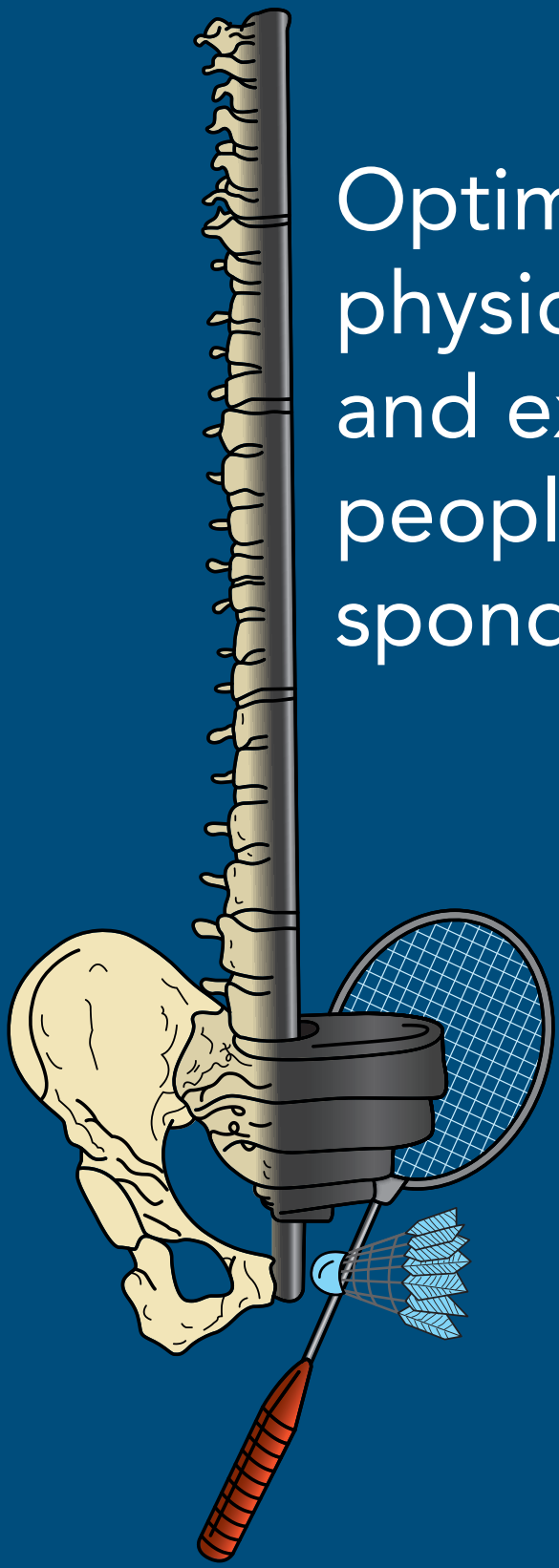

Optimizing physical activity and exercise in people with axial spondyloarthritis

Bas Hilberdink

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ISBN: 978-94-6423-940-9

Cover by: Dennis Hendriks || ProefschriftMaken.nl
Cover artwork by: Meike Hilberdink-Piekaar
Printed by: ProefschriftMaken.nl

The studies in this thesis were financially supported by the Dutch Arthritis Society (ReumaNederland).

The printing of this thesis was financially supported by Paramedisch Centrum voor Reumatologie en Revalidatie (PCRR Hilberdink).

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Proefschrift

Ter verkrijging van
de graad van doctor aan de Universiteit Leiden,
op gezag van rector magnificus prof.dr.ir. H. Bijl,
volgens besluit van het college voor promoties
te verdedigen op dinsdag 1 november 2022
klokke 15.00 uur

door

Sebastiaan Hilberdink

geboren te Groningen
in 1989

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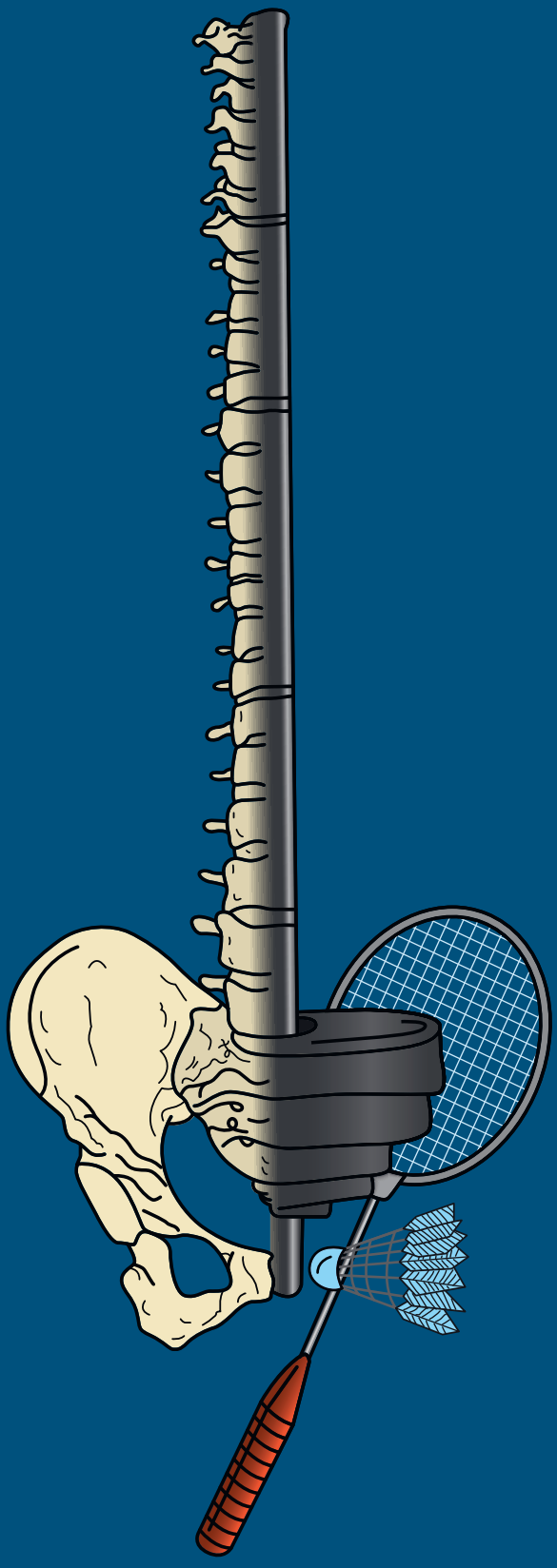
We should not exercise the body without the joint assistance of the mind;
nor exercise the mind without the joint assistance of the body

Plato

Table of contents



Chapter 1

General introduction

Axial spondyloarthritis and its treatment

Epidemiology, pathophysiology and clinical characteristics

Axial spondyloarthritis (axSpA) is a chronic inflammatory rheumatic disease primarily affecting the spine and sacroiliac joints (1-3). It is characterized by inflammatory back pain and stiffness (1, 2, 4). As shown in Figure 1, extraspinal articular and peri-articular characteristics of axSpA are peripheral arthritis, enthesitis and dactylitis. Extra-articular manifestations may include (among others) anterior uveitis, psoriasis and inflammatory bowel disease (2, 3, 5).

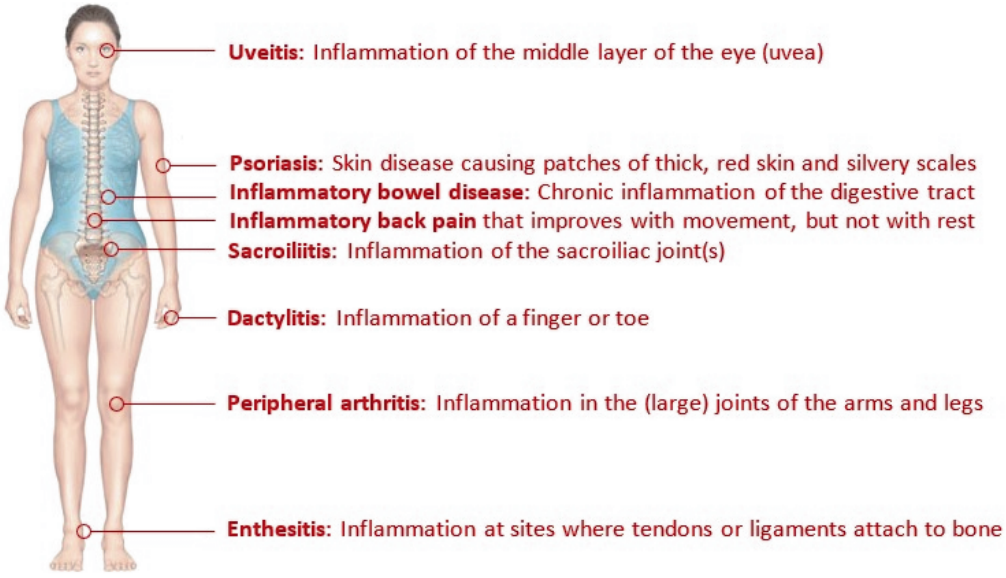


Figure 1. Common clinical features of axial spondyloarthritis

AxSpA encompasses both non-radiographic axSpA (nr-axSpA) and radiographic axSpA, also known as ankylosing spondylitis (AS). Nr-axSpA and AS are distinguished by the absence or presence of structural damage to the sacroiliac joints on radiographs (1, 2, 4). Among patients with nr-axSpA, magnetic resonance imaging (MRI) may show signs of inflammation in the spine and sacroiliac joints (6). It was found that within two years, 10-12% of the patients with nr-axSpA develop structural damage and fulfill the criteria for AS (7, 8). However, not all nr-axSpA patients will ultimately develop radiographic sacroiliitis and progress to AS (1, 2). Similarly, not in all AS patients new bone formation (syndesmophytes) will form over time in the sacroiliac joints and spine (1, 2): approximately 60-70% of AS patients develop bony growths eventually leading to vertebrae fusion (9, 10).

The onset of axSpA is typically before the age of 45 years, often in people in their twenties (5, 11). The global prevalence of axSpA among adults is between 0.2% and 1.4% (1, 11, 12). Overall, axSpA is equally prevalent in men and women (5, 13), while nr-axSpA is more prevalent in women and AS in men (7, 14). In the remainder of this thesis, the term axSpA refers to both nr-axSpA and AS.

People with axSpA have an increased risk for comorbidities, such as osteoporosis (15), depression (16, 17) or cardiovascular diseases (15, 16, 18, 19). These comorbid conditions are associated with more disease activity, reduced work productivity, decreased quality of life, lower treatment response and higher mortality (16). People with axSpA are also more likely to have common cardiovascular disease risk factors, such as decreased cardiorespiratory fitness (20-23), hypertension (16) and obesity (16, 24).

General management of axSpA

Several national and international guidelines provide comprehensive recommendations for the treatment of people with axSpA. An example of these is the '2016 Update of the ASAS-EULAR management recommendations for axial spondyloarthritis' (2), a set of recommendations from a collaboration between the Assessment of SpondyloArthritis international Society (ASAS) and the European Alliance of Associations for Rheumatology (EULAR). These recommendations state (among others) that the optimal management requires a combination of pharmacological and non-pharmacological modalities, in order to maximize health-related quality of life by controlling symptoms and inflammation, preventing progressive structural damage and preserving and normalizing function and social participation.

In this and other sets of recommendations (2, 3, 19, 25, 26), multiple treatment modalities are advocated. This thesis mainly covers non-pharmacological treatment modalities, in particular physical activity, exercise and physical therapy, as shown in Figure 2.

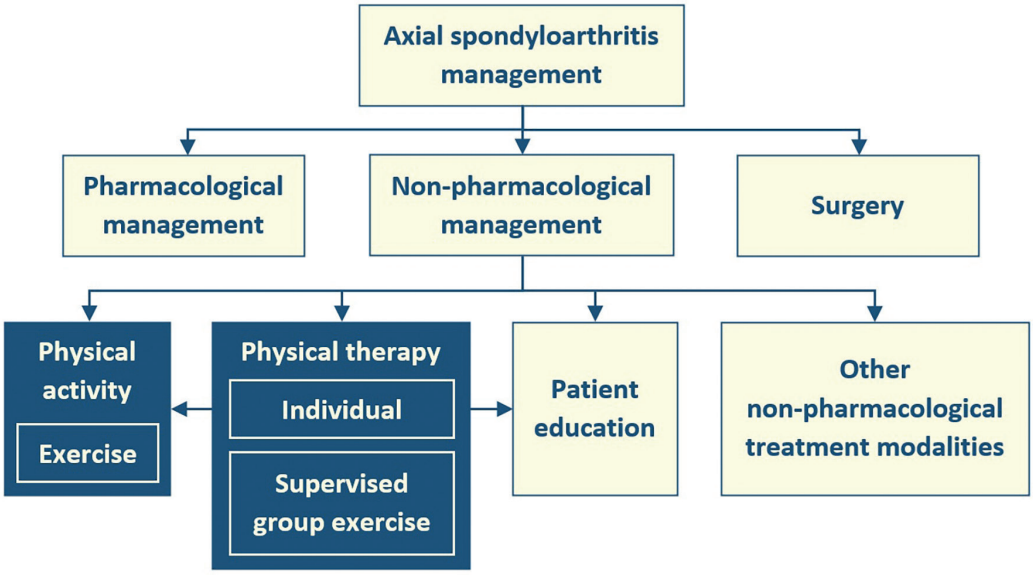


Figure 2. Recommended treatment modalities, with this thesis' focus highlighted in blue

- Pharmacological management: Non-steroidal anti-inflammatory drugs (NSAIDs) are recommended as a first-line drug treatment (2, 3, 25). Moreover, in case of persistent high disease activity, the initiation of biological disease-modifying antirheumatic drugs (bDMARDS), particularly tumor necrosis factor inhibitors (TNFi), is advocated (2, 3, 25).
- Non-pharmacological management: Sets of recommendations particularly advocate education, physical activity and physical therapy (2, 3, 19, 25-27), but patients with axSpA can also use other non-pharmacological treatment modalities, e.g. occupational therapy or vocational rehabilitation.
    - *Physical activity and exercise*: According to the 2018 EULAR recommendations for physical activity (27), exercise and physical activity according to public health recommendations are effective, feasible and safe for people with axSpA.
    - *Physical therapy*: In various guidelines, it is stated that physical therapy should be considered (2, 3) and should include exercise therapy (3, 25, 28). In some countries, including the Netherlands, exercise therapy can also be provided by certified exercise therapists (in Dutch: Oefentherapeuten Cesar and Mensendieck (29)). In this thesis, the terms physical therapy and physical therapist therefore also refer to the profession of exercise therapists.

- *Patient education*: It is recommended to educate patients on axSpA and on the benefits of a healthy lifestyle, including a healthy diet, smoking cessation and regular exercise (2, 19, 25, 28), which may have a beneficial effect on the course of the disease (30) and on the cardiovascular risk (19). Furthermore, education can cover a much wider range of topics, e.g. medication use, fall prevention, sleep, psychosocial support, coping, pain-, stress- and fatigue-management, joint protection, energy conservation, environmental modifications, assistive technologies, orthoses and available treatment possibilities: the content of the education should be individually tailored and needs-based (28, 31). Multiple health care professionals can be involved in patient education, such as the rheumatologist, clinical nurse specialist, general practitioner, physician assistant, physical therapist, certified exercise therapist, social worker, psychologist, occupational therapist, dietitian, podiatrist, dermatologist or gastroenterologist.
- *Other non-pharmacological treatment modalities*: Recommendations may also mention other non-pharmacological treatment modalities, such as occupational therapy, vocational rehabilitation, cognitive behavioural therapy, podiatry and medical nutrition therapy, which are especially common in multi-disciplinary treatment (26).

- Surgical management: Sets of recommendations particularly suggest to consider total hip arthroplasty in axSpA patients with refractory hip pain or disability and radiographic evidence of structural damage (2, 3).

This thesis focuses mainly on physical activity, exercise and physical therapy (as highlighted in Figure 2).

Physical activity, exercise and physical therapy

Definitions

Although exercise has been recommended to axSpA patients for a long time (32-34), in recent years there appears to be more focus on physical activity in general (20, 27, 35). This is probably caused by recent developments in public healthcare, including: a) definition and promotion of health enhancing physical activity recommendations for the general population (36-38); b) new insights in the increased cardiovascular risk in axSpA patients (15, 16, 18, 19); and c) new evidence on the benefits and safety of (high-intensity) aerobic physical activity in axSpA patients (27, 28, 39-42). Before elaborating further on physical activity and exercise, it is important to define the relevant concepts:

- Physical activity (PA) is defined as "any bodily movement produced by skeletal muscles that results in energy expenditure" (43).
- Exercise is a subcategory of PA that is "planned, structured and repetitive and has as a final or an intermediate objective to improve or maintain physical fitness" (43). Other categories of PA are occupational, household, transport or leisure-time activities. Exercise can be performed supervised or unsupervised, individually or in a group and land-based or aquatic. It can also be used as a therapeutic intervention: exercise therapy (28, 29, 44).
- Exercise therapy consists of practicing functional movements and performing aerobic, mobility, strength and/or neuromotor exercises in order to optimize physical functioning and participation (28, 29). This can be provided individually or in a group by a physical therapist or, in some countries, by a certified exercise therapist (29, 44). Exercise therapy is often supplemented with patient education (28, 44, 45).

Most therapeutic interventions concern combinations of supervised and unsupervised exercises and education including general PA promotion. In the literature, the terms used for these various aspects often overlap (2, 25, 28, 35, 46, 47).

Physical activity and exercise in axSpA

Sufficient engagement in both overall PA and exercise are important for people with axSpA. Exercise interventions have shown to have positive effects on cardiorespiratory function, spinal mobility, pain, stiffness, fatigue, disease activity, physical functioning and quality of life (32, 42, 47-56). However, the effects are often small (54, 55). Supervised exercise appears to be more beneficial than unsupervised exercise (57). Furthermore, maintaining an adequate PA level is important for general health and well-being, for prevention of comorbidities such as osteoporosis, depression and cardiovascular diseases and for their beneficial effects on cardiovascular risk factors such as hypertension and obesity (37, 46, 58). These preventive effects are particularly important for people with axSpA, because they have an increased risk for these comorbidities and risk factors (15-17).

In order to achieve optimal effects, a combination of aerobic, mobility and strengthening exercises according to general PA recommendations shown in Table 1 is recommended for axSpA patients (27, 28, 35, 46, 48). Some guidelines also recommend neuromotor exercise (27, 28, 46).

Recent literature suggests that in the general population vigorous-intensity aerobic exercise has superior benefits over moderate-intensity aerobic exercise (60-63). Exercise with vigorous-intensity has shown to be beneficial and safe in axSpA patients (42, 64).

Table 1. General physical activity recommendations (27, 36, 59)

	Recommended weekly dosage of PA
Aerobic physical activity	≥150 minutes with moderate-intensity, ≥75 minutes with vigorous-intensity or an equivalent combination Increased amounts have more health benefits
Mobility exercise	≥2 days
Strength exercise	2-3 days
Neuromotor exercise	≥2 days

Physical therapy in axSpA

Individual physical therapy

Based on the available scientific evidence and consensus among different stakeholders and experts (including patients, physical and exercise therapists, rheumatologists and researchers), detailed Dutch recommendations on physical therapy in people with axSpA were published in 2019 (28). In these recommendations, it is advised to provide:

- Periodic assessments, including evaluation of physical functioning, PA behavior, personal needs and potential barriers and facilitators.
- A personalized exercise program, tailored to individual needs, disease status and the periodic assessments and including aerobic, mobility, strengthening and neuromotor exercises, possibly supplemented with breathing exercises, all with the appropriate intensity, duration and frequency, according to the ACSM criteria (37). Exercise intensity should be monitored by heartrate or with a Borg Rating of Perceived Exertion Scale (65).
- Patient education on (among others) axSpA, PA, exercise, coping and lifestyle.

