance to the exercise because of the sensation of pushing their bodies to near exhaustion.

*Priorities and commitment.* The exercise program was described as being time and energy consuming and therefore required planning into daily life. Social activities were also put on hold to prioritize the program. However, this was not perceived as a major problem by the respondents because they knew they were committed to the program for only a limited period of time.

*Initial ambivalence.* Before entering the exercise program, the respondents viewed high-intensity exercise as something reserved for healthy people and athletes. They feared that having previously been restricted to lower-intensity activities by other health care professionals, their bodies might not be able to manage high-intensity exercise. However, through experiencing such exercise, the respondents described being able to push themselves to the edge of their capacity for the first time, gaining positive effects without risking their health.

**2. Increased faith in one's own body.** *Positive physiological effects.* Respondents explained that they experienced positive physiological results from their exercise in terms of improved physical fitness, energy, and general health. This was perceived as an affirmation to their achievement and inspired them to continue with the program. These effects appeared to be important for the respondents because they described having invested so much time, commitment, and mental energy to the program.

*Elevated mood.* The exercise program appeared to have had a positive effect on the respondents' mental state because they described an elevated mood after exercising. A positive feeling of embodiment and new insight into what their bodies were capable of seem to have increased their faith in their own bodies.

**3. Changed attitude toward exercise.** *Self-created exercise routines.* Through individual consultations with the physiotherapist about possible obstacles to exercise and possible alternatives to introduced exercise, the respondents learned to create routines and personal arrangements for their exercise. Also, the structure of the exercise program, including supervision, a fixed time, a physical location, and an exercise group, was described as facilitating participation.

*Acceptance and management of symptom fluctuations.* The respondents described how they learned to distinguish between pain related to muscle soreness and pain or other symptoms related to the disease. In parallel, they learned to adjust their exercise level to their daily symptoms. During this process, the respondents appeared to accept fluctuations in their pain and energy levels that affected their ability to exercise.

*Changed motivation.* A wish for improved health and fitness was described as an important initial motivator for committing to the program. Also, personal drive was described as a prerequisite for managing the exercise program. The

**Table 2.** The five main categories identified with their subcategories and quotations to illustrate the categories

| Categories  | Subcategory                                       | Quotations <sup>a</sup>  |
|---|---|--|
| 1. High-intensity exercise as a challenge for body and mind     | Mental and physical challenges                    | "It was actually a rather tough exercise, if one does it exactly as one should do, with intervals and your pulse going up and down..." (7)   |
|   | Priorities and commitment                         | "I never missed a single time. If something else intervened, I just said that I couldn't, that I needed to exercise." (11)   |
|   | Initial ambivalence                               | "I was a little surprised that they dared to engage us at this level. They really didn't know who we were. Would our hearts make it through the first time or would we just drop dead? Because I was very tired that evening and the day after..." (7)   |
| 2. Increased faith in one's own body                            | Positive physiological effects                    | "This was a fun type of exercise compared to standing and twisting a wooden stick. Because, if you are going to give so much of your time, it seems important that it really delivers, and that afterward you really feel that you got good results." (8)  |
|   | Elevated mood                                     | "You felt tired in your whole body, but in a positive way. Not like you just finished digging a ditch, but it was a positive feeling, like the whole body got a good workout. Endorphins, I believe, made you feel a bit exhilarated." (11)  |
| 3. Changed attitude toward exercise                             | Self-created exercise routines                    | "I almost thought that it was too tough, the thing about doing it on your own. After you had already done it [supervised exercise] here twice a week then you had to do it one more time. But at the same time, I think that it [the third weekly session] helped, because I actually do it at home these days." (4)   |
|   | Acceptance and management of symptom fluctuations | "A few times when I wasn't feeling well I didn't achieve the higher intervals. I kept doing my best but I never got up to the higher levels. But it was okay to think that certain times I might not get all the way. I have accepted that." (1)   |
|   | Changed motivation                                | "There's the wish to get better. I guess that's the motivation, clear and simple." (2)   |
|   | Competent guidance                                | "The physiotherapist had control over the situation, was knowledgeable of both the concept and the disease, and gave us supportive feedback." (8)  |
| 4. Taking charge of one's own health by challenging the disease | Reversal of a downward spiral                     | "Well, now it's time for redemption. Now you have completely new tools and things. Now you'll make it on your own for a year or two. But you'll be needing support, especially from a physiotherapist, I would think." (2)   |
|   | Changed perspective on the disease                | "I felt as though I became a bit more positive towards my disease. Because I have felt as though it has hampered me, and I felt that I couldn't do certain things. I felt a bit limited by my disease. And this exercise program made me feel as though I wasn't limited anymore, because you can actually exercise like everyone else, even though you may need to make adjustments." (8) |
| 5. Exercise in a social context                                 | Stimulating context                               | "Well, it starts in the dressing room with someone going on about something or another, and that's what sports are like. Yes, I believe we are a team, that's how I experience it, and in sports, the dressing room is almost the most important thing." (7)   |
|   | Identification with one's peers                   | "The advantage of having the group is the feeling of; well if the other nine survive, probably so will I. As in, if the others are able to fight on, then I must be as well. They have the same diagnosis and the same situation, and if they can manage without pain, then of course I can as well. Because, we're pretty much the same." (2)   |
|   | Support from one's own social environment         | "Then I also went for walks, most often with my wife.... She is much better than me. Well, she and my daughter are such types, they have to exercise." (3)   |