Supervised group exercise

After a period of individual physical therapy, patients with axSpA are encouraged to engage in supervised group exercise (SGE) if deemed necessary, in order to maintain (improvements in) physical functioning over time (28, 46).

Differences in effectiveness between SGE and supervised individual exercise are largely unknown, but SGE is found to have better effects on symptoms, cardiorespiratory fitness and physical functioning than unsupervised individual exercise in axSpA patients (32, 46, 47, 66). Therefore, axSpA-specific SGE has been

implemented in many countries since the early nineties, including the Netherlands, where it is organized by many local patient associations spread across the country.

An evaluation of SGE was done in the Netherlands in 1991, showing that it consisted of relatively long, weekly sessions, combining land-based and aquatic mobility and strengthening exercises and sports activities (e.g. badminton and volleyball), supervised by physical therapists (67, 68). However, 30 years later, the current situation with respect to the organization, usage and contents of SGE in the Netherlands is unknown. Such information is also limited for other countries: it appears that, similar to the Netherlands, SGE in Switzerland and the United Kingdom generally focuses on mobility and strength, uses land-based and often aquatic exercises, is performed once weekly and supervised by a physical therapist (40, 69, 70).

Optimizing physical activity and exercise

Although the proportion of patients with axSpA engaging in sufficient moderate-intensity aerobic PA is comparable to the general population, only a small minority seems to engage in vigorous-intensity aerobic PA (71-76). This might be caused by specific PA and exercise barriers axSpA patients experience due to their disease, e.g. pain, stiffness, fatigue, limited functioning and comorbidities. Furthermore, it appears that, apart from SGE and individual exercise therapy programs, the majority of axSpA patients does not engage in exercise activities with mobility and strength components (76, 77), let alone with an appropriate dosage according to the public health recommendations for health enhancing PA. However, the evidence on engagement in specific types of exercise is limited and does not take engagement in SGE or therapeutic exercise programs into account (78). Therefore, more research on engagement in specific exercise types, including their dosage, both in patients with and without physical therapy, seems warranted.

Findings of such research could subsequently guide interventions promoting adequately dosed PA and exercise in axSpA patients. Such interventions should also account for axSpA-specific exercise barriers. After all, engagement in the adequate types and dosage of PA requires a change in patients' behavior and behavior change is a complex process for which only providing advice is often insufficient (79-82). Exercise interventions could be provided through physical therapists and can take place on an individual basis or in a group setting.

Individual physical therapy

Individual physical therapy might be an appropriate setting for optimizing PA and exercise behavior. After all, most exercise interventions for axSpA patients are

provided by physical therapists and they play an important role in the promotion of PA (27, 28, 83). In addition, the large majority of axSpA patients have individual physical therapy treatment during the course of their disease (83).

Regarding the contents of individual physical therapy programs for axSpA patients, it was recently found that although the majority of these programs included advice on home exercise, just a minority included strength and aerobic exercises during treatment (83). Meanwhile, recent literature shows that the addition of aerobic and strength exercises to mobility exercise has extra benefits and is safe for people with axSpA (27, 41, 42, 47). Thus, although individual physical therapy might be a suitable setting for optimizing PA and exercise, there appears to be room for improvement of its contents.

Supervised group exercise

AxSpA-specific SGE appears to focus mainly on mobility exercises and in lesser extent on strengthening and aerobic exercises, let alone with appropriate dosage (35). The exercise program from three decades ago on which axSpA-specific SGE classes in the Netherlands are based, mainly focused on mobility and strength exercises and not specifically on (high-intensity) aerobic exercises (67, 68). Those exercise programs took place once weekly, without promotion of additional PA or (home) exercise (67). The current contents of SGE are however unknown, as well as the engagement of SGE participants in other exercise activities besides SGE.

Thus, it may be warranted to examine the current SGE contents and the weekly exercise engagement of SGE participants, in order to assess if there is room for improvement. If certain SGE enhancements are identified, the patient perspective towards current SGE and towards the proposed changes should be explored (84-86). This way, relevant barriers and facilitators for implementation of these potential enhancements can be identified (64). Subsequently, the proposed enhancements can be tested in a few regions using a pilot implementation, prior to a nationwide implementation. In such a pilot implementation, a hybrid study design would be ideal to evaluate both the effects and feasibility (87, 88). This study design could both speed the scientific progress and help translate the research findings into routine practice (87, 88).

Optimizing exercise in axSpA patients not using physical therapy

Not all axSpA patients use individual physical therapy or SGE. Thus, in order to optimize PA and exercise of those without physical therapy, an intervention without involvement of a physical therapist is needed. The requirement of such an intervention would be that it is context- and population-specific, targeting axSpA-specific barriers and facilitators. Regarding the developmental process for such an intervention, there are many different (theory- and evidence-based) approaches

(89) and the Intervention Mapping framework appears particularly suitable: it provides detailed guidelines to identify relevant environmental and personal factors before selecting corresponding intervention components (90). Intervention Mapping uses a stepwise approach, guiding the path from problem identification to solution development, while combining literature with stakeholders' perspectives.

Aims of this thesis

Given the potential need for improvement of PA and exercise of axSpA patients and the knowledge gaps found in the available literature, this thesis aims to:

1. Describe the current PA and exercise engagement of axSpA patients in the Netherlands and their relationship with physical therapy use.
2. Identify the need for evidence-based enhancements in axSpA-specific SGE in the Netherlands and evaluate the effectiveness and feasibility of the implementation of these enhancements.
3. Determine the components needed for an intervention to optimize PA and exercise of axSpA patients in general.

These aims are addressed in the following chapters:

- **Chapter 2** includes a study on the engagement of axSpA patients with and without physical therapy (individual and/or SGE) in aerobic PA.
- **Chapter 3** compares engagement in aerobic, mobility and strength exercise between axSpA patients using and not using SGE.
- **Chapter 4** describes the current organization and content of SGE for people with axSpA in the Netherlands and it is examined if the content meets recent scientific insights and how the quality can be further improved.
- **Chapter 5** outlines a study on the satisfaction of axSpA patients with current SGE and their perspective on potential evidence-based SGE enhancements.
- **Chapter 6** includes an evaluation of the effects and feasibility of a pilot implementation of enhancements of SGE in four regions.
- **Chapter 7** describes the intervention components needed for an intervention aiming to optimize exercise behavior of axSpA patients, using the Intervention Mapping protocol.
- **Chapter 8** provides a summary and a general discussion of the findings of this thesis.

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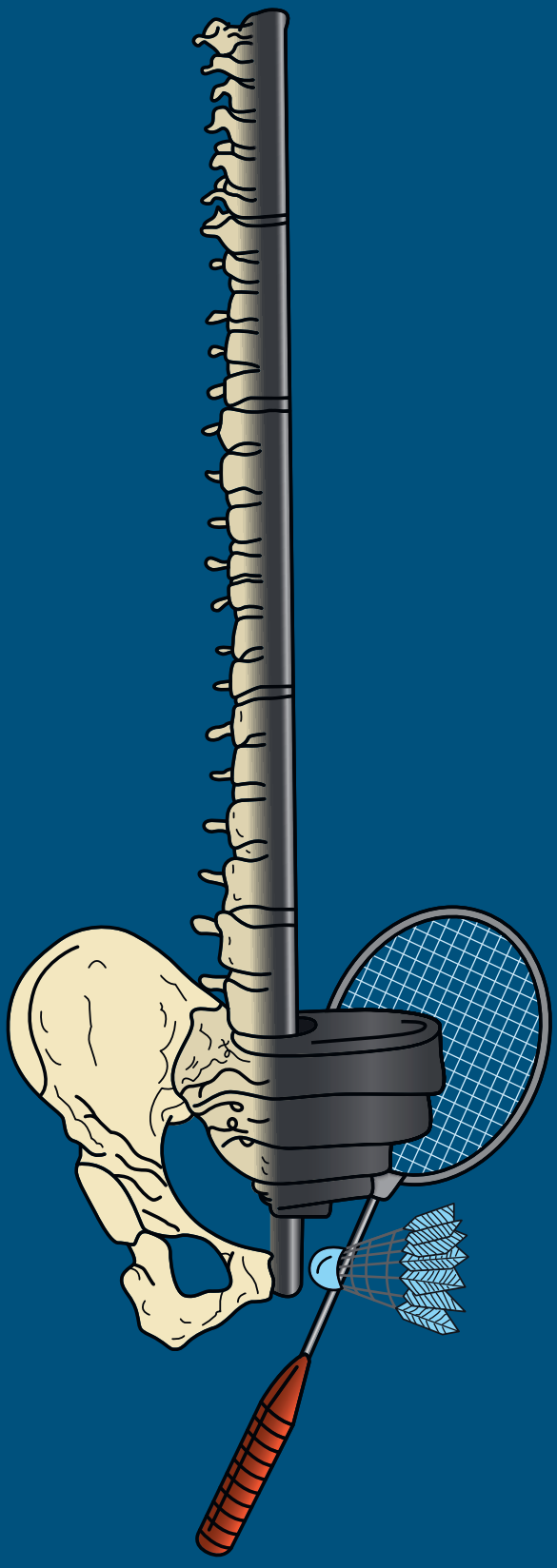

Chapter 2

Adequately dosed aerobic physical activity in people with axial spondyloarthritis: associations with physical therapy

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Rheumatology International 2020;40(9):1519-1528

Abstract

Objective

This study aimed to compare the engagement in moderate- and vigorous-intensity PA in axSpA patients with and without current physical therapy (PT).

Methods

In this cross-sectional study, a survey, including current PT treatment (yes/no) and PA, using the 'Short QUestionnaire to ASsess Health-enhancing PA' (SQUASH), was sent to 458 axSpA patients from three Dutch hospitals. From the SQUASH, the proportions meeting aerobic PA recommendations (≥150 min/week moderate-, ≥75 min/week vigorous-intensity PA or equivalent combination; yes/no) were calculated. To investigate the association between PT treatment and meeting the PA recommendations, odds ratios (OR) with 95% confidence intervals (95% CI) were estimated using logistic regression models, adjusting for sex, age, health status and hospital.

Results

The questionnaire was completed by 200 patients, of whom 68%, 50% and 82% met the moderate-, vigorous- or combined-intensity PA recommendations, respectively. Ninety-nine patients (50%) had PT treatment, and those patients were more likely to meet the moderate- (OR 2.09 [95% CI 1.09–3.99]) or combined-intensity (OR 3.35 [95% CI 1.38–8.13]) PA recommendations, but not the vigorous-intensity PA recommendation (OR 1.53 [95% CI 0.80–2.93]). Aerobic exercise was executed in 19% of individual PT programs.

Conclusion

AxSpA patients with PT were more likely to meet the moderate- and combined-intensity PA recommendations, whereas there was no difference in meeting the vigorous-intensity PA recommendation. Irrespective of having PT treatment, recommendations for vigorous-intensity PA are met by only half of the patients. Implementation should thus focus on aerobic PA in patients without PT and on vigorous-intensity PA in PT programs.

Introduction

Axial spondyloarthritis (axSpA) is a chronic inflammatory rheumatic disease, with back pain and stiffness as main symptoms and encompassing both non-radiographic and radiographic axSpA (ankylosing spondylitis) (1, 2). The literature shows that axSpA is associated with both decreased cardiorespiratory fitness (3-6) and an increased risk of cardiovascular disease (7, 8), which are interrelated (9-12). Adequately dosed aerobic physical activity (PA) according to public health recommendations improves cardiorespiratory fitness in people with axSpA (13, 14) and might reduce the cardiovascular risk. For this reason, it is advocated in international recommendations on PA in people with rheumatic and musculoskeletal conditions (15). Aerobic PA concerns PA executed with moderate or vigorous intensity. Recent studies suggest that vigorous-intensity PA is most effective in improving cardiorespiratory fitness and reducing cardiovascular risk (10, 16-18) and it shows to be both beneficial and safe for people with axSpA (19, 20). Therefore, especially vigorous-intensity PA should be pursued by people with axSpA, at least by those without an increased risk of cardiovascular complications during exercise.

This raises the question to what extent people with axSpA are actually engaged in aerobic PA, either or not with vigorous intensity. A previous study reported that evidence on PA engagement of people with axSpA is limited and heterogeneous in nature (3). Nevertheless, it appears that the engagement in adequately dosed aerobic PA is insufficient, in particular in vigorous-intensity aerobic PA (21-24). Three studies, all using accelerometers, showed that people with axSpA engaged less in vigorous-intensity PA than population controls, while the total amount of PA was comparable (21-23). Another study found that more people with axSpA comply with the moderate-intensity PA recommendation (57%) than with the vigorous-intensity PA recommendation (32%), using a non-validated PA questionnaire (24). That study used the PA recommendation prescribing moderate-intensity PA for ≥30 minutes on ≥5 days per week or vigorous-intensity PA for ≥20 minutes on ≥3 days. Other studies on aerobic PA in people with axSpA (3, 21, 23, 25) were based on the recommendation by the World Health Organization (WHO) (26), which does not state a required minimum frequency, but prescribes ≥150 minutes of moderate-intensity PA, ≥75 minutes of vigorous-intensity PA per week or an equivalent combination of this. It was reported that this recommendation was met by approximately half of patients (21, 23, 25), but no distinction was made between the proportions of people meeting the moderate- or vigorous-intensity PA recommendations. None of the studies distinguished between leisure time and work-related aerobic PA either, whereas leisure time PA appears to have greater health benefits (27-31) and is probably more easily modifiable than work-related PA. This superiority of leisure time PA could probably be caused by the difference

in the nature of activities or by more opportunities to rest when desired and recover between sessions (27, 29).

Another limitation of previous studies on aerobic PA among people with axSpA, besides not distinguishing between moderate- and vigorous-intensity PA and between leisure time and work-related aerobic PA, is that none of the studies so far took the role of physical therapy (PT) into account. This is striking as relatively many axSpA patients have PT treatment (32) and it is generally acknowledged that apart from other health professionals, physical therapists play an important role in the promotion of PA (15). However, it appears that aerobic PA may not be included in PT treatments often (32) and that the aerobic PA employed in exercise programs for people with axSpA is often inadequately dosed (20, 33-35).

To implement aerobic PA recommendations in people with axSpA, it is important to know what the focus of implementation activities should be, both in patients with and without PT treatment. Due to the physical limitations for which axSpA patients seek PT treatment, it is not necessarily expected that patients with PT are more inclined to meet the aerobic PA recommendations. Moreover, PT programs may not include (advice on) aerobic PA [32]. Given the lack of knowledge on the association between having PT treatment and meeting aerobic PA recommendations among people with axSpA, the aim of the present study was to compare the engagement in moderate- and vigorous-intensity PA (during work and leisure time) in axSpA patients with and without PT treatment.

Methods

Study design and setting

This cross-sectional, multicenter study consisted of a once-only survey among people with axSpA living in the southwestern region of the Netherlands. In this survey, participants were asked whether they had either individual or group PT treatment, to compare PA of patients with and without any guidance from a physical therapist. In the Netherlands, PT for people with axSpA can both be offered on an individual basis or by means of axSpA-specific supervised group exercise. This group exercise usually consists of weekly land- and water based exercises supervised by a physical therapist and is organized by local patient associations for people with a rheumatic disease (34). The study obtained ethical approval from the Leiden University Hospital Ethical committee (P14.326). The reporting of this study was done in accordance with the checklist for cross-sectional studies from the 'Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement'.

Patients

In 2015, registers of three hospitals in the southwestern region of the Netherlands (Leiden University Medical Center in Leiden, Haga Hospital in The Hague and Reinier de Graaf Gasthuis in Delft) were screened for patients with a confirmed diagnosis of axSpA who had ever visited the rheumatology outpatient clinic. The survey was sent by postal mail to eligible patients, including an invitation letter on behalf of their treating rheumatologist, an information leaflet, an informed consent form and a pre-stamped envelope. No reminders were sent.

Assessments

The survey was self-developed and first pilot-tested by patient representatives affiliated with the Dutch Arthritis Society. It measured the following variables:

a. Demographic and clinical characteristics: sex, age, year of diagnosis and use of medication related to axSpA (painkillers (acetaminophen or opioid painkillers); Non-Steroidal Anti-Inflammatory Drugs (NSAIDs), biological Disease-Modifying Antirheumatic Drugs (DMARDs); synthetic DMARDs; no medication related to axSpA).
b. Health status, using the Assessment of Spondyloarthritis International Society Health Index (ASAS-HI), which is a valid, reliable and responsive questionnaire measuring functioning, health and disease impact in people with axSpA (36, 37). The ASASHI includes 17 questions and results in a score between 0 and 17, with a lower score indicating a better health status.
c. PT treatment, by asking whether they had PT treatment, either at the time the study was conducted (*current PT*; yes/no) or ever in the past (yes/no). Moreover, it was asked whether they were or had been treated individually in a practice (yes/no) and/or in a group with axSpA-specific group exercise therapy (yes/no). Furthermore, for individual PT, the duration (>5 years, >3 years, >1 year, >6 months or <6 months), frequency (less than weekly, weekly, twice weekly, more than twice weekly) and contents (15 treatment options) of PT treatment were recorded. These 15 treatment options were clustered according to the four groups of treatment modalities as described in the national physical therapists' professional profile developed by the Royal Dutch Society of Physical Therapy (38): Counseling (including education on home exercise; coping; and PA and sports); Exercise (including active joint range of motion exercises; muscle strengthening exercises; aerobic exercises; balance exercises; and relaxation exercises); Manual treatment (including passive mobilization; and massage); and Applying physical modalities (including thermotherapy; kinesiotaping; electrotherapy; ultrasound; and dry needling).
d. Aerobic physical activity, using the validated Dutch version of the 'Short QUestionnaire to ASsess Health-enhancing PA' (SQUASH) (39, 40). The SQUASH

consists of 17 items asking respondents to recall PA as performed during a regular week in the past 12 months, yielding the time duration per PA intensity and the type of aerobic PA. The SQUASH categorizes PA into PA during commuting, (light and heavy) work, (light and heavy) household, walking, cycling, gardening, odd jobs and sports. For the purpose of this study, these categories were dichotomized into leisure time PA, including recreational walking, recreational cycling, exercise and sports, and non-leisure time PA, which includes PA during commuting, work, household, gardening and odd jobs. Using the compendium of Ainsworth (41), a research assistant (JP) assigned the correct MET-values to the corresponding activities. The SQUASH uses a syntax to categorize the activities into light-, moderate- and vigorous-intensity PA, by combining activities' MET-values with both participants' age and a subjective effort-score (slow, average, fast) that participants assigned to each activity. Aerobic PA includes all PA performed with at least moderate-intensity. The SQUASH-data were used to calculate whether patients met the moderate- (≥150 minutes/week), vigorous- (≥75 minutes/week) and/or combined-intensity (≥75 minutes/week vigorous- and/or ≥150 minutes/week moderate- or vigorous-intensity PA) aerobic PA recommendations by the WHO (26). This was examined both for PA during all daily activities and during leisure time specifically.

Statistical analyzes

The returned questionnaires were scanned and analyzed by Cardiff® Software (California, United States) and manually checked and corrected afterwards. Descriptive statistics were used to describe patient characteristics, the proportions meeting the aerobic PA recommendations and the engaged types of leisure time and non-leisure time aerobic PA. This was done for the total group of participants and for patients with and without PT guidance separately. Results were reported as percentages or medians with minimum (Min) and maximum (Max) values, where appropriate.

To investigate the differences in characteristics between patients with and without PT, the median test for independent samples was used for continuous data and Pearson's chi-square test for categorical data. In addition, six logistic regression models were estimated with meeting the moderate, vigorous or combined-intensity PA recommendations, both during all daily activities and during leisure time, as the dependent variables and current PT treatment (individual and/or group) as independent variable. To control for confounding, sex, age, health status and hospitals were included in the models as independent variables. All statistical analyzes were performed with IBM SPSS Statistics for Windows, version 23.0 (IBM Corp., Armonk, N.Y., USA).

Results

Patients

The questionnaire was sent to 458 axSpA patients of whom 206 returned it (response rate 45%). Six of them were excluded because the SQUASH data were either missing (n=3) or invalid (n=3).

Table 1. Differences in characteristics between axial spondyloarthritis patients with (n=99) and without (n=101) current physical therapy (PT), participating in a survey on physical activity and PT.

	Total group (n=200)	With PT (n=99)	Without PT (n=101)	*P* [a]
Sex, male, *n* (%)	138 (69)	70 (71)	68 (68)	.679
Age, years, median (Min-Max)	57 (23-93)	59 (23-85)	54 (23-93)	.066
Disease duration, years, median (Min-Max)	23 (1-58)	25 (1-58)	17 (2-58)	.127
Medication use, *n* (%)				
Painkiller [b]	78 (39)	42 (42)	36 (36)	.326
NSAID	123 (62)	64 (65)	59 (58)	.365
Biological DMARD	77 (39)	39 (39)	38 (38)	.797
Synthetic DMARD	25 (13)	11 (11)	14 (14)	.557
None	16 (8)	5 (5)	11 (11)	.128
ASASHI score, median (Min-Max)	5.3 (0-14.9)	6.0 (0-13.4)	5.0 (0-14.9)	.669
Being employed, *n* (%)	110 (55)	55 (56)	55 (54)	.990

[a] *P*-value of chi-square test (for nominal variables) or median test (for continuous variables) for differences between patients with and without PT.
[b] Acetaminophen or opioid painkillers.
Min = minimum value. Max = maximum value. NSAID = Non-Steroidal Anti-Inflammatory Drugs. DMARD = Disease-Modifying Antirheumatic Drugs. ASASHI = Assessment of Spondyloarthritis International Society Health Index.

Patient characteristics are presented in Table 1, for the total group and for patients with and without PT separately. The majority of patients was male (69%), the median age 57 years and the median disease duration 23 years. The median ASASHI score was 5.3, indicating moderate health status (37). Ninety-nine patients had PT treatment at the time the study was conducted: 77 had individual PT treatment in a private practice only, 11 participated in axSpA-specific group exercise therapy only and 11 had both individual PT treatment in a private practice and group exercise therapy (on two different days). The group exercise therapy consisted of a standardized program comprising weekly land- and water based mobility and strengthening exercises and sports (mostly volleyball) in most patients (34).

Table 2 shows the duration, frequency and contents of current individual PT treatment. Among the 88 participants who were receiving individual PT at the time the study was conducted, the duration of treatment was more than five years in 66 patients (75%) and the treatment took place less than once week in 44 patients (50%). Furthermore, the individual PT treatment included counseling in 67 (76%), exercise in 47 (53%), manual treatment in 80 (91%) and the application of physical modalities in 24 (27%). Regarding contents with a direct link to aerobic PA recommendations, education on PA and sports was reported by 37 patients (42%) and aerobic exercise during PT treatment by 17 (19%). Among the 101 participants without current PT, 84 had PT treatment ever in the past. No statistically significant differences regarding sex, age, disease duration, medication use, ASASHI score and being employed were found between patients with and without PT.

Table 2. Duration, frequency and contents of individual physical therapy (PT) in people with axial spondyloarthritis (axSpA) participating in a survey on physical activity and PT (n=88).

	AxSpA patients with individual PT (n=88)
PT duration, n (%)	
> 5 years	66 (75)
3-5 years	8 (9)
1-3 years	5 (6)
6 months-1 year	4 (5)
< 6 months	5 (6)
PT frequency, n (%)	
More than twice weekly	0
Twice weekly	13 (15)
Weekly	30 (34)
Less than weekly	44 (50)
PT contents, n (%)	
Counseling	67 (76)
Education on home exercise	54 (61)
Education on coping	31 (35)
Education on physical activity and sports	37 (42)
Exercise	47 (53)
Active joint range of motion exercises	28 (32)
Muscle strengthening exercises	36 (41)
Aerobic exercises	17 (19)
Balance exercises	11 (13)
Relaxation exercises	3 (3)
Manual treatments	80 (91)
Passive mobilization	62 (71)
Massage	50 (57)
Physical modalities	24 (27)
Thermotherapy	9 (10)
Kinesiotaping	2 (2)
Electrotherapy or ultrasound	16 (18)
Dry needling	4 (5)

Aerobic PA recommendations

Table 3 presents the proportions of participants meeting the aerobic PA recommendations during all daily activities and during leisure time. This table shows that for all daily PA, the moderate, vigorous- and combined-intensity PA recommendations were met by 68%, 50% and 82% of the participants, respectively. With respect to meeting the aerobic PA recommendations by taking only leisure time PA into account, the proportions of participants meeting the moderate-, vigorous- and combined-intensity PA recommendations were 48%, 42% and 67%, respectively. Moreover, 68% of the participants engaged in any moderate-intensity leisure time activities, whereas 50% of participants engaged in any vigorous-intensity leisure time activities.

Table 3. Differences in meeting combined-, moderate- and vigorous-intensity physical activity (PA) recommendations during all daily activities and during leisure time between axial spondyloarthritis patients with (n=99) and without (n=101) current physical therapy (PT), participating in a survey on physical activity and PT.

	Total group (n=200)	With PT (n=99)	Without PT (n=101)	OR [a]	95% CI
Meeting combined-intensity PA recommendation					
With all daily PA, n (%)	164 (82)	88 (89)	76 (75)	**3.35**	**1.38–8.13**
With leisure time PA, n (%)	133 (67)	72 (73)	61 (60)	1.81	0.94–3.49
Meeting moderate-intensity PA recommendation					
With all daily PA, n (%)	136 (68)	74 (75)	62 (61)	**2.09**	**1.09–3.99**
With leisure time PA, n (%)	96 (48)	55 (56)	41 (41)	**1.86**	**1.03–3.36**
Meeting vigorous-intensity PA recommendation					
With all daily PA, n (%)	100 (50)	54 (55)	46 (46)	1.53	0.80–2.93
With leisure time PA, n (%)	84 (42)	42 (42)	42 (42)	1.01	0.53–1.90

[a] Odds ratio adjusted for sex, age, health status and affiliated hospitals using multivariate logistic regression models.

OR = odds ratio. CI = Confidence Interval. All daily PA = PA during commuting, household, work, gardening and odd-jobs and leisure PA. Leisure time PA = recreational walking and cycling, exercise and sports. Combined-intensity PA recommendation = 150 minutes/week at least moderate-intensity PA or 75 minutes/week vigorous-intensity PA. Moderate-intensity PA recommendation = 150 minutes/week moderate-intensity PA. Vigorous-intensity PA recommendation = 75 minutes/week vigorous-intensity PA.

PT and aerobic PA recommendations

To study the association between PT treatment and aerobic PA, only current PT treatment was considered, since almost all participants (92%) had ever had PT. The differences between patients with and without current PT regarding the meeting of aerobic PA recommendations are shown in Figure 1 and Table 3. Table 3 shows that, considering all daily PA, patients with PT are significantly more likely to meet the moderate- (OR 2.09 [95% CI 1.09–3.99]) and combined-intensity (OR 3.35 [95% CI 1.38–8.13]) PA recommendations than patients without current PT after adjusting for sex, age, health status and hospital. When only including leisure time PA, patients with PT are more likely to meet the moderate-intensity PA recommendation (OR 1.86 [95% CI 1.03–3.36]) than patients without PT, with no differences for the vigorous- or combined-intensity PA recommendations.

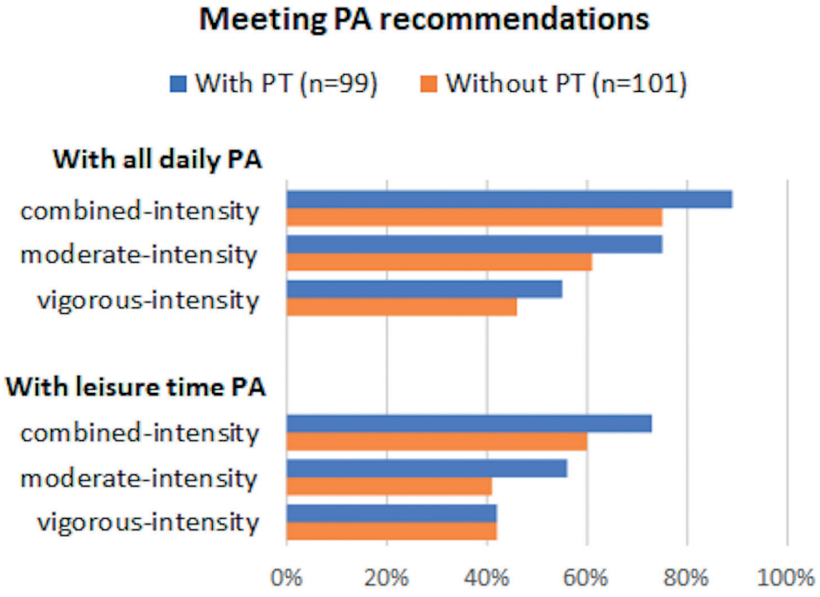

Figure 1. Proportions of axSpA patients with and without physical therapy (PT) meeting the combined-, moderate- and vigorous-intensity PA recommendations, both when including all daily PA and when only including leisure time PA.

Types of aerobic activities

Figure 2 presents the proportions of axSpA patients with and without PT engaging weekly in different forms of leisure or non-leisure time aerobic PA. There were no statistically significant differences between the proportions of participants with and without PT engaging in the different types of aerobic activities, besides engagement in group exercise and aqua-aerobics; these types of aerobic PA were executed by significantly more patients with PT. This difference is likely to be due to participants with group PT, which often consists of group exercise and hydrotherapy in the Netherlands (34). In both groups, it appeared that walking (69%) and cycling (57%) were the most frequently performed aerobic activities.

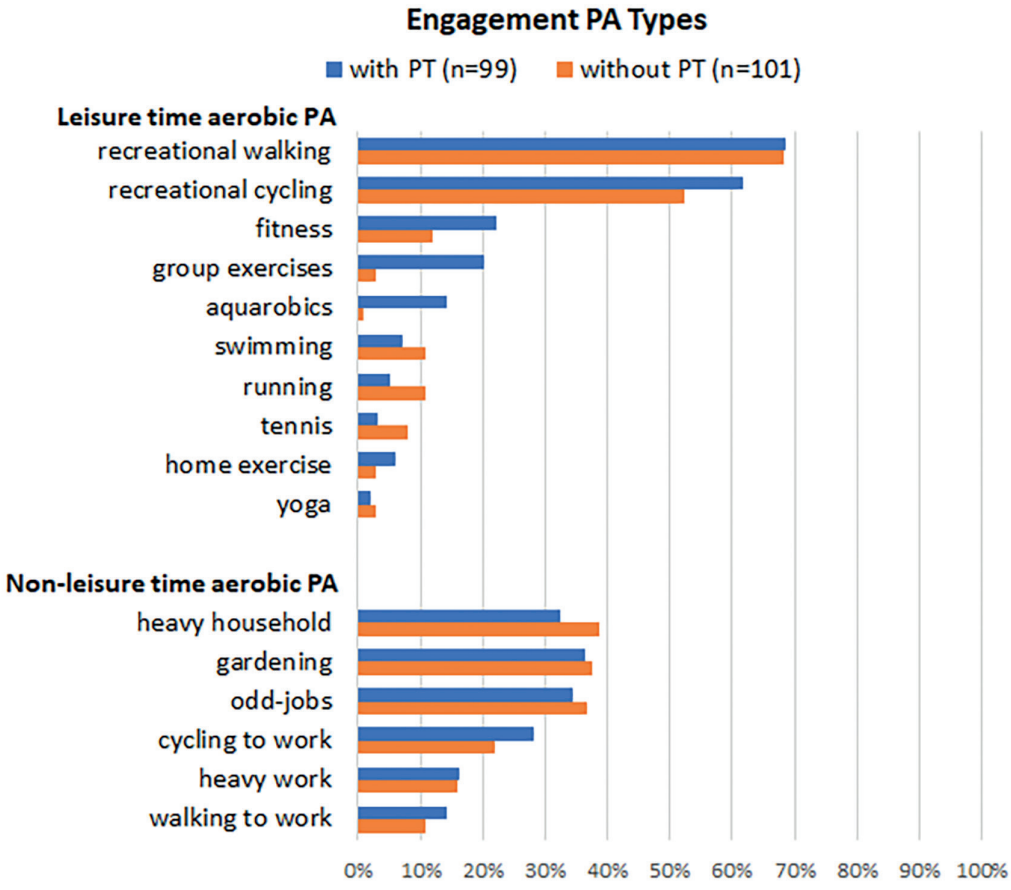

Figure 2. Proportions of axSpA patients with and without physical therapy (PT) engaging in different forms of leisure time aerobic PA (with >2% patients participating) and other aerobic PA types.

Discussion

This study found that people with axSpA who were having PT treatment were more likely to meet the moderate- and combined-intensity aerobic PA recommendations than those without PT, whereas there were no differences in meeting the vigorous-intensity PA recommendation. Irrespective of current PT treatment, the proportion of participants meeting the vigorous-intensity PA recommendation was relatively low and often not attained with leisure time activities.

The finding that having PT treatment was associated with meeting aerobic PA recommendations was not necessarily expected, because PT programs may not include aerobic PA and those who need PT treatment are expected to have more physical limitations and may thus be less physically active. In our study, PT treatment was related to more aerobic PA, but this did not pertain to vigorous-intensity PA. Given the cross-sectional design of the study, it remains unclear whether the association between PT and aerobic PA is a result of PT treatment or that axSpA patients who are already relatively active are more inclined to seek PT treatment. Either way, the findings show that specifically axSpA patients without PT should be better educated on the benefits of aerobic PA. It is recently recommended that all health professionals in rheumatology should promote aerobic PA (15), but especially physical therapists could play an important role in such education, in particular since most individuals with axSpA have PT treatment at some point during their disease course, as confirmed in the present study. However, there is room for improvement in those with PT as well. Our study showed that education on PA is currently only provided in 42% of axSpA patients with individual PT in the Netherlands. In addition, aerobic exercise was only executed during PT in 19% of individual PT programs. This is unfavorable, as guided practice is one of the most important intervention components to optimize exercise behavior of axSpA patients (42). Ideally, axSpA patients could experience and practice vigorous-intensity PA under supervision of a physical therapist. Therefore, aerobic PA should be included more often in individual PT programs, in particular with vigorous intensity.

The finding that particularly vigorous-intensity PA was performed insufficiently by relatively many axSpA patients is consistent with previous findings (21-24). Similar to patients without PT, only half of those with PT met the vigorous-intensity PA recommendation. This finding could be related to results from previous studies, showing that appropriately dosed aerobic PA is often not included in (PT) exercise programs (33, 34). A recent study on content of PT in axSpA patients found that in the Netherlands, aerobic exercises are only performed during individual PT in 22% of patients (32). Hence, when implementing vigorous-intensity PA among people with axSpA, barriers and facilitators of both patients and therapists should be accounted for. A cross-sectional study examining these barriers and facilitators (19)

found that motivation, disease symptoms and group heterogeneity could act as both barriers and facilitators according to patients and physical therapists. An implementation strategy could include education for therapists on how to motivate patients for vigorous-intensity PA and how to tailor and adjust it to varying symptoms, individual preferences and other potential variances among individual patients, such as the presence of comorbidity.

An important note when implementing vigorous-intensity PA is that caution is needed with sedentary individuals and people with an increased risk of cardiovascular complications during exercise (17, 43, 44). Still, for most axSpA patients, vigorous-intensity PA should ultimately be aimed for, since this appears to have more health benefits (10, 16-18) and is more time-efficient (45), while time is an important exercise barrier in axSpA (19, 46, 47).

Regarding the types of actual activities, about half of the participants did not engage in any vigorous-intensity PA during leisure time at all. Studies reporting on the superiority of leisure time PA suggest that possible explanations for the greater benefits of leisure time PA are the difference in nature of activities and the presence of more opportunities to rest and recover when needed (27, 29). The observation that recreational walking and cycling were the most popular forms of aerobic PA in our study could guide physical therapists in their advice and guidance on specific activities that are likely to be maintained in daily life. It is nevertheless conceivable that preferences for recreational activities may vary not only among individuals but among countries as well.

Overall, the proportion of patients meeting the WHO PA recommendation in the current study was much higher than in previous studies, namely 82% as opposed to around 50% in previous studies (21, 23, 25). It is conceivable that the discrepancy might be due to the use of the SQUASH questionnaire. Another recent Dutch study using the SQUASH questionnaire among the general population and people with osteoarthritis found even slightly higher proportions of participants meeting the combined-intensity PA recommendation (48). Nevertheless, despite the probable overestimation of the amount of aerobic PA, the current results are useful to compare subgroups within a population; the SQUASH has indeed shown to be fairly valid and reliable for within group comparisons (39, 40, 49). Therefore, the SQUASH can be regarded as a valid measure to investigate the main objective of this study; to compare moderate- and vigorous-intensity PA between axSpA patients with and without PT. This comparison appears to not have been studied before and is important information to account for when implementing the aerobic PA recommendation.

This study has a number of limitations. First, because of the cross-sectional study design, no conclusions can be drawn about any causal relationships between having

PT and aerobic PA. Second, and as already addressed, by using a self-report questionnaire the amount of PA might have been overestimated (49). Another limitation of the SQUASH is that it does not measure sedentary time. Moreover, it asks participants to recall their PA during a regular week in the past twelve months, whereas the groups compared in this study are based on having PT treatment at the time the study was conducted. As 89% of participants with individual PT were treated for more than 12 months, possibly not in all patients with PT, but at least in most of them, the actual influence of PT treatment on PA have been measured. Finally, the generalizability of our study is limited because the response rate was moderate (45%) and patients were recruited from only three hospitals in one region of the Netherlands. Although the participants of this study were relatively old (3), their sex ratio (3) and the proportion with PT (50) were comparable to other studies.

In conclusion, axSpA patients with PT were more likely to meet the moderate- and combined-intensity but not the vigorous-intensity aerobic PA recommendations than those without PT. These findings imply first of all that in axSpA patients without PT, aerobic PA must be promoted. Second, as vigorous-intensity PA appears insufficiently implemented among those with PT, additional education of physical therapists regarding the importance of and requirements for vigorous-intensity exercise as an essential element of PT programs for axSpA patients seems warranted. With the education of physical therapists, it should be noted that only 19% of patients with PT reported executing aerobic exercise as part of their PT treatment. This may indicate that there is a window of opportunity for physical therapists to increase patients' engagement with vigorous-intensity PA. Future research should thus focus on interventions to optimize aerobic PA in axSpA patients without PT and on the implementation of vigorous-intensity exercise in PT programs.