<sup>a</sup>The number after each quote refers to the specific respondent.

exercise program appeared to have stimulated the respondents to a motivational change because after a while, they started to compete against themselves and others in the group. For some, the process went even further: after the program ended, they continued to exercise in a similar way for the sheer enjoyment of it.

*Competent guidance.* The respondents described the importance of being guided and acknowledged by a competent leader who gave individual feedback and instructions when any obstacle arose. Also, the physiotherapist's demanding yet sympathetic approach was valued by the respondents who expressed a need for extra support during the high-intensity sessions.

**4. Taking charge of one's own health by challenging the disease.** *Reversal of a downward spiral.* The respondents described the path of their rheumatic disease over the years as a downward spiral, with increased stiffness, pain, and a need for more pain relievers. They had slowly adapted to a life of pain and activity limitations. The respondents described how they, with the exercise program, had received tools to manage their disease and felt more independent, and therefore they could better control their disease.

*Changed perspective on the disease.* The respondents described having gained a different perspective on their disease after attending the program. From being physically limited, they now felt like any other healthy person, and exercise was no longer

a reminder of their functional limitations. As they improved in one aspect of their health, they seemed to become more aware of the importance of other aspects, influencing their overall health in a positive direction.

**5. Exercise in a social context.** *Stimulating context.* The supervised exercise sessions were described by the respondents as pleasant and fun events to look forward to, contributing to the cohesion of the group. Some of the respondents, lacking inner motivation to exercise, found the support they needed to be physically active through the social context. Some described attending the supervised sessions as important because they felt socially responsible to the others in the group, resulting in a positive social pressure helping the respondents to prioritize their exercise.

*Identification with one's peers.* The respondents described the importance of identifying with others. Knowing that the other group members shared the same disease and physical limitations helped them push through periods of increased symptoms and lack of energy. Furthermore, being at the same level of physical fitness enabled the respondents to identify with the others, motivating them to perform despite their personal adversities.

*Support from one's own social environment.* Respondents' support from their families and partners was seen as paramount for adhering to the exercise program. Some respondents also described family members' support as especially important when they lacked inner motivation to perform the individual home sessions.

## DISCUSSION

The findings of this qualitative study indicate that patients with axSpA experience high-intensity exercise as a physical and mental challenge but also as a manageable exercise mode to improve physical fitness and overall well-being.

Respondents were very challenged by the physical exhaustion, which for some evoked an initial mental resistance toward strenuous exercise. High level of exertion has previously been found to be associated with negative affective responses 29,30, corresponding to our results. The respondents struggled with ambivalent feelings toward the program as they initially questioned the appropriateness of such an intense exercise mode, given their disease.

However, rapid improvements in physical fitness appeared to have led to positive feelings of achievement and accomplishment that strengthened their faith in their own bodies. It is plausible that these rapid and positive embodied feelings helped respondents to cope with negative physical sensations and ambivalence and that this ability to cope stimulated them to adhere to the exercise program. These results are in line with previous findings of studies in healthy individuals, suggesting that increased enjoyment during

high-intensity exercise might be due to the satisfaction of meeting a challenge and the stimulation of more demanding exercise than the enjoyment of the activity itself (31).

Increased faith in one's own body during the challenging exercise program seems to have changed the respondents' attitudes and motivations toward exercise. The physiotherapist's guidance and faith in the respondents' abilities to perform at the expected intensity level was stressed by the respondents as being very important to their performance. This indicates that the physiotherapist's instructions, feedback, and confidence enhanced respondents' self-efficacy to exercise at a high intensity. This is in line with previous studies emphasizing the role of the physiotherapist in patients' self-efficacy during challenging exercise (32-35).

When aiming to include a new exercise program into one's daily life, motivation plays a prominent role for adherence (36). In the present study, respondents described a wish for improved health as an initial motivator. Previous research has demonstrated that adherence to physical activity increases when it is understood to lead to potential health benefits (37). The present study shows that as the exercise period progressed, respondents experienced increased enjoyment and a spirit of competition, indicating a transformation toward a more self-determined and volitional action to exercise (37,38).