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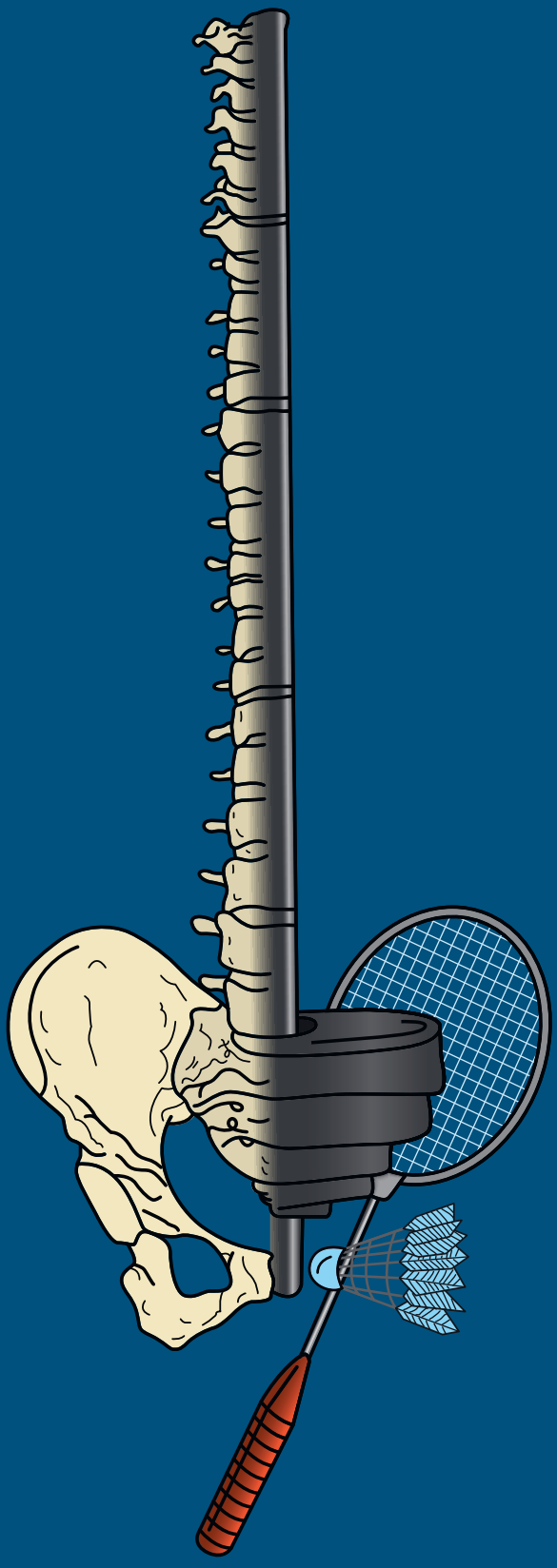

Chapter 3

Differences in characteristics, health status and fulfilment of exercise recommendations between axial spondyloarthritis patients with and without supervised group exercise

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Seminars in Arthritis and Rheumatism 2022;55:152035.

Abstract

Objective

Since decades, supervised group exercise (SGE) is recommended for people with axial spondyloarthritis (axSpA). This study examines if weekly SGE contributes to fulfillment of exercise recommendations in axSpA patients.

Methods

Cross-sectional data from three studies with axSpA patients in the Netherlands, including two with outpatient populations (n=196 and n=153) and one with SGE participants (n=128), were analyzed. Sociodemographic and disease characteristics, SGE participation, health status (ASAS Health Index), spinal mobility and fulfillment of the recommendations for leisure-time aerobic (≥150 min/week moderate-intensity or ≥75 min/week vigorous-intensity) and strength and mobility (≥2 sessions/week) exercise (measured with SQUASH-questionnaire) were assessed. Differences between patients with and without SGE were analyzed.

Results

In the two outpatient populations (n=349), 17 patients (5%) used SGE. The SGE participants (n=145) were significantly older, had longer disease duration, were less frequently employed, used less medication and had worse spinal mobility than patients without SGE (n=332). There were no significant differences in health status. Patients with SGE fulfilled the moderate-intensity aerobic (89% vs. 69%) and strength and mobility (44% vs. 29%) exercise recommendations more often than patients without SGE, but the aerobic exercise recommendation was less often fulfilled with vigorous-intensity exercise (5% vs. 12%).

Conclusion

SGE is used by just few, especially older, axSpA patients and contributes to fulfilling recommendations for moderate-intensity, mobility and strength exercise. Both in patients with and without SGE, only a minority fulfilled the recommendations for vigorous-intensity, strength and mobility exercises. Therefore, future promotion of exercise should focus on implementing these types of exercise.

Introduction

Axial spondyloarthritis (axSpA) is a chronic inflammatory rheumatic disease primarily affecting the spine (1, 2). Patients with axSpA are recommended to engage in aerobic, strength and mobility exercises, dosed according to public health recommendations, to positively influence symptoms, cardiorespiratory fitness, functioning and quality of life (3-7). Supervised group exercise (SGE) in particular has been recommended for many years for axSpA patients (7-9), as it was found to have a better effect on symptoms, fitness and functioning than home exercise (7, 8, 10, 11). In some countries, including the Netherlands and Switzerland, local patient associations organize SGE specifically for axSpA patients: these exercise groups typically combine land-based and aquatic exercises and sports activities and are often supervised by a physical therapist (12-14). However, although axSpA patients are recommended to engage in aerobic, strength and mobility exercises at least twice a week (3, 5), current SGE in the Netherlands focuses primarily on mobility and strength exercise and takes place just once a week (5, 12, 13). To improve the quality of exercise in SGE participants, recent studies sought to implement SGE enhancements, including greater focus on (high-intensity) aerobic exercises and educating patient about additional (home) exercises (14, 15). Therefore, it is important to know how many and which axSpA patients engage in SGE and to what extent they currently engage in exercise according to public health exercise recommendations, also compared to patients without SGE.

It is not entirely clear which axSpA patients participate in SGE, although this is useful information for future exercise promotion. Findings from previous studies suggest that only a small minority of axSpA patients engages in axSpA-specific SGE (12, 16, 17) and that this concerns relatively old axSpA patients (12, 13). This should be taken into account when providing personal exercise advice, as older axSpA patients, on average, have worse spinal mobility (18), slightly worse health status (19, 20) and a higher risk of comorbidities (21).

While many studies have examined engagement in physical activity among axSpA patients, few studies focused specifically on leisure time exercise and no study looked at the differences between axSpA patients with and without SGE. Exercise is a subcategory of physical activity and concerns planned, structured and repetitive activities performed in leisure time and specifically aimed at gaining health benefits (22). Previous studies showed that in axSpA patients the amount of moderate-intensity physical activity was comparable to the general population, while engagement in vigorous-intensity physical activity was lower (16, 23-28), despite the particularly promising effects in axSpA patients (29). The engagement of axSpA patients in mobility (approx. 30%) and strength (approx. 10%) exercises appears to be lacking (6, 23, 30), but the evidence for this is limited. Given the current content of axSpA-specific SGE (12, 13), SGE contributes to engagement in mobility and

strength exercises. However, SGE may prevent patients from participating in other exercise activities, because they already engage in SGE, resulting in not meeting the recommended exercise frequency (≥2 sessions/week (3)).

Thus, it is important to know how many and which axSpA patients participate in SGE and whether SGE contributes to meeting the exercise recommendations. Therefore, this study aims to compare axSpA patients with and without SGE regarding sociodemographic and disease characteristics, health status and engagement in leisure time exercise.

Material and Methods

In this cross-sectional study, data from three cohorts of axSpA patients in the Netherlands were used:

1. Cohort 1 (n=196) concerns data from a cross-sectional study of the Leiden University Medical Center (LUMC), including patients with an axSpA diagnosis confirmed by a rheumatologist from registries of three hospitals in the southwest of the Netherlands (LUMC in Leiden, Haga Hospital in The Hague and Reinier de Graaf Gasthuis in Delft). Eligible patients who had ever visited the rheumatology outpatient clinics from these hospitals were invited for this study in 2015. There was a 45% response rate and the participants´ sex ratio and proportion using physical therapy was comparable to other axSpA studies (16). The study used a survey to examine physical therapy use and physical activity (16).
2. Cohort 2 (n=153) concerns data from the Groningen Leeuwarden Axial Spondyloarthritis (GLAS) cohort, an ongoing prospective longitudinal observational cohort study of two hospitals in the north of the Netherlands (University Medical Center Groningen (UMCG) and Medical Center Leeuwarden (MCL)), with standardized follow-up of axSpA patients fulfilling the modified New York criteria (31) or the ASAS classification criteria for axSpA (32). As part of a validation study, an axSpA-specific physical activity questionnaire, the (m)SQUASH, was added to the GLAS assessment protocol and presented to all consecutive patients participating in GLAS in 2018 (33). These data were used for the present analysis.
3. Cohort 3 (n=128) concerns data from an SGE cohort, with axSpA patients from four regions geographically spread across the Netherlands (Leiden, Mid Limburg, the Gooi and the Hague) where local patient associations affiliated to the Dutch Arthritis Society organize axSpA-specific SGE. The four regions in this cohort participated in a pilot project to implement proposed SGE enhancements (13), which was conducted between 2015 and 2018. Of the 130

SGE participants, almost all patients agreed to participate (n=128). Only baseline data was used for the current study.

The necessary amendments to analyze the data for the present study were approved by the local ethics committees of the LUMC, Haga and RdGG (METC-LDD P14.326/DJ/dj) and UMCG and MCL (GLAS RTPO 364/604).

Assessments

From the three cohorts, data on sociodemographic and disease characteristics, health status and leisure time exercise were gathered.

- Sociodemographic and disease characteristics: Data on age, sex, time since diagnosis (disease duration) and use of medication related to axSpA, i.e. analgesics (acetaminophen or opioids, not available in Cohort 2), Non-Steroidal Anti-Inflammatory Drugs (NSAIDs), biologicals and Disease-Modifying Antirheumatic Drugs (DMARDs), were included. Additionally, employment status was derived from the physical activity questionnaire described below. In Cohort 1 and Cohort 3, data on individual physical therapy use (yes/no) and duration of SGE engagement (years) were also available.
- Disease-related health status: Patients completed questionnaires, including the Bath Ankylosing Spondylitis Disease Activity Index (BASDAI), which measures disease activity (34), the Bath Ankylosing Spondylitis Functional Index (BASFI), which measures physical functioning (35), the Ankylosing Spondylitis Quality of Life (ASQoL) questionnaire, which measures quality of life (36), and the ASAS Health Index (ASAS HI), which measures participants' health status (19). Spinal mobility was assessed with lateral spinal flexion, chest expansion, cervical rotation (from seated position) and the modified Schober's test (37). ASAS HI data were available for Cohorts 1 and 3 and for a subset of Cohort 2. In Cohort 1, no other data on disease-related outcomes were available and ASQoL data were only available in Cohort 2.
- Leisure time exercise: The Short Questionnaire to Assess Health-enhancing physical activity (SQUASH) (38) was used in Cohort 1 and Cohort 3 to assess exercise engagement. The modified (m)SQUASH, an axSpA-specific adaptation of the SQUASH (33), was used in Cohort 2. Both the SQUASH and mSQUASH measure all physical activity during an average week in the past month. This study focuses only on leisure time exercise and, therefore, only extracted frequency and duration of recreational walking, cycling and other exercise activities that patients reported to engage in from these questionnaires. Both questionnaires also allowed to identify which patients from Cohorts 1 and 2 engaged in SGE. All exercise activities were assigned the corresponding MET-value using Ainsworth's compendium (39); this was done identically for both the SQUASH and the mSQUASH. Duration (minutes/week) and frequency

(sessions/week) of all aerobic exercise activities were calculated, as well as engagement in vigorous-intensity exercise (yes/no) and fulfillment of the World Health Organisation (WHO) recommendations for aerobic exercise (moderate-intensity exercise, defined as ≥3 MET, for ≥150 min/week and/or vigorous-intensity exercise, defined as ≥6 MET, for ≥75 min/week and/or an equivalent combination) (40). In addition, the frequency of engagement in exercise types with strength and mobility components was calculated, i.e. gym, aquatic and home exercise, SGE, competitive sports, climbing and body and mind exercise (yoga, Pilates or tai chi). It was then assessed whether the recommended frequency for these strength and mobility exercises (≥2 sessions/week) was fulfilled (yes/no).

Statistical analyzes

For Cohorts 1 and 2, SGE engagement was extracted from the physical activity questionnaires. The SGE participants from Cohorts 1 and 2 were combined with SGE participants from Cohort 3 after assessing if the data from the three cohorts could be combined. Descriptive statistics were used to report sociodemographic and disease characteristics, health status and exercise engagement, for patients with and without SGE separately. Results were reported as means and standard deviations (SD) or medians and interquartile range (IQR) for normally and non-normally distributed continuous variables, respectively. Numbers and percentages were reported for categorical variables. To examine whether the data from the three cohorts could be combined, characteristics of patients with and without SGE were compared between the three different cohorts using the Mann-Whitney U test for non-normally distributed continuous variables and the Chi-Square test for categorical variables.

A 'cross-walk' procedure of ASQoL data into ´expected ASAS HI´ scores was performed for patients in Cohort 2 with no available ASAS HI data. For this 'cross-walk', the models of Pike at al. (41) were applied and validated using data of 34 participants of the current study who had both ASAS HI and ASQoL data available. A Bland-Altman plot (Figure A1 in Appendix A) showed no proportional bias in these data.

To examine the differences between patients with and without SGE, Chi-square tests and Mann-Whitney U tests were used where appropriate. In addition, univariate and multivariate regression models were performed to examine the associations of SGE with fulfillment of the aerobic, strength and mobility exercise recommendations and to correct for potential covariates, i.e. age, sex, employment and ASAS HI (42, 43). For the associations with aerobic exercise recommendations, multinomial regression models were used, because the dependent variable consisted of three categories: not fulfilling any aerobic exercise recommendation

(reference category), fulfilling only the moderate-intensity exercise recommendations (≥ 150 minutes per week) and fulfilling the vigorous-intensity exercise recommendation (≥ 75 minutes per week). For the strength and mobility exercise recommendation (≥2 sessions/week), logistic regression models were used. Exploratory analyzes were performed to examine the associations of duration of SGE participation with ASAS HI and exercise engagement, using Spearman's correlation. All statistical analyzes were performed with IBM SPSS Statistics for Windows, version 23.0 (IBM Corp., Armonk, N.Y., USA).

Results

Patient characteristics

Among the three cohorts (n=477), 145 axSpA patients participated in SGE: in addition to the 128 SGE participants from Cohort 3, also 17 of 349 patients (5%) in the outpatient populations of Cohort 1 (n=13/196) and Cohort 2 (n=4/153). In these 145 patients, the median duration of SGE participation was 22 years (IQR 9-25). Before comparing patients with and without SGE, it was assessed if the data from the three cohorts could be combined by comparing the 17 SGE participants from Cohorts 1 and 2 with the 128 from Cohort 3 as well as the patients without SGE from Cohorts 1 and 2. The subgroups in the different cohorts proved to be sufficiently comparable: between SGE participants from Cohorts 1 and 2 and Cohort 3, only the difference in employment status reached statistical significance and in the patients without SGE from Cohorts 1 and 2, only age and disease duration were significantly different (see Supplementary Table S1). Therefore, the data were combined.

The differences in characteristics between patients with (n=145) and without (n=332) SGE are presented in Table 1. AxSpA patients with SGE were significantly older ($p < 0.001$), had longer disease duration ($p < 0.001$) and were less likely to use biologicals ($p < 0.001$) and analgesics ($p < 0.05$). Furthermore, a lower proportion of SGE participants were employed ($p < 0.05$), but this difference was not significant when stratifying subgroups for being younger or older than 65 years. Additional analysis showed that although not using NSAIDs, biologicals or DMARDS was associated with engaging in SGE, these patients did not report a higher use of analgesics or individual physical therapy (data not shown).

Table 1. Differences between axSpA patients with and without SGE in patient characteristics.

	Patients with SGE (n=145)	Patients without SGE (n=332)	*P* [a]
Age, years, Med (IQR)	61 (52-70)	53 (41-63)	**<0.001**
Sex, male, n (%)	92/139 (66)	214/331 (65)	0.750
Disease duration, years, Med (IQR)	27 (15-36)	15 (6-30)	**<0.001**
Individual physical therapy use [b], n (%)	41/97 (42)	81/182 (45)	0.720
Medication use, n (%)			
No NSAID, biological or DMARD	36/125 (29)	35/314 (11)	**<0.001**
NSAID	70/125 (56)	199/303 (66)	0.060
Biological	23/125 (18)	129/316 (41)	**<0.001**
DMARD	15/125 (12)	50/316 (16)	0.307
Analgesics [b]	32/121 (26)	69/183 (38)	**0.041**
Being employed, n (%)	64/135 (47)	186/320 (58)	**0.036**
Employment among under 65s	58/87 (67)	180/254 (71)	0.462
Employment among over 65s	6/48 (13)	8/67 (12)	0.928

[a] P-value of Mann Whitney U Test (continuous variables) or Chi Square Test (categorical variables).

[b] Not assessed in Cohort 2 (only in Cohorts 1 and 3)

AxSpA = axial spondyloarthritis; SGE = supervised group exercise; NSAID = nonsteroidal anti-inflammatory drug; DMARD = disease-modifying antirheumatic drug.

Disease-related health-status

The ASAS HI was available for 353 participants. In addition, 'cross-walking' of ASQoL data was applied in 59 participants to calculate the expected ASAS HI (see Supplementary Figure S1). This resulted in a total of 412 ASAS HI scores. The other health-status variables were available in fewer participants, because these were not measured in Cohort 1. As shown in Table 2, there were no significant differences in ASAS HI, BASFI or BASDAI between patients with and without SGE. AxSpA patients with SGE had significantly worse lateral spinal flexion ($p = 0.01$) and cervical rotation ($p < 0.001$), but not when adjusting for age ($p = 0.321$ and 0.064, respectively). Duration of SGE participation was not significantly associated with ASAS HI scores (data not shown).

Table 2. Differences between axSpA patients with and without SGE in different disease-related outcomes.

	Patients with SGE		Patients without SGE		*P* [a]
	N	Med (IQR)	N	Med (IQR)	
ASAS Health Index [b]	133	5.0 (3.0-7.0)	279	5.0 (2.0-8.3)	0.678
BASFI [c]	56	4.0 (1.9-5.5)	110	2.8 (1.0-5.7)	0.156
BASDAI [c]	80	3.8 (2.3-4.8)	141	3.4 (1.7-6.0)	0.591
Spinal mobility [c]					
Lateral spinal flexion	85	9.5 (5.4-14.7)	137	12.3 (8.3-16.3)	**0.010**
Chest expansion	86	2.5 (1.7-4.0)	137	3.0 (1.0-5.0)	0.369
Cervical rotation	44	52 (40-70)	137	70 (60-80)	**<0.001**
Modified Schober's test	44	3.5 (2.4-4.8)	137	4.0 (3.0-5.0)	0.542

[a] P-value of Mann Whitney U Test. When adjusting for age, there was no significant difference between axSpA patients with and without SGE.
[b] Original ASAS Health Index: n=353. Expected ASAS Health by 'cross-walking' the Ankylosing Spondylitis Quality of Life (ASQoL) scores (Pike et al., 2021): n=59.
[c] Not assessed in Cohort 1 (only in most in Cohort 2 and partially in Cohort 3)
AxSpA = axial spondyloarthritis; SGE = supervised group exercise; Med = median; IQR = interquartile range; BASFI = Bath Ankylosing Spondylitis Functional Index; BASDAI = Bath Ankylosing Spondylitis Disease Activity Index.

Leisure time exercise

Table 3 and Figure 1 show the differences in weekly exercise engagement between axSpA patients with and without SGE. Compared to axSpA patients without SGE, patients with SGE were significantly more likely to fulfill the moderate-intensity (89% vs. 69%) and the combined WHO aerobic exercise recommendations (90% vs. 74%), while they were less likely to fulfill the aerobic exercise recommendation with vigorous-intensity exercise (5% vs. 12%). In both patients with and without SGE, only a small minority engaged in any vigorous-intensity exercise (7% vs. 16%, respectively).

Table 3. Difference between axSpA patients with and without SGE in weekly exercise engagement.

	Patients with SGE (n=135)	Patients without SGE (n=320)	*P* [a]
WHO aerobic exercise recommendations, n (%)	121 (90)	236 (74)	**<0.001**
Moderate-intensity exercise ≥150 min/wk	120 (89)	222 (69)	**<0.001**
Vigorous-intensity exercise ≥75 min/wk	7 (5)	38 (12)	**0.029**
Aerobic exercise [b] duration, minutes, Med (IQR)	420 (285-660)	283 (120-540)	**<0.001**
Aerobic exercise [b] frequency, sessions, Med (IQR)	6 (4-9)	5 (2-9)	**0.035**
Strength/mobility exercise [c] ≥2 sessions, n (%)	59 (44)	92 (29)	**0.002**
Exercise types, n (%)			
Recreational walking	92 (68)	222 (69)	0.796
Recreational cycling	84 (62)	179 (56)	0.215
Aquatic exercise (besides SGE)	33 (24)	41 (13)	**0.002**
Gym exercise	17 (13)	69 (22)	**0.026**
Home exercise	9 (7)	23 (7)	0.843
Running	3 (2)	26 (8)	**0.019**
(Competitive) sports	10 (7)	25 (8)	0.882
Body and mind exercise	5 (4)	10 (3)	0.752
Other sports	2 (2)	8 (3)	0.498

[a] P-value of Mann Whitney U Test (continuous variables) or Chi Square Test (categorical variables).

[b] This includes all exercise with at least moderate-intensity (≥3 MET), including SGE.

[c] This includes exercise types with potential strength and mobility components, including SGE.

AxSpA = axial spondyloarthritis; SGE = supervised group exercise; min/wk = minutes per week; Med = median; IQR = interquartile range.

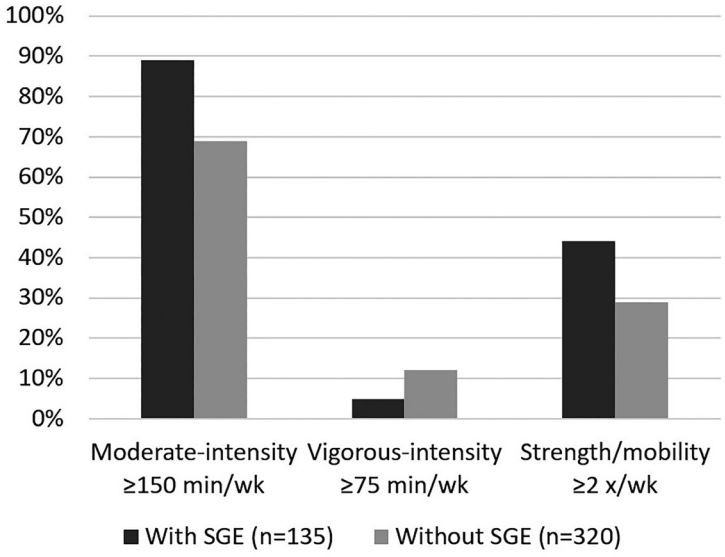

Figure 1. Differences in fulfillment of exercise recommendations between axial spondyloarthritis patients with and without supervised group exercise (SGE). Min/wk = minutes per week; x/wk = sessions per week.

Furthermore, the recommendation for strength and mobility exercise (≥2 sessions/week) was fulfilled by 44% of patients with SGE (including the weekly SGE engagement) and by 29% of patients without SGE ($p < 0.01$). SGE participants engaged in aquatic exercise significantly more often ($p < 0.01$) and in running and gym exercise less often (both $p < 0.01$) than patients without SGE. Walking and cycling were the most popular forms of exercise in both groups.

Tables 4 and 5 present the results of the multinominal and logistic regression analyzes. After adjusting for age, sex, being employed and ASAS HI scores, SGE participation was significantly associated with fulfilling the aerobic recommendation with only moderate-intensity exercise as well as the strength and mobility exercise recommendation.

Finally, exploratory analyzes showed that duration of SGE participation was not significantly associated with exercise engagement (data not shown).

Table 4. Multinomial regression analyzes exploring factors associated with fulfilling aerobic exercise recommendations in axSpA patients (n=402).

	Univariable			Multivariable		
	Exp(*B*)	95% CI	*P*	Exp(*B*)	95% CI	*P*
Fulfilling recommendation with only moderate-intensity						
SGE engagement (no)	0.28	0.15-0.51	**<0.001**	0.35	0.18-0.67	**0.002**
Age (years)	1.03	1.01-1.04	**0.003**	1.01	0.99-1.03	0.602
Sex (male)	1.08	0.68-1.71	0.756	1.09	0.63-1.87	0.765
Being employed (no)	2.00	1.25-3.19	**0.004**	2.36	1.29-4.34	**0.006**
ASAS Health Index (0-17)	0.97	0.90-1.03	0.306	0.94	0.87-1.01	0.080
Fulfilling recommendation with vigorous-intensity						
SGE engagement (no)	0.87	0.33-2.34	0.788	0.96	0.33-2.78	0.945
Age (years)	1.00	0.98-1.03	0.957	1.01	0.98-1.05	0.553
Sex (male)	3.98	1.54-10.30	**0.004**	2.31	0.83-6.41	0.108
Being employed (no)	0.61	0.28-1.35	0.222	1.04	0.36-2.98	0.948
ASAS Health Index (0-17)	0.71	0.61-0.82	**<0.001**	0.73	0.63-0.85	**<0.001**

Reference category = not fulfilling aerobic exercise recommendations.
AxSpA = axial spondyloarthritis; SGE = supervised group exercise.

Table 5. Logistic regression analyzes exploring factors associated with fulfilling strength/mobility exercise recommendation in axSpA patients (n=402).

	Univariable			Multivariable		
	Exp(*B*)	95% CI	*P*	Exp(*B*)	95% CI	*P*
SGE engagement (yes)	1.92	1.27-2.92	**0.002**	1.82	1.16-2.88	**0.010**
Age (years)	1.01	0.99-1.02	0.455	1.00	0.98-1.01	0.603
Sex (female)	0.88	0.58-1.33	0.547	0.88	0.55-1.39	0.568
Being employed (yes)	0.85	0.58-1.26	0.427	0.70	0.43-1.14	0.155
ASAS Health Index (0-17)	0.94	0.88-0.99	**0.027**	0.93	0.87-0.99	**0.016**

Dependent variable = fulfilling the strength and mobility exercise recommendation (≥2 sessions per week).
AxSpA = axial spondyloarthritis; SGE = supervised group exercise.

Discussion

This study showed that just a small minority of axSpA patients participated in SGE; only 5% of two outpatient cohorts in different regions in the Netherlands. After combining the data of these two outpatient populations with that of a cohort of SGE participants, it was found that patients engaging in SGE were older, had longer disease duration, were less frequently employed, used less medication and had worse spinal mobility, yet fulfilled the recommendations for (moderate-intensity) aerobic and strength and mobility exercise more often than patients without SGE. Both among patients with and without SGE, the vast majority fulfilled the aerobic exercise recommendation with moderate-intensity exercise (89% and 69%, respectively), mainly through (brisk) walking and cycling, and only a minority fulfilled it with vigorous-intensity exercise (5% and 12%) or fulfilled the recommendation for strength and mobility exercise (44% and 29%). These findings were in line with previous studies (6, 16, 23-28, 30), showing that although most axSpA patients engage in sufficient moderate-intensity exercise, just a minority engages in vigorous-intensity, mobility and strength exercise. These results demonstrate that SGE contributes to fulfilling the recommendations for aerobic, mobility and strength exercise. Apparently, SGE participation does not prevent engagement in other exercise activities, but comes as an addition to it.

The observed differences in age, disease duration, employment and spinal mobility between patients with and without SGE were in line with indications from previous studies (12, 13, 18). However, both the lower medication use in patients with SGE and the comparable health status between patients with and without SGE were surprising, as health status and physical functioning may deteriorate with age in axSpA patients, similar to spinal mobility (18-20). It can be speculated that SGE participation prevented deterioration of health status and the need for analgesics, since previous studies have shown positive effects of SGE on symptoms, fitness and functioning (7, 8, 10, 11). However, another possibility is that patients with better health status and a more active coping choose to participate in SGE.

The findings of this study could guide future exercise promotion, which should likely have different aims for axSpA patients with and without SGE, as SGE participants are apparently an aging subgroup within the axSpA population. For patients with SGE, the current findings support previously proposed SGE enhancements advocating for higher intensity aerobic exercise during SGE and for patient education about more frequent exercise to meet mobility and strength exercise recommendations (12, 13). For patients without SGE, it seems justified to encourage more weekly exercise engagement, either by promoting SGE or other appropriate exercise activities. Physical therapists are in a good position to provide such exercise promotion, as the vast majority of axSpA patients uses physical therapy over the course of their disease (16, 17).

Since there are many differences in personal exercise preferences and in SGE availability between regions (12), future studies could explore which exercise activities are suitable and equally effective alternatives to SGE. Cycling and (brisk) walking proved to be the most popular exercise activities: while they may be suitable for aerobic exercise, they are not suitable for mobility and strength and are rarely performed at high-intensity. Therefore, patients should be educated about other appropriate exercise activities that may include high-intensity, strength and mobility components, such as a home, gym or aquatic exercise program. Such education requires a personalized approach, taking into account key barriers and facilitators, including personal motivation and self-efficacy (6, 44). Furthermore, to support maintenance of exercise over time, it might help to promote group exercise activities for some patients (6).

Some study limitations should be noted. First, while combining data of three cohorts resulted in a larger, more generalizable study population with more statistical power for analysis, it also resulted in missing data and in variation in the assessments used. This was partially resolved by 'cross-walking' ASQoL data to expected ASAS HI scores and by using only the leisure time exercise questions of the SQUASH and the mSQUASH, which were identical. Another limitation is that both the SQUASH and mSQUASH are known to overestimate the intensity of physical activity (33, 45). The proportion engaging in mobility and strength exercise may also have been overestimated, as it is uncertain what types of exercise participants actually performed when reporting to exercise at home or in the gym, for example. Finally, a relatively low explained variance was found in the regression models. This may have been caused by not measuring motivation and self-efficacy, both important determinants of exercise behavior (6).

In conclusion, SGE contributes to fulfilling the exercise recommendations in axSpA patients, but only few, especially older patients, seem to participate in it. Furthermore, future exercise promotion should focus on more engagement in exercise activities with vigorous-intensity and with strength and mobility components, as only a minority is sufficiently engaged in this. These types of exercise should be implemented both within SGE and among the general axSpA population.

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Supplementary data

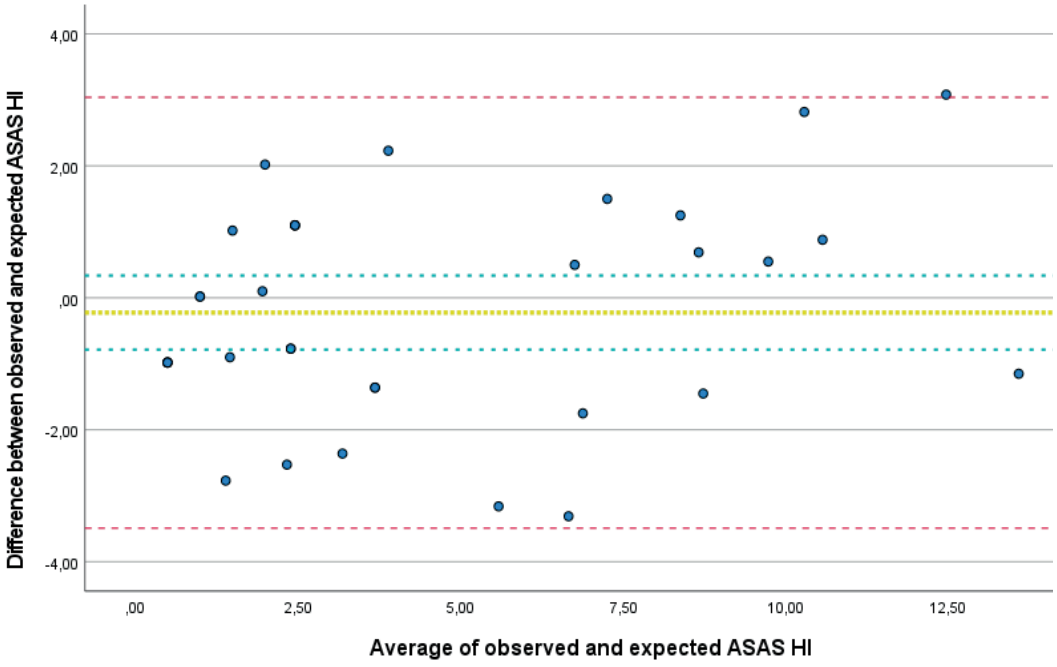


Figure S1. Bland-Altman plot to analyse agreement between observed and expected (from ASQoL) ASAS HI scores (N=34).
*Yellow line = Mean; Blue lines = 95% confidence interval (1,96 * SE Mean); red lines = limits of agreement (1,96 * SD). ASAS HI = ASAS Health Index; ASQoL = Ankylosing Spondylitis Quality of Life.*

The Bland-Altman plot shows there is no proportional bias in the data, as the observed ASAS HI scores agree equally through the range of measurements with the ASAS HI scores expected from the ASQoL data. The absence of proportional bias was confirmed by a univariate regression analysis and a one-sample t-test.

Table S1. Comparison of characteristics of axSpA patients with and without SGE among three different cohorts.

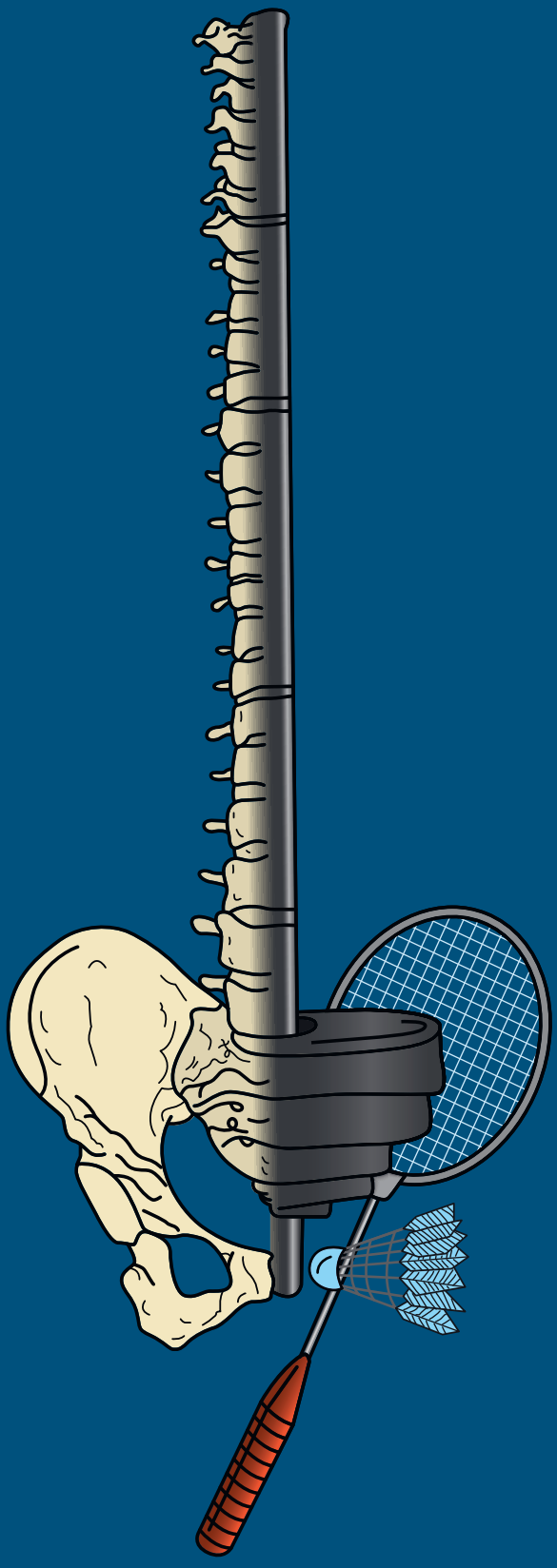
	With SGE			Without SGE		
	Cohort 1&2 (n=17)	Cohort 3 (n=128)	*P* [a]	Cohort 1 (n=183)	Cohort 2 (n=149)	*P* [a]
Age, years, Med (IQR)	62 (51-73)	60 (52-69)	0.686	57 (45-67)	50 (37-57)	**<0.001**
Sex, male	13/17 (77)	79/122 (64)	0.339	126/182 (69)	88/149 (59)	0.054
Disease duration, years, Med (IQR)	29 (17-37)	27 (15-36)	0.683	23 (9-35)	11 (5-19)	**<0.001**
Individual physical therapy use [b]	4/13 (31)	37/84 (44)	0.367	81/182 (44)	n/a	n/a
Medication use						
No NSAID, biological or DMARD	3/17 (18)	33/108 (31)	0.275	24/183 (13)	11/131 (8)	0.190
NSAID	12/17 (71)	58/108 (54)	0.192	113/183 (62)	86/120 (72)	0.075
Biological	6/17 (35)	17/108 (16)	0.053	70/183 (38)	59/133 (44)	0.275
DMARD	3/17 (18)	12/108 (11)	0.441	23/183 (13)	27/133 (20)	0.063
Analgesics [b]	6/13 (46)	26/108 (24)	0.088	69/183 (38)	n/a	n/a
Being employed	4/17 (24)	60/118 (51)	**0.035**	100/177 (57)	90/147 (61)	0.390

Reporting frequency (and percentage) unless stated otherwise.

[a] P-value of Mann Whitney U Test (continuous variables) or Chi Square Test (categorical variables).

[b] Not assessed in Cohort 2 (only in Cohorts 1 and 3)

AxSpA = axial spondyloarthritis; SGE = supervised group exercise; Med = median; IQR = interquartile range; NSAID = nonsteroidal anti-inflammatory drug; DMARD = disease-modifying antirheumatic drug; Cohort 1 = LUMC-study (among outpatient clinic population); Cohort 2 = GLAS cohort (among outpatient clinic population); Cohort 3 = SGE Cohort (among SGE participants).



Chapter 4

Organisation and content of supervised group exercise for people with axial spondyloarthritis in the Netherlands

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Rheumatology International 2021;41(2):391-401

Abstract

Objective

Supervised group exercise (SGE) is recommended for people with axial spondyloarthritis (axSpA). Recent literature suggests that its contents and dosage must probably be revised. As a first step towards renewal, this study examined the current SGE organisation and content for people with axSpA in the Netherlands.

Methods

A pen-and-paper survey was sent to the boards of the 82 local patient associations affiliated with the Dutch Arthritis Society in 2016. One member of each board was asked to complete questions on the nature and organisation of SGE and one of the supervising therapists to complete questions on the SGE supervision and contents.

Results

The questionnaire was returned by representatives of 67/82 (82%) local patient associations, of which 17 (25%) provided axSpA-specific SGE (16/17 SGE programmes with both land-based exercise and hydrotherapy and 1/17 with only hydrotherapy). These involved in total 56 groups with 684 participants and 59 supervisors, of whom 54 were physical therapists and 21 had had postgraduate education on rheumatic and musculoskeletal diseases (RMDs). Besides mobility and strengthening exercises and sports (17/17), most programmes included aerobic exercise (10/17), but rarely with heart rate monitoring (1/17), patient education (8/17), periodic assessments (2/17) or exercise personalisation (1/17).

Conclusion

In the Netherlands, a quarter of local patient associations organised axSpA-specific SGE, mostly containing land-based exercises combined with sports and hydrotherapy. Most supervisors lacked postgraduate education on RMDs and most programmes lacked intensity monitoring, patient education, periodic assessments and personalisation, which are needed for optimising exercise programmes according to current scientific insights.