Exercising in a supportive social context was described as facilitating the respondents' adherence to the program. Facing the challenges of the exercise program together and striving for a common goal appeared to reinforce the cohesiveness of the group. Also, feeling an obligation to support the others made the respondents prioritize their exercise, furthering the positive group dynamics. These results correspond with previous findings reporting the dynamics and camaraderie of group exercise and the sense of social responsibility to others as motivators for physical activity (22). Sharing the same disease and obstacles appeared to have helped the respondents to identify with the others in the group, encouraging them to carry on even during difficult times. Exercise in homogeneous groups has also previously been identified as valuable by patients with rheumatic diseases in increasing their motivation to exercise (23,33). Because the exercise program was perceived as time consuming, support from the respondents' family was vital, which is in line with previous findings (39,40).

Regular exercise on a health-enhancing level is an important lifestyle factor that promotes good health. As the respondents managed to change one lifestyle factor, such as exercise, they became more aware of the importance of other aspects of health and its importance to their overall well-being. It might be that their increased knowledge and confidence about exercising at a higher level gave the respondents the tools to handle the challenges of their disease. These results suggest that a well-functioning exercise program helps patients take control of their own illness and improve their health.

Moderate and high-intensity exercise for improving aerobic capacity and muscle function is included in recent guidelines for

patients with inflammatory arthritis diseases (8). However, high-intensity exercise has shown to be superior to moderate exercise in terms of maximizing cardiac health outcomes (41). Some health care professionals still appear to be ambivalent toward high-intensity exercise because of the potential risk of inflammatory flare-ups (18,19), which influences their choice of exercise recommendations (42). Recent research shows, however, that when high-intensity exercise is adequately guided and executed (20), it is well tolerated by patients with axSpA.

Some of our findings in the present study have direct implications for how to improve patients' adherence and participation in exercise at a high-intensity level. Supervision by a competent physiotherapist or other health professional with knowledge of both rheumatic disease and high-intensity exercise seems to be important, especially for those patients who have a low self-efficacy for exercise. Furthermore, diagnosis-specific exercise groups appear to support adherence to exercise. Social interactions between patients sharing the same disease and similar physical limitations appear to enhance motivation to continued exercise during periods of increased symptoms and personal setbacks. This implicates that social context is an important aspect of managing high-intensity exercise.

To our knowledge, this is the first study to examine the experiences with high-intensity exercise among patients with axSpA. A qualitative research approach with semistructured interviews was applied, enabling us to follow the respondents' perspectives on exercise in context and probe for deeper meanings in the discussed topics. To strengthen the credibility of the data, patients from two separate exercise groups were invited to participate in the interviews. The heterogeneity in age, sex, and ethnicity of the study population also enriched the material. Both women ( $n = 5$ ) and men ( $n = 9$ ) were included, which is regarded as a strength of our study. To ensure trustworthiness, two researchers collaborated on the data analysis. For further validation, researchers knowledgeable in qualitative methods were invited to discuss the results. These added methodological strategies are expected to strengthen the dependability and thus the overall trustworthiness. The sample size can be regarded as small, but the interviews were rich and nuanced. Qualitative research has limited generalizability because new categories could be identified in other contexts. Transferability has to be judged by the reader, but as authors, we consider the results to be relevant when planning high-intensity exercise for patients with axSpA. The majority of the respondents in the present study had an ankylosis spondyloarthritis diagnosis; thus, we regard the results of the present study to be generalized for patients with both radiographic and nonradiographic axSpA. Experiences with exercise usually vary within a diagnosis group because of several factors. In this study, we have highlighted how exercise on a high-intensity level was experienced by patients with an inflammatory rheumatic disease.

In conclusion, high-intensity exercise was experienced as challenging and demanding yet manageable for patients with

axSpA. Rapid physical improvement from the exercise increased respondents' faith in their own bodies, which appeared to have strengthened their commitment to the exercise program. The new experience seemed to have changed the respondents' attitudes and motivations to exercise, helping them to cope with the disease. Group exercise under the supervision of a competent physiotherapist enhanced the respondents' self-efficacy for strenuous exercise. Insight into these experiences is important when planning high-intensity exercise for patients with axSpA.

## AUTHOR CONTRIBUTIONS

All authors were involved in drafting the article and revising it critically for important intellectual content, and all authors approved the final version to be published. Drs. Bilberg and Mannerkorpi had full access to all of the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis.

**Study conception and design.** Bilberg, Dagfinrud, Mannerkorpi.

**Acquisition of data.** Bilberg.

**Analysis and interpretation of data.** Bilberg, Sveaas, Dagfinrud, Mannerkorpi.

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