Introduction

Axial spondyloarthritis (axSpA) is an inflammatory rheumatic disease that primarily affects the spine and sacroiliac joints and is characterised by chronic back pain and stiffness that often decreases with exercise (1, 2). Exercise is proven effective in reducing symptoms and increasing spinal mobility, cardiorespiratory fitness and physical functioning of people with axSpA (3-10). The literature in particular demonstrates that supervised group exercise (SGE) is more effective in improving quality of life, spinal mobility and patient global assessment than unsupervised, individual exercise (5, 10-13). However, it must be noted that the evidence supporting SGE in AxSpA is mostly based on studies that were published quite some time ago and the main focus of the interventions in these trials concerned joint mobility exercises (10, 14). This contrasts with recent literature suggesting that SGE for people with axSpA would ideally also include patient education and muscle strengthening and aerobic exercises, with the right frequency and intensity, that are personalised according to regular reassessments (6-11, 15, 16).

The implementation of these new insights in current practice of SGE in axSpA however appears to be insufficient. In the Netherlands, the nature and contents of many of the SGE programmes for axSpA patients are still based on an intervention used in a randomised, controlled trial from a few decades ago (17). In that period, an inventory of practice was made, finding that there were 31 SGE classes in the Netherlands, which all used land-based joint mobility and muscle strengthening exercises (100%), often combined with sports (84%) and hydrotherapy (72%) (18). The SGE classes took place weekly, with an average duration of 95 minutes (range 50 and 155). Furthermore, the large majority of the supervisors were physical therapists (90%) and only few had had postgraduate education on SGE (8%) (18). A recent study in four regions in the Netherlands where SGE for patients with axSpA is provided showed that current practice appears similar to the situation in 1991 (19). That study suggests that SGE contents and dosage must be revised to meet current scientific insights. Additional knowledge regarding current SGE engagement, organisation and content among people with axSpA from other studies appears to be scarce. Two Swiss studies report that 68 axSpA-specific SGE groups are organised by the Ankylosing Spondylitis Association of Switzerland, in which SGE is provided mostly on land, often complemented with hydrotherapy, on a weekly basis, supervised by a physical therapist and focusing on muscular strength and joint mobility (20, 21). In the United Kingdom, it is reported that land-based SGE and hydrotherapy are organised by 74 and 65 branches from the National Axial Spondyloarthritis Society (NASS), respectively (22). No information is provided on the specific contents or organisational characteristics of SGE for people with axSpA. Regarding overall SGE use, a recently published cross-sectional study on the engagement of people with axSpA in SGE found that in the Netherlands and

Switzerland 9% and 30% of the respondents are attending SGE, respectively, and that these numbers are declining over time, while the average age of SGE participants is increasing (23).

Since detailed information on the actual provision of SGE for axSpA on the national level is missing, this study examines the current use, content, supervision and organisational characteristics of SGE for axSpA patients in the Netherlands. This is a first step towards a revision of the content and dosage of SGE; a development which appears to be supported not only form a scientific viewpoint but from the patients' perspective as well (19).

Methods

Design

This cross-sectional study, conducted in 2016, constituted the basis for a follow-up project aiming to improve SGE for people with axSpA. The first step concerned a pilot implementation project including four local patient associations (19). A survey was sent to the boards of 82 local patient associations affiliated with the Dutch Arthritis Society in the Netherlands at that time. The medical ethics committee of the Leiden University Medical Center approved the study protocol and judged that a full review was not needed due to the observational nature of the study and that subjects who were invited were free to complete the survey or not (CME file P14.326). The study was conducted in line with the national and international regulations regarding the handling of personal data in research (24).

Subjects

At the time of sending the survey in 2016, 82 local patient associations were affiliated with the Dutch Arthritis Society: some of these associations are axSpA-specific and some are for patients with any rheumatic and musculoskeletal disease (RMD), including axSpA (25). All associations organising SGE for people with axSpA, regardless of whether the SGE was exclusively for people with axSpA or not, were included in the present study.

Assessments

A pen-and-paper survey was sent to the boards of the patient associations accompanied by an invitational letter, signed by the Patient Interests department of the Dutch Arthritis Society. This questionnaire approach was chosen, as the Dutch Arthritis Society was involved in the distribution and collection of the surveys and this was well in line with their usual way of communication with the local patient associations. The survey contained two parts: one part to be completed by

a board representative and the second part by a supervisor of SGE, but only in case SGE was provided (either axSpA-specific or for any RMD). The survey was self-developed and used dichotomous-, multiple-answer- (MA) and open-field questions.

Part One, to be completed by a board representative, included the following topics:

- SGE characteristics: number and nature of therapeutic SGE (land-based, hydrotherapy or combination); number of participants and duration and frequency of sessions of therapeutic SGE; number and nature of other SGE (e.g. walking or running, Nordic Walking, Tai Chi).
- Organisational characteristics: responsibilities of associations (regarding organising and financing accommodation, equipment, supervision or membership campaigns); funding sources (agreements with health insurances, membership dues, sponsoring and funding from Dutch Arthritis Society); existence and frequency of structural and incidental evaluations of SGE contents and organisation with members and supervisors (dichotomous questions).
- Recruitment of supervisors: nature of activities (advertising online, by the departing supervisor or through own network); selection criteria for supervisors (experience with guiding axSpA patients, experience with guiding exercise groups, membership local rheumatism network or adequate education); perceived success in finding adequate supervision.
- Recruitment of members (patients): nature of activities (advertising in own media, in door-to-door magazines, through general practitioners, through physical therapists or through rheumatology clinics); developments in number of members over time (inclined, unchanged or declined).
- Barriers: experienced barriers and challenges which the board member would like to see changed or improved (open-field question).

Part Two, to be completed by a supervisor of SGE (either axSpA-specific or for any RMD);

- Characteristics of supervisors: number of SGE supervisors per association and per group; professional background (physical therapist, physical therapy student or sports and exercise instructor); years of experience with SGE (<1 year, 1–5 years, >5 years); completion of postgraduate education on RMD (yes/no); membership of a professional local rheumatology network (yes/no).
- SGE contents: therapy modalities used (joint mobility exercises, muscle strengthening exercises, aerobic exercise, breathing exercises, functional exercises, walking exercises, swimming exercises, relaxation exercises, volleyball or other sports or passive mobilisation techniques). In addition, there were questions on the use of heart rate monitoring (yes/no), providing

education on axSpA (yes/no), periodic assessments (yes/no; if so, frequency and measurement instruments used) and exercise personalization (individual goal setting and training schedule; yes/no).

Statistical analysis

The analyses were done separately for axSpA-specific SGE and for SGE for people with any RMD. The categorical data are presented as frequencies and percentages and the continuous data as means with standard deviations or medians and range, where appropriate. The statistical analyses were performed using IBM SPSS Statistics for Windows, version 23.0 (IBM Corp., Armonk, NY, USA).

Results

The questionnaire was returned by the board members of 67 of the 82 (82%) local patient associations. Forty-three (64%) of these 67 associations were involved in organising SGE for people with axSpA: 17/67 (25%) provided SGE specifically for axSpA and 26/67 (39%) for people with any RMD (not exclusively for axSpA). From all these 43 associations involved in organising SGE, a supervisor had completed survey Part Two on SGE contents and supervisor characteristics (*n*=43). As shown in Table 1, axSpA-specific SGE (*n*=17 associations) was offered to 56 groups, including a total of 684 participants, whereas SGE for any RMD (*n*=19 associations; seven respondents did not provide these data) was offered to 167 groups, including 1940 participants.

SGE characteristics and contents

As shown in Table 1, the SGE in the 17 local patient associations organising axSpA-specific SGE consisted most frequently of a programme combining land-based exercise and hydrotherapy (16/17, 94% of these associations). Two associations (12%) organised hydrotherapy only programmes, of which one also organised the combination programme. In addition to these therapeutic SGE programmes, four associations (24%) also organised other SGE, which included only sports, i.e. volleyball, Nordic Walking or Tai Chi classes, specifically for people with axSpA.

With regard to SGE for any RMD, which was organised by 26 local patient associations, most associations organised a programme with only hydrotherapy (19/26, 73% of these associations), followed by the programme combining land-based exercise and hydrotherapy (12/26, 46% of associations). Furthermore, seven (27%) organised a programme with solely land-based therapeutic SGE and seven (27%) provided other SGE, which involved yoga or Tai Chi in four cases and Nordic Walking in the other three cases. Eleven associations (42%) provided more than one type of programme.

The frequency of SGE was once weekly for all associations besides one, where participants participated in the hydrotherapy three times weekly. The duration varied between the different types of programmes, with the combination programme taking the longest (mostly 90 minutes or more), the land-based SGE programmes having a median of 60 minutes and the programmes with only hydrotherapy having a median duration of 45 minutes in the axSpA-specific SGE and 60 minutes in the SGE for any RMD.

Table 1. Characteristics of supervised group exercise (SGE) programmes for people with axSpA in the Netherlands.

	axSpA-specific SGE (LPA *n*=17)	SGE for any RMD (LPA *n*=26)
Total number of groups, *n*	56	167 (LPA *n*=19)[a]
Total number of participants, *n*	684	1940 (LPA *n*=19)[a]
Combined land- and hydrotherapy groups, *n* (%)	31/56 (55.4)	28/167 (16.8)
Number of LPA organising this, *n* (%)	16/17 (94.1)	12/26 (46.2)
Groups per LPA, Mdn (range)	2 (1-4)	1 (1-15)
Total number of participants, n	370	262 (LPA *n*=19)[a]
Participants per LPA, Mdn (range)	20 (12-75)	18 (8-80)
Frequency, sessions per week, Mdn (range)	1 (1-1)	1 (1-1)
Duration, minutes per session, Mdn (range)	102.5 (45-180)	90 (60-150)
Land-based only therapy groups, *n* (%)	0/56 (0)	7/167 (4.2)
Number of LPA organising this, *n* (%)	n/a	7/26 (26.9)
Groups per LPA, Mdn (range)	n/a	1.5 (1-3)
Total number of participants, n	n/a	79 (LPA *n*=19)[a]
Participants per LPA, Mdn (range)	n/a	16 (6-41)
Frequency, sessions per week, Mdn (range)	n/a	1 (1-1)
Duration, minutes per session, Mdn (range)	n/a	60 (45-90)
Hydrotherapy only groups, *n* (%)	13/56 (23.2)	120/167 (71.9)
Number of LPA organising this, *n* (%)	2/17 (11.8)	19/26 (73.1)
Groups per LPA, Mdn (range)	6.5 (3-10)	6 (1-19)
Total number of participants, n	168	1466 (LPA *n*=19)[a]
Participants per LPA, Mdn (range)	84 (45-123)	80 (3-230)
Frequency, sessions per week, Mdn (range)	1 (1-1)	1 (1-3)
Duration, minutes per session, Mdn (range)	45 (30-60)	60 (30-60)

Table continues

Table 1 (Continued). Characteristics of supervised group exercise (SGE) programmes for people with axSpA in the Netherlands.

	axSpA-specific SGE (LPA *n*=17)	SGE for any RMD (LPA *n*=26)
Other SGE[b], *n* (%)	11/56 (19.6)	12/167 (7.2)
Number of LPA organising this, *n* (%)	4/17 (23.5)	7/26 (26.9)
Groups per LPA, Mdn (range)	2 (1-6)	5 (2-5)
Total number of participants, n	136	133 (LPA *n*=19)[a]
Participants per LPA, Mdn (range)	24.5 (12-75)	40 (18-75)
Frequency, sessions per week, Mdn (range)	1 (1-1)	1 (1-1)
Duration, minutes per session, Mdn (range)	60 (60-90)	60 (60-90)

[a] Seven respondents did not provide these data.
[b] This refers to other forms of SGE with only sports, i.e. yoga, Tai Chi, volleyball classes and Nordic Walking groups.
AxSpA: axial spondyloarthritis; RMD: rheumatic and musculoskeletal disease; LPA: local patient association; Mdn: median; n/a: not applicable.

Table 2. Modalities of supervised group exercise (SGE) for people with axSpA in the Netherlands.

	axSpA-specific SGE (total LPA *n*=17)		SGE for any RMD (total LPA *n*=26)	
	On land (*n*=17)	In water (*n*=17)	On land (*n*=18)	In water (*n*=24)
Therapy modalities, *n* (%)				
Mobility exercises	15/17 (88.2)	16/17 (94.1)	18/18 (100)	22/24 (91.7)
Strengthening exercises	15/17 (88.2)	17/17 (100)	18/18 (100)	22/24 (91.7)
Aerobic exercises	10/17 (58.8)	8/17 (47.1)	11/18 (61.1)	10/24 (41.7)
Breathing exercises	11/17 (64.7)	6/17 (35.3)	11/18 (61.1)	14/24 (58.3)
Functional exercises	4/17 (23.5)	n/a	7/18 (38.9)	n/a
Walking exercises	13/17 (76.5)	16/17 (94.1)	8/18 (44.4)	20/24 (83.3)
Swimming exercises	n/a	14/17 (82.4)	n/a	15/24 (62.5)
Relaxation exercises	12/17 (70.6)	11/17 (64.7)	14/18 (77.8)	18/24 (75)
Sports	15/17 (88.2)	15/17 (88.2)	10/18 (55.6)	15/24 (62.5)
Volleyball	12/17 (70.6)	n/a	7/18 (38.9)	n/a
Passive mobilisation	6/17 (35.3)	5/17 (29.4)	7/18 (38.9)	7/24 (29.2)

AxSpA: axial spondyloarthritis; RMD: rheumatic and musculoskeletal disease; LPA: local patient association; n/a: not applicable.

Table 3. Additional contents during supervised group exercise (SGE) for people with axSpA in the Netherlands.

	axSpA-specific SGE (LPA *n*=17)	SGE for any RMD (LPA *n*=26)
Use of heart rate monitoring during exercise, *n* (%)	1 (5.9)	1 (3.8)
Providing education on axSpA, *n* (%)	8 (47.1)	9 (34.6)
Using periodic assessments, *n* (%)	2 (11.8)	6 (23.1)
Frequency assessments, times per year, Mdn (range)	1 (1-1)	2 (1-4)
Exercise personalisation according to assessments, *n* (%)	1 (5.9)	5 (19.2)

AxSpA: axial spondyloarthritis; RMD: rheumatic and musculoskeletal disease; LPA: local patient association; Mdn: median.

As shown in Table 2, the most common exercise modalities in both axSpA-specific SGE and SGE for any RMD and on land as well as in water were joint mobility exercises and muscle strengthening (between 88% and 100%), whereas functional exercises were least popular (24% in axSpA-specific SGE and 39% in SGE for any RMD). Aerobic exercises were used by around half: on land by 59% and 61% of associations with axSpA-specific SGE and SGE for any RMD, respectively, and in water by 47% and 42%, respectively.

Table 3 shows that both in axSpA-specific SGE as well as with SGE for any RMD, the use of heart rate monitoring (6% and 4%, respectively), periodic assessments (12% and 23%) and personalisation according to assessments (6% and 19%) was relatively rare. If measurement instruments were used, the 6 Minute Walk Test (12% and 19%, respectively) and joint mobility tests (both 12%) were most often employed. Education on axSpA was provided in 47% of axSpA-specific SGE programmes and in 35% of SGE programmes for any RMD.

SGE supervisor characteristics

In all but one association, there was one supervisor guiding the exercise groups (in the other case, two supervisors guided one group). Table 4 presents the characteristics of the SGE supervisors. It shows that both in axSpA-specific SGE and in SGE for people with any RMD, most supervisors were physical therapists (92% and 71%, respectively) and had experience for more than one year in supervising SGE (90% and 84%, respectively). Furthermore, a minority of the supervisors had postgraduate education on RMD (36% and 20%, respectively) and were a member of a local rheumatology network (17% and 7%, respectively).

Table 4. Supervisor characteristics of supervised group exercise (SGE) for people with axSpA in the Netherlands.

	axSpA-specific SGE (LPA *n*=17)	SGE for any RMD (LPA *n*=26)
Total number of supervisors, n	59	87
Number of supervisors per LPA, Mdn (range)	3.5 (1-11)	3 (1-13)
Number of supervisors per group, Mdn (range)	1 (1-2)	1 (1-1)
Professional background supervisors		
Physical therapist, *n* (%)	54/59 (91.5)	62/87 (71.3)
Physical therapy student, *n* (%)	3/59 (5.1)	4/87 (4.6)
Sports and exercise instructor, *n* (%)	2/59 (3.4)	21/87 (24.1)
Experience guiding group exercise		
<1 year, *n* (%)	6/59 (10.2)	13/82 (15.9)
1-5 years, *n* (%)	18/59 (30.5)	40/82 (48.8)
>5 years, *n* (%)	35/59 (59.3)	29/82 (35.4)
Postgraduate education on RMD, *n* (%)	21/59 (35.6)	16/87 (19.5)
Membership local rheumatology network, *n* (%)	10/59 (16.9)	6/87 (7.3)

AxSpA: axial spondyloarthritis; RMD: rheumatic and musculoskeletal disease; LPA: local patient association; Mdn: median.

Recruitment and selection of supervisors

As shown in Table 5, both for axSpA-specific SGE and SGE for any RMD, the most common procedures for recruitment of supervisors were through own networks of the associations (88% and 65%, respectively), followed by recruitment by the departing supervisor (47% and 54%, respectively). In both types of associations, the top three used selection criteria for supervisors were: experience with supervising exercise groups (65% and 69%, respectively), experience with supervising and/or treating people with axSpA (59% and 50%, respectively) and adequate postgraduate education (29% and 27%, respectively). The large majority of associations reported to be successful in finding supervisors meeting their criteria (94% and 77%, respectively).

Table 5. Recruitment characteristics of supervised group exercise (SGE) for people with axSpA in the Netherlands.

	axSpA-specific SGE (LPA *n*=17)	SGE for any RMD (LPA *n*=26)
Procedures for recruitment of supervisors		
Advertising online (e.g. vacancy website), *n* (%)	0 (0)	2 (7.7)
By the departing supervisor, *n* (%)	8 (47.1)	14 (53.8)
Through own network, *n* (%)	15 (88.2)	17 (65.4)
No recruitment activities	1 (5.9)	7 (26.9)
Selection criteria for supervisors		
Experience with guiding axSpA patients, *n* (%)	10 (58.8)	13 (50)
Experience with guiding exercise groups, *n* (%)	11 (64.7)	18 (69.2)
Membership local rheumatology network, *n* (%)	1 (5.9)	5 (19.2)
Adequate education, *n* (%)	5 (29.4)	7 (26.9)
No selection criteria used, *n* (%)	3 (17.6)	2 (7.7)
Success in finding adequate supervision , *n* (%)	16 (94.1)	20 (76.9)
Membership campaign activities		
Advertising in own media, *n* (%)	8 (47.1)	21 (80.8)
Advertising in door-to-door magazines, *n* (%)	1 (5.9)	4 (15.4)
Advertising through general practitioners, *n* (%)	7 (41.2)	13 (50)
Advertising through physical therapists, *n* (%)	8 (47.1)	21 (80.8)
Advertising through rheumatology clinics, *n* (%)	17 (100)	24 (92.3)
Developments in number of members over time		
Increased, *n* (%)	1 (5.9)	10 (38.5)
Unchanged, *n* (%)	10 (58.8)	8 (30.8)
Decreased, *n* (%)	6 (35.3)	8 (30.8)

AxSpA: axial spondyloarthritis; RMD: rheumatic and musculoskeletal disease; LPA: local patient association.

Recruitment of members

Concerning membership campaign activities (Table 5), the most frequently employed activities were similar for axSpA-specific SGE and SGE for any RMD: advertisement through rheumatology clinics was used by most associations (100% and 92%, respectively), followed by advertisement in own media and through physical therapists (both 47% and 81%, respectively). With regard to developments in number of members over time, Table 5 shows that just one of 17 (6%) associations with axSpA-specific SGE experienced an increase in memberships and six (35%) a decrease, whereas among the 26 associations with SGE for any RMD, ten (39%) reported an increase and eight (31%) a decrease.

Organisational characteristics of SGE

As shown in Table 6, all local patient associations had financial responsibilities and all but three had organisational responsibilities (arranging accommodation or equipment or recruiting supervisors or members). Few associations had direct agreements with health insurance companies and in all but one association the funding sources included membership contributions as well as funding from the Dutch Arthritis Society, sometimes supplemented with commercial sponsoring. Respondents indicated that some patients were (partly) reimbursed for their membership contributions by their health insurance company.

With regard to the evaluation of the organisation of SGE, either structurally or incidentally, this was done with supervisors by all but one associations. However, evaluations among participating patients were done less frequent, namely by 24% and 27% of associations organising axSpA-specific SGE and SGE for any RMD, respectively.

A large majority of the board representatives reported barriers or aspects they would like to see improved, both among the associations with axSpA-specific SGE (88%) and associations with SGE for people with any RMD (81%). The most reported barrier was related to funding (41% and 27%, respectively), followed by finding new (or younger) members (41% and 8%, respectively). Other mentioned barriers concerned facilities, internal communication (by board with supervisors and members), finding new supervisors and difference in exercise level within groups, but all these barriers were mentioned by two associations or fewer.

Table 6. Organisational characteristics of supervised group exercise (SGE) for people with axSpA in the Netherlands.

	axSpA-specific SGE (LPA *n*=17)	SGE for any RMD (LPA *n*=26)
Responsibilities of LPA regarding SGE		
Organising SGE accommodation, *n* (%)	15 (88.2)	14 (53.8)
Financing SGE accommodation, *n* (%)	16 (94.1)	24 (92.3)
Organising SGE equipment, *n* (%)	15 (88.2)	7 (26.9)
Financing SGE equipment, *n* (%)	16 (94.1)	10 (38.5)
Organising SGE supervision, *n* (%)	16 (94.1)	19 (73.1)
Financing SGE supervision, *n* (%)	15 (88.2)	23 (88.5)
Organising SGE membership campaigns, *n* (%)	15 (88.2)	23 (88.5)
No organisational SGE responsibilities, *n* (%)	1 (5.9)	2 (7.7)
No financial SGE responsibilities, *n* (%)	0 (0)	0 (0)
Agreements with health insurances[a], *n* (%)	3 (17.6)	4 (15.4)
Funding sources		
Member contributions[a], *n* (%)	17 (100)	25 (96.2)
Sponsoring, *n* (%)	5 (29.4)	6 (23.1)
Funding from Dutch Arthritis Society, *n* (%)	17 (100)	25 (96.2)
Evaluating group exercise with members		
Structurally, *n* (%)	12 (70.6)	13 (50)
Frequency, times per year, Mdn (range)	1 (1-4)	1 (1-9)
Incidentally, *n* (%)	1 (5.9)	9 (34.6)
No evaluation with members, *n* (%)	4 (23.5)	4 (15.4)
Evaluating group exercise with supervisors		
Structurally, *n* (%)	10 (58.8)	18 (69.2)
Frequency, times per year, Mdn (range)	1 (1-2)	2 (1-7)
Incidentally, *n* (%)	7 (41.2)	7 (26.9)

[a] Some members declare their contributions with their health insurance themselves, which is sometimes (partly) reimbursed.

AxSpA: axial spondyloarthritis; RMD: rheumatic and musculoskeletal disease; LPA: local patient association; Mdn: median.

Discussion

As a first step towards evidence-based revision of the practice of axSpA-specific SGE, this cross-sectional study examined the organisation and contents of SGE for people with axSpA in the Netherlands using a survey among local patient associations. It was found that 17 out of 67 associations responding to the survey offered axSpA-specific SGE, with most programmes combining land-based exercises, sports and hydrotherapy. Most supervisors lacked postgraduate education on RMDs and the application of intensity monitoring, patient education, periodic assessments and personalisation, needed for optimising the dosage in particular of aerobic exercise, was rare.

When compared with a similar Dutch cross-sectional study from 1994 (18), it appears that little has changed over the last two and a half decades. Current practice in The Netherlands also appears to be in line with relatively recent studies on the delivery of SGE for patients with axSpA from Switzerland and the United Kingdom (20-22). In all, the focus is still mainly on joint mobility and muscle strengthening exercises, combined with sports and hydrotherapy, provided during once weekly sessions of relatively long duration.

These findings show that there is room for improvement, in particular regarding the provision of adequately dosed aerobic exercises (9-11, 16, 26). Recent literature suggests that especially aerobic exercise with high intensity is beneficial for people with axSpA (16, 27). To ascertain the execution of aerobic exercise with adequate intensity, implementation of intensity monitoring as well as a more personalised approach are needed, with every participant undergoing a comprehensive assessment, setting of individual goals, and periodic evaluations (11). Furthermore, recent recommendations from the European League Against Rheumatism (EULAR) prescribe aerobic exercise to be performed with moderate- or vigorous-intensity on at least five or three days per week, respectively (8). Once weekly SGE is thus not sufficient to achieve this frequency, so there should at least be education and personalised advice on additional exercise and physical activity acquired throughout the week. As patient education is currently only provided in less than half of the programmes, this element requires attention.

Although the data were collected in 2016, they constituted the basis for a pilot implementation project that was done in 2017 and 2018 in four regions (out of 17 regions providing axSpA-specific SGE and out of a total of 43 regions providing SGE for any RMD) (19), which has shown that it is highly likely that the situation has not changed since 2016 (apart from the four pilot regions). After all, from close contact with the Dutch Arthritis Society and many local patient associations during this project, there were no signs of any changes after 2016. Moreover, the pilot implementation showed to be hampered by various barriers. The SGE

enhancements are therefore currently still warranted and a desired future action is to engage with local patient associations and other stakeholders to jointly examine how to cope with potential barriers during future implementations.

To implement the proposed SGE enhancements, the supervisors require adequate education. However, similar to a few decades ago (18), the large majority of SGE supervisors in this study consisted of physical therapists without a postgraduate education on RMDs. Physical therapists´ knowledge on RMDs is an important facilitator for the implementation of high-intensity aerobic exercise (21) and is one of the core competencies of health professionals in rheumatology (28). Improving the knowledge of physical therapists could be hampered by the limited availability of postgraduate education on RMDs in many European countries, in particular with a specific focus on exercise and axSpA (29). A number of (online) courses for health professionals addressing axSpA in English are available, such as those developed by the EULAR (30) or by the National Axial Spondyloarthritis Association (NASS) from the United Kingdom (31). However, lack of English language skills could be a barrier for participation among health professionals in many non-English speaking countries (29). Fortunately, in the Netherlands, recommendations for physical therapists on exercise and axSpA recently became available (32) as well as a course on implementing these recommendations (33).

In addition to availability of appropriate education, it is also important that SGE supervisors are motivated to participate in such courses and that patient associations use postgraduate education on RMDs as a selection criterium when recruiting supervisors. In this study, only a minority of the supervisors had postgraduate education and less than 30% of associations used it as a selection criterium. However, it is likely that patient associations currently limit the demands on their supervisors, because the payment for supervising SGE is probably lower than for regular therapy (personal communication). Limited funding could be the main obstacle, since funding was the SGE barrier mentioned most often by the boards of the patient associations. Funding mainly exists of contributions from members themselves and from the Dutch Arthritis Society. Only a few associations have direct agreements with health insurances. When implementing the SGE enhancements, this barrier should be taken into account and suitable payment of SGE supervisors should be provided.

When implementing the suggested SGE enhancements, the patients´ perspective should be accounted for. One study, examining the perspective of axSpA-specific SGE participants towards current SGE and the proposed SGE enhancements, found that the majority of axSpA patients was satisfied with the current axSpA-specific SGE, but also agreed with intensity monitoring, periodic assessments and exercising more frequently (19). Half of the participants were in favour of education and a large majority found specialised supervision highly important. However, that study

also showed that the majority of SGE participants in the Netherlands had a relatively high age and participated in SGE for a long time (19). This is in line with the current finding that recruiting new and younger SGE members is a challenge mentioned most often (besides funding) by the associations' boards. In order to attract younger axSpA patients, it may help to implement more education on self-management, as was found in one study using focus groups (34), or by exploring and using technological possibilities such as web-based home exercise programmes (35), which provide more flexibility in exercise times, costs and distance than traditional SGE sessions (36). Furthermore, a study among axSpA patients registered in a hospital in the United Kingdom found that over half of them were not familiar with the NASS (37). In order to recruit more (young) SGE members, it might help to increase awareness regarding associations organising axSpA-specific SGE.

There are three study limitations to be mentioned. First, by using a non-validated survey, the data could be affected by various forms of bias, including social desirability bias regarding the contents of SGE. To limit the risk of this bias, it was made clear to participants that the survey was meant to make an inventory of the current SGE situation and to assess the needs to improve it, rather than to make a judgement of the quality of the SGE they provided. Moreover, as this study included a survey among both board members and the SGE supervisors, it is expected that the combined responses provide a realistic picture of the situation. Second, there were no specific questions in the survey about providing home exercise advice. Advice on home exercise is important for achieving adequate exercise frequency and findings from another study suggest that it is currently lacking in axSpA-specific SGE (19). Finally, this study only examined SGE organised by local patient associations affiliated with the Dutch Arthritis Society and axSpA-specific SGE organised outside of these associations were not included. However, it seems unlikely that axSpA-specific SGE exists beyond these associations in the Netherlands. As this study showed a high response rate among the local patient associations (82%), the results may be well generalisable to all axSpA-specific SGE in the Netherlands.

In conclusion, most SGE programmes for patients with axSpA in the Netherlands contained a combination of land-based exercises and hydrotherapy, with the main focus on joint mobility, muscle strength and sports. To meet current scientific insights, there should be more focus on adequately dosed aerobic exercises, by implementing intensity monitoring, patient education, periodic assessments and exercise personalisation and by providing and promoting postgraduate education for supervisors.

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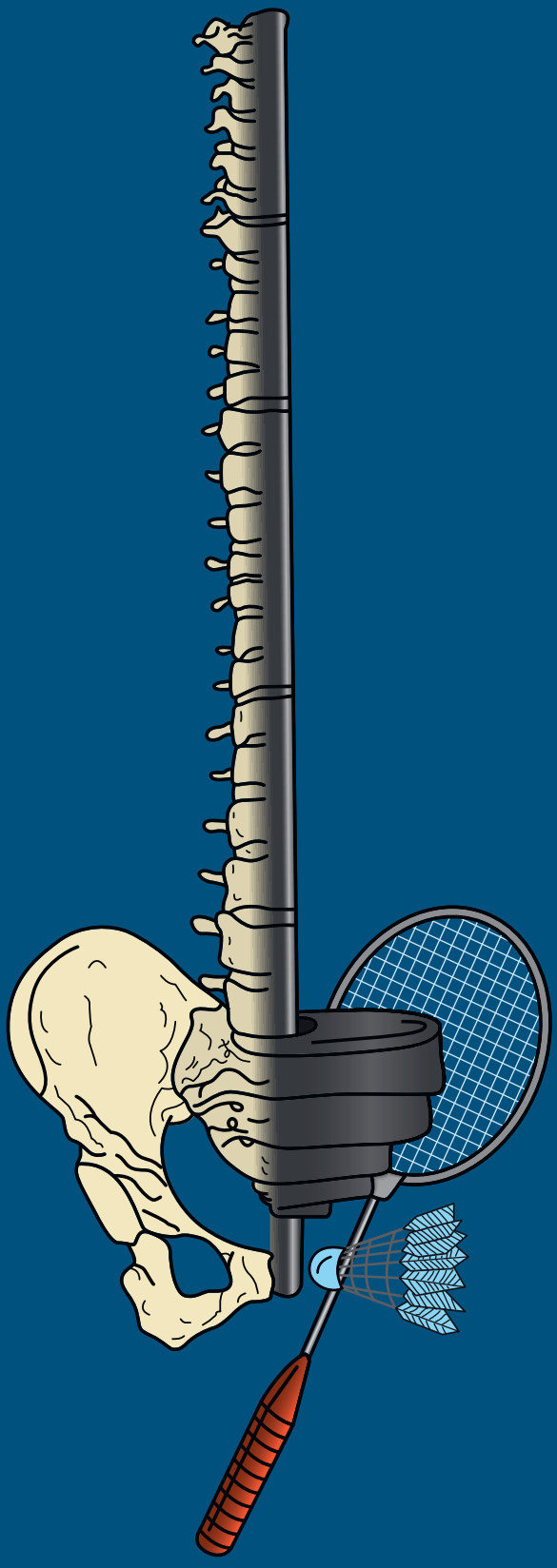

Chapter 5

Supervised group exercise in axial spondyloarthritis: patients' satisfaction and perspective on evidence-based enhancements

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Arthritis Care & Research 2020;72(6):829-837

Abstract

Objective

Supervised group exercise (SGE) has been proven effective in patients with axial spondyloarthritis (SpA), but its contents and dosage do not always comply with current scientific insight. This aim of this study was to describe axial SpA patients' satisfaction with current SGE and perspective on potential evidence-based SGE enhancements.

Methods

Patients with axial SpA who participated in SGE in 4 regions in the Netherlands (n = 118) completed a cross-sectional survey on their satisfaction with features of their current SGE (8 questions scored on a 3-point Likert scale; 1 overall grade, scored according to an 11-point scale) and their perspective on the introduction of appropriately dosed cardiorespiratory and strengthening exercise, monitoring of exercise intensity, periodic reassessments, patient education, and supervision by physical therapists with specific expertise (4 dichotomous questions and one 5-point Likert scale).

Results

Most patients were satisfied with the current total intensity (84 of 112 patients [75%]), duration (93 of 111 patients [84%]), and load (89 of 117 patients [76%]) of the program and the proportion of mobility (102 of 114 patients [90%]), strengthening (90 of 115 patients [78%]), and cardiorespiratory exercise (82 of 114 patients [72%]). The median overall grade of the program was a 7 (interquartile range 7–8). Most patients agreed with the implementation of more frequent (home) exercise (73 of 117 patients [62%]), heart-rate monitoring (97 of 117 patients [83%]), and annual reassessments (97 of 118 patients [82%]), whereas 50% agreed with the introduction of patient education (37 of 74 patients). The majority found supervision by therapists specializing in axial SpA to be of high importance (105 of 118 patients [89%]).

Conclusion

The majority of SGE participants with axial SpA were satisfied with current SGE but also agreed with enhancements in line with scientific evidence. Current satisfaction levels indicate that a planned implementation strategy, including education and addressing potential barriers and facilitators for the uptake of enhancements, is warranted.

Introduction

Axial spondyloarthritis (SpA) is a chronic inflammatory rheumatic disease that predominantly affects the spine and sacroiliac joints and causes chronic back pain and stiffness. Regular exercise is considered to be a key component in the management of (1-3) axial SpA and has been shown to reduce disease activity, pain, and stiffness and improve physical functioning, chest expansion, spinal mobility, and cardiorespiratory function in patients (4-9) with axial SpA. Additionally, regular exercise has the potential to reduce depressive symptoms (10, 11). With supervised group exercise (SGE), greater improvements in quality of life, spinal mobility, and patient global assessment were achieved as compared to unsupervised, individual exercise programs (5, 12-15). SGE appears similarly effective for patients with radiographic axial SpA (also known as ankylosing spondylitis) and those with nonradiographic axial SpA (16). Recently, results of a systematic review on the effectiveness of exercise either on land or in water in patients with radiographic axial SpA (17) demonstrated the added value of hydrotherapy and education within SGE (including 35 trials).

In many countries, SGE for patients with axial SpA was instituted a few decades ago and mostly consisted of mobility, posture, and respiratory exercises (sometimes supplemented with strengthening and cardiorespiratory exercise) that occurred on a weekly or twice weekly basis with a duration of up to 180 minutes (5, 18, 19). These programs may not be consistent with the current body of knowledge, which suggests that exercise for patients with axial SpA should be individually tailored and include mobility, strengthening, and cardiorespiratory exercise with the right intensity, duration, and frequency (3, 5, 8, 13, 15, 17, 20). In a systematic literature review, Dagfinrud et al (18), examined exercise programs from 12 randomized controlled trials for patients with radiographic axial SpA and reported that most exercise programs included mobility exercise (11 of 12 programs), but only less than half (5 of 12 programs) included strengthening or cardiorespiratory exercise. Strikingly, only 1 exercise program met the American College of Sports Medicine recommendations (21) for developing cardiorespiratory fitness, and none met the recommendations for developing muscular strength (18). It has also been stated that patients should be educated about axial SpA and physical activity, have regular reassessments, and be guided by experts on exercise specifically for those with axial SpA (3, 13, 15, 20, 22-24). Patient education on physical activity and patient monitoring currently appear to be lacking (18, 25).

All of the aforementioned insights would imply that several enhancements in current practice might be needed in order to improve the contents and quality of SGE for patients with axial SpA. As a prerequisite for successful implementation, it is important to explore the current perspective of various stakeholders on this matter, including patients' perspectives (26-29). The literature on patient

perspective, specifically regarding SGE for patients with axial SpA, is scarce. A cross-sectional study by Niedermann et al (26), which used a survey of 575 patients with axial SpA, explored barriers to and facilitators for vigorous cardiorespiratory exercise and identified motivation and disease symptoms as the most important factors for implementing vigorous cardiorespiratory training in exercise programs; these results underpinned the need to address motivation and tailor exercise programs to a patient's individual level. Such needs were also demonstrated in a qualitative study by O'Dwyer et al (30), in which the attitudes of 17 patients with axial SpA toward their current exercise program were explored using individual, semistructured interviews and thematic analysis. The study by O'Dwyer and colleagues demonstrated a desire of patients for exercise to be modified to personal abilities and interest. Another qualitative study (31), which included 11 patients distributed throughout 2 focus groups, concluded that patients prefer more education on axial SpA–specific exercise and better monitoring of exercise by specialized therapists. These 3 studies underline the importance that patients with axial SpA attribute to education and personalization of exercise, which could only be made possible with regular monitoring of exercise and periodic reassessments of patients' individual levels, abilities, and interests.

Little is known about the perspectives of axial SpA patients on SGE and potential enhancements. The present study will therefore examine the satisfaction of axial SpA patients with current SGE and their perspective toward proposed enhancements of the contents and guidance of SGE.

Patients and Methods

Study design

The present study comprised the baseline data that was gathered between 2015 and 2017 as part of a pilot project on the implementation of enhancements for SGE for axial SpA patients in 4 regions (R1, R2, R3, and R4) in the Netherlands. The baseline assessment included a cross-sectional survey among the participants of an axial SpA–specific SGE. The pilot implementation project is ongoing and includes a baseline assessment of patients' perspectives on current and future SGE, a training of health professionals to apply a set of evidence-based enhancements, and an evaluation of patients' experiences and satisfaction with the revised programs. The proposed enhancements for SGE were based on literature and consisted of 1) periodic reassessments of (changes in) strength, mobility, physical fitness, and functioning, including the setting of individual goals, thereby enabling the development of a personalized exercise program; 2) introduction of appropriately dosed (high intensity) cardiorespiratory and strengthening exercises; 3)

introduction of standard monitoring of the intensity of cardiorespiratory exercises; 4) increase of the exercise frequency (by means of home exercise programs); and 5) provision of education on axial SpA–specific exercise.

The study protocol was reviewed by the medical ethical review board of the Leiden University Medical Center (MEC file P14.326), who determined that the study protocol did not need a full review based on the observational nature of the research being embedded in regular care. The study was financially supported by the Dutch Arthritis Society ('ReumaNederland,' grant BP14-1-161).

Setting

In the Netherlands, SGE for axial SpA patients is mostly organized by local patient associations for people with rheumatic diseases. Of all 82 local patient associations affiliated with the Dutch Arthritis Society in the Netherlands, 18 organize SGE for axial SpA patients. Six of these, geographically spread across the Netherlands, were approached for participation in the pilot implementation project. Four were willing to participate and were located in Leiden (R1), The Hague (R2), Mid Limburg (R3), and The Gooi (R4). Two regions were unwilling to participate, 1 region without explanation and the other because of the inability of the involved physical therapists to attend the training needed to apply the SGE enhancements. The SGE groups from the 18 local associations that organize SGE for axial SpA patients are guided by physical or exercise therapists. The majority of these therapists had guided these groups for at least 5 years, but only less than half had attended additional training in leading patients with a rheumatic disease. Reimbursement for SGE varies between SGE participants' health insurance programs; some participants receive full or partial reimbursement, and some receive none. Some SGE participants also receive individual physical therapy in addition to SGE.

Characteristics of SGE

The SGE classes in the 4 included regions had all been in effect since the early 1990s and were based on a program used in a randomized controlled trial (19).. That program was administered weekly and consisted of 3 elements, including land-based training that comprised mobility exercises, sports activities, and hydrotherapy. The present SGE programs in the 4 regions were similar in the sense that they were administered weekly and had the same structure (i.e., using land-based training, sports activities, and hydrotherapy) (see Supplementary Table S1). However, there were differences regarding the features of the land-based training, with cardiorespiratory exercise only being regularly employed in region R3. There was also a difference in the total duration of the program, which varied between 90 and 135 minutes, due to differences in duration and structure of the land-based training. In regions R1 and R3, 45 minutes were spent on mobility, strengthening, and/or cardiorespiratory exercises, followed by 45 minutes of sports activities,

whereas in regions R2 and R4, 45–60 minutes were spent in total on both land-based training and sports activities. These differences may have been caused over time by preferences of the separate SGE regions. Hydrotherapy lasted 45 minutes in all regions.

Patients

The implementation project started in region R1 in 2015 and was continued in 2017 in the other 3 regions. A package of numbered pen and paper questionnaires and patient information letters was sent to the 4 local patient associations, who were responsible for inviting their SGE participants for study participation. These local patient associations arranged the distribution and collection of questionnaires among the SGE participants, and they alone maintained the link between the numbered questionnaire and SGE participants to guarantee anonymity. Patients were eligible for the study if they were willing and able to fill in the survey, and they were reminded by their patient association when the questionnaire was not returned within 2 weeks after issuance. Eventually, the local patient associations returned all completed pen and paper questionnaires to the researchers.

Assessments

The survey was self-developed and first pilot-tested by SGE members in region R1. Consequently, 1 question was slightly modified and 1 was removed. The final survey consisted of 3 parts. The first part comprised patient characteristics, including sex, age, year of diagnosis, medication use (painkillers, nonsteroidal antiinflammatory drugs, disease-modifying antirheumatic drugs, and biologics), duration of exercise group participation, and number of days per week in which they are active for ≥30 minutes with at least a moderate intensity. Patients reporting ≥5 days of activity for ≥30 minutes were classified as being active according to the European League Against Rheumatism recommendations for physical activity in people with inflammatory arthritis and osteoarthritis (20).

The second part of the survey assessed patient satisfaction toward the current contents and guidance of their SGE as follows: 1) how they experienced the overall intensity, duration, and load of the exercise programs (too much, just right, or not enough), 2) how satisfied they were with the composition of the program, i.e., the proportion of mobility, strengthening, and cardiorespiratory exercises (too much, enough, or too little), 3) how they experienced the opportunities for personal exercises and adjustments (too little, sufficient, or not necessary), 4) which positive effects they experienced as a result of the group exercise, and 5) how they graded the SGE program overall (grades 0–10, anchors 0 = “very bad” and 10 = “excellent”).

The third part of the survey evaluated the patients' perspectives on potential SGE enhancements, including their views toward periodic (annual) reassessments of

mobility, strength, fitness, and physical function (in favor or not), heart-rate monitoring (in favor or not), exercising more than once a week (in favor or not), receiving education about exercise and axial SpA (in favor or not), and the importance of being guided by a therapist who specialized in axial SpA ("extremely important," "very important," "neutral," "unimportant," or "very unimportant").

In a fourth part of the survey, which was applicable only to region R1, 6 more questions were used. These included preferences toward the following: 1) engaging in SGE more often but for less time, twice weekly (in favor or not), and SGE combined with an alternative exercise activity (in favor or not); 2) delivery of additional individual exercise (leaflet/internet, personally tailored, app/DVD, remote guidance, on own initiative, or not in favor); 3) delivery of additional guided exercise (regular sport, other axial SpA–specific exercise group, axial SpA–specific webcam guidance, personally tailored with expert guidance, or not in favor); 4) duration of additional exercise (<1 hour, 1 hour, 1.5 hours, or >1.5 hours); 5) frequency of additional exercise (1, 2, 3, or >3 extra weekly sessions); and 6) willingness to pay for additional exercise sessions (amount per session in €).

Statistical analyses

First, descriptive statistics were used for the characteristics of the study participants, their satisfaction with current SGE, and agreement with potential enhancements, both for the total group and for the 4 regions. Results were reported as frequencies (and percentages), mean ± SD, or median with interquartile range, where appropriate. To examine any differences between the 4 regions, one-way analysis of variance (ANOVA) was used for continuous data, with a Bonferroni post hoc test to determine which regions differed and a chi-square test for categorical data. Both one-way ANOVA and chi-square tests are useful for comparing 4 groups for statistical significance. Analyses were performed using SPSS, version 23.

Results

Participants

The survey was sent to 130 participants and was returned by 118 (91%), with similar return rates in the 4 regions: region R1, 43 of 48 participants (90%); region R2, 17 of 18 participants (94%); region R3, 35 of 41 participants (85%); and region R4, 23 of 23 participants (100%). Table 1 shows patient characteristics overall and for each region separately. The majority of patients (64%) were male, and the mean ± SD age was 60 ± 12 years. Overall, the characteristics of the patients in the 4 regions were similar, except for the extent to which SGE was reimbursed ($\chi^2(6) = 76.86$, $P <$

0.001) and the duration of SGE participation, which was shorter in region R1 than in region R3 (F[3,111] = 3.12, *P* < 0.05).

Table 1. Characteristics of axial SpA patients participating in SGE in 4 regions in the Netherlands [a]

	Overall (n=118)	R1 (n=43)	R2 (n=17)	R3 (n=35)	R4 (n=23)	*P* [b]
Female sex	42 (35.6)	12 (27.9)	7 (41.2)	14 (40)	9 (39.1)	0.62
Age, mean ± SD years	59.7 ± 11.6	58.5 ± 12.8	56.2 ± 11.6	62.6 ± 10.3	60.2 ± 10.7	0.24
Disease duration, mean ± SD years	24.9 ± 14.2	25.1 ± 17.7	24.1 ± 8.5	24.9 ± 11.1	25.0 ± 15.3	0.99
Medication use						
Painkiller	28 (23.7)	10 (23.3)	6 (35.3)	7 (20.0)	5 (21.7)	0.66
NSAID	64 (54.2)	25 (58.1)	4 (23.5)	21 (60.0)	14 (60.9)	0.06
DMARD	10 (8.5)	3 (7.0)	1 (5.9)	2 (5.7)	4 (17.4)	0.40
Biological	19 (16.1)	5 (11.6)	4 (23.5)	6 (17.1)	4 (17.4)	0.71
None	27 (22.9)	7 (16.3)	5 (29.4)	9 (25.7)	6 (26.1)	0.22
Days per week active ≥30 minutes						
Mean ± SD	4.8 ± 2.2	4.5 ± 2.3	4.9 ± 2.1	4.9 ± 2.1	5.5 ± 2.0	0.40
≥5 days, no./total no. (%)	66/107 (61.7)	21/39 (53.8)	8/13 (61.5)	20/33 (60.6)	17/22 (77.3)	0.22
SGE, mean ± SD years	17.8 ± 9.9	14.7 ± 9.1	20.7 ± 10.0	20.8 ± 10.4	17.0 ± 9.4	0.03
Reimbursement						
Full	52 (44.1)	41 (95.3)	1 (5.9)	6 (17.1)	4 (17.4)	<0.001
Partial	18 (15.3)	2 (4.7)	4 (23.5)	5 (14.3)	7 (30.4)	0.03
None	48 (40.7)	0 (0)	12 (70.6)	24 (68.6)	12 (52.2)	<0.001

[a] Values are the number (%) unless indicated otherwise. SpA = spondyloarthritis; SGE = supervised group exercise; NSAID = nonsteroidal antiinflammatory drug; DMARD = disease-modifying antirheumatic drug.

[b] *P*-value of chi-squared test for categorical data and of one-way ANOVA for continuous data. *P*-value < 0.05 indicates a significant difference between the four regions.

Patients' satisfaction with current SGE

The results of the patients' experiences and satisfaction with current SGE are shown in Table 2. Overall, the majority of patients were satisfied with the SGE. Most participants viewed cardiorespiratory (72%) and strengthening (78%) exercise as receiving enough attention, even in the regions where these exercise types are not included. The proportions of patients judging cardiorespiratory exercise and strengthening as getting too little attention were 27% and 21%, respectively, whereas the proportion of patients perceiving mobility exercise as getting too little attention was 9%. Chi-square test findings showed that significantly more participants in R3, the sole location that targeted cardiorespiratory as well as strengthening and mobility exercise, graded their SGE with at least a score of 7, which was the overall median SGE grade ($\chi^2(3) = 8.16$, $P < 0.05$) (Table 2). Also, significantly fewer participants from the SGE programs with the longest duration (regions R1 and R3) judged the SGE duration as being too short ($\chi^2(3) = 16.22$, $P < 0.01$).

Table 2. Experiences and satisfaction of axial SpA patients with current SGE in 4 regions in the Netherlands [a]

	Overall (n=118)	R1 (n=43)	R2 (n=17)	R3 (n=35)	R4 (n=23)	*P*
Overall intensity						
Too high	11/112 (9.8)	4/41 (9.8)	0/14 (0)	5/34 (14.7)	2/23 (8.7)	0.43
Just right	84/112 (75)	31/41 (75.6)	11/14 (78.6)	27/34 (79.4)	15/23 (65.2)	0.71
Too low	17/112 (15.2)	6/41 (14.6)	3/14 (21.4)	2/34 (5.9)	6/23 (26.1)	0.18
Overall duration						
Minutes	115	135	100	135	90	
Too long	9/111 (8.1)	5/41 (12.2)	1/15 (6.7)	3/32 (9.4)	0/23 (0)	0.39
Just right	93/111 (83.8)	36/41 (87.8)	12/15 (80)	28/32 (87.5)	17/23 (73.9)	0.64
Too short	9/111 (8.1)	0/41 (0)	2/15 (13.3)	1/32 (3.1)	6/23 (26.1)	0.001
Overall load						
Too heavy	15/117 (12.8)	6/43 (14)	1/17 (5.9)	4/34 (11.4)	4/23 (17.4)	0.73
Just right	89/117 (76.1)	31/43 (72.1)	12/17 (70.6)	29/34 (82.9)	17/23 (73.9)	0.67
Too easy	13/117 (11.1)	6/43 (14)	4/17 (23.6)	1/34 (2.9)	2/23 (9.7)	0.13
Mobility exercises						
Too much	2/114 (1.8)	0/41 (0)	0/15 (0)	2/35 (5.7)	0/23 (0)	0.19
Just right	102/114 (89.5)	37/41 (90.2)	11/15 (73.3)	32/35 (91.4)	22/23 (95.7)	0.03
too little	10/114 (8.8)	4/41 (9.8)	4/15 (26.7)	1/35 (2.9)	1/23 (4.3)	0.07
Strengthening exercises						
too much	1/115 (0.9)	0/42 (0)	0/15 (0)	1/35 (2.9)	0/23 (0)	0.50
enough	90/115 (78.3)	32/42 (76.2)	11/15 (73.3)	28/35 (80)	19/23 (82.6)	0.55
too little	24/115 (20.9)	10/42 (23.8)	4/15 (26.7)	6/35 (17.1)	4/23 (17.4)	0.88
Cardiorespiratory exercises						
too much	1/114 (0.9)	1/42 (2.4)	0/15 (0)	0/35 (0)	0/22 (0)	0.62
enough	82/114 (71.9)	29/42 (69)	11/15 (73.3)	28/35 (80)	14/22 (63.6)	0.37
too little	31/114 (27.2)	12/42 (28.6)	4/15 (26.7)	7/35 (20)	8/22 (36.4)	0.64
Opportunities personal exercise						
too little	18/116 (15.5)	9/43 (20.9)	0/16 (0)	4/35 (11.4)	5/22 (22.7)	0.15
sufficient	49/116 (42.2)	20/43 (46.5)	9/16 (56.3)	11/35 (31.4)	9/22 (40.9)	0.41
not necessary	49/116 (42.2)	14/43 (32.6)	7/16 (43.8)	20/35 (57.1)	8/22 (36.4)	0.15

Table continues

Table 2 (Continued). Experiences and satisfaction of axial SpA patients with current SGE in 4 regions in the Netherlands [a]

	Overall (n=118)	R1 (n=43)	R2 (n=17)	R3 (n=35)	R4 (n=23)	*P*
Experienced effects						
no deterioration	96/118 (81.4)	32/43 (74.4)	14/17 (82.4)	29/35 (82.9)	21/23 (91.3)	0.40
less stiffness	70/118 (59.3)	26/43 (60.5)	11/17 (64.7)	16/35 (45.7)	17/23 (73.9)	0.18
more endurance	31/118 (26.3)	13/43 (30.2)	5/17 (29.4)	8/35 (22.9)	5/23 (21.7)	0.83
less pain	23/118 (19.5)	10/43 (23.3)	3/17 (17.6)	6/35 (17.1)	4/23 (17.4)	0.89
more strength	21/118 (17.8)	7/43 (16.3)	3/17 (17.6)	6/35 (17.1)	5/23 (21.7)	0.96
less medication	20/118 (16.9)	9/43 (20.9)	2/17 (11.8)	6/35 (17.1)	3/23 (13)	0.79
other	34/118 (28.8)	14/43 (32.6)	8/17 (47.1)	7/35 (20)	5/23 (21.7)	0.18
none	4/118 (3.4)	2/43 (4.7)	0/17 (0)	2/35 (5.7)	0/23 (0)	0.53
SGE Grade						
Median (IQR)	7 (7-8)	8 (7-8)	7 (6-8)	8 (7-8)	7 (7-8)	0.47
Grade ≥7	103/118 (87.2)	36/43 (83.7)	12/17 (70.6)	34/35 (97.2)	20/23 (91.2)	0.04

[a] Values are the number/total number (%) of participants unless indicated otherwise. SpA = spondyloarthritis; SGE = supervised group exercise; IQR = interquartile range.
[b] *P* value of chi-square test for categorical data and of one-way analysis of variance for continuous data. $P < 0.05$ indicates a significant difference between the 4 regions.

Patients' perspective on potential SGE enhancements

In Table 3, the perspective of participants toward potential SGE enhancements is shown. Most proposed enhancements were positively appraised by the majority of patients, with the proportions being highest for the introduction of heart-rate monitoring (83%) and annual reassessments (82%). However, 37% of participants were not in favor of exercising more than once a week in any form (either supervised or unsupervised and group or individual), and 50% expressed a need for education on axial SpA and exercise. Almost all SGE participants (89%) found exercise guidance by a therapist specializing in axial SpA very or extremely important. Analysis using the chi-square test showed that in regions R1 and R2, where the land-based training did not specifically focus on strengthening and cardiorespiratory exercise, fewer patients were in favor of heart-rate monitoring ($\chi^2(3) = 21.82$, $P < 0.001$) (Table 3). The proportion of participants willing to exercise more frequently was lower in regions R1 and R3, where SGE takes the longest ($\chi^2(3) = 18.84$, $P < 0.001$). Finally, the proportion of participants in favor of education was significantly higher in region R2 ($\chi^2(2) = 8.64$, $P < 0.05$).

Table 3. Participants' perspective on potential, evidence-based enhancements of SGE for axial SpA patients in 4 regions of the Netherlands [a]

	Overall (n=118)	R1 (n=43)	R2 (n=17)	R3 (n=35)	R4 (n=23)	*P* [b]
Periodic reassessment, in favor	97/118 (82.2)	31/43 (72.1)	16/17 (94.1)	28/35 (80)	22/23 (95.7)	0.06
Heart-rate monitoring, in favor [c]	97/117 (82.9)	27/43 (62.8)	14/17 (82.4)	34/35 (97.1)	22/22 (100)	<0.001
Exercise more frequently, in favor	73/116 (62.4)	19/42 (45.2)	14/16 (87.5)	19/35 (54.3)	21/23 (91.3)	<0.001
Education axial SpA and exercise, in favor [d]	37/74 (50)	NA	13/16 (81.3)	16/35 (45.7)	8/23 (34.8)	0.01
Importance expert guidance						
Extremely important	51/118 (43.2)	16/43 (37.2)	10/17 (58.8)	15/35 (42.9)	10/23 (43.5)	0.51
Very important	54/118 (45.8)	21/43 (48.8)	6/17 (35.3)	16/35 (45.7)	11/23 (47.8)	0.81
Neutral	11/118 (9.3)	4/43 (9.3)	1/17 (5.9)	4/35 (11.4)	2/23 (8.7)	0.93
Unimportant	1/118 (0.8)	1/43 (2.3)	0/17 (0)	0/35 (0)	0/23 (0)	0.62
Very unimportant	0/118 (0)	0/43 (0)	0/17 (0)	0/35 (0)	0/23 (0)	NA

[a] Values are the number/total number (%) of participants unless indicated otherwise. SGE = supervised group exercise; SpA = spondyloarthritis; NA = not applicable.
[b] *P* value of chi-square test for categorical data and of one-way analysis of variance for continuous data. $P < 0.05$ indicates a significant difference between the 4 regions.
[c] In region 1 (R1), the view on heart-rate monitoring during 20–30 minutes of bike exercise was asked, and in the other regions, just the view on heart-rate monitoring was asked.
[d] Not measured in R1

Table 4 shows the patients' perspective on additional exercise activities besides current SGE, which was only measured in the pilot in region R1. Almost half of participants (45%) would agree to initiate an alternative individual or guided exercise activity in addition to their SGE. Personally tailored exercise was favored as additional exercise by the highest proportion of participants. An exercise duration of 1.5 hours, with a frequency of once a week (in addition to current SGE), was most in favor.

Table 4. Specific views on nature of guidance duration and frequency of additional exercise besides current SGE of participants in Region 1 [a]

	R1 (n=43)
Exercise more often	
SGE twice a week	10 (23.3)
SGE combined with an alternative individual or group exercise activity	19 (45.2)
Delivery of additional individual exercise	
From leaflet or internet	3 (7.0)
Personally tailored	10 (23.3)
From app or DVD	6 (14.0)
Remote, interactive guidance (through app, online or e-mail)	4 (9.3)
On own initiative	6 (14.0)
Not in favor of individual exercise	8 (18.6)
Delivery of additional guided exercise	
Regular sport with non-axial SpA-specific guidance	1 (2.3)
Another axial SpA-specific group exercise activity	6 (14.0)
Axial SpA-specific exercise with online webcam guidance	2 (4.7)
A personally tailored exercise program with expert guidance	7 (16.3)
Not in favor of another organized exercise activity	7 (16.3)
Duration additional exercise	
Less than 1 hour	1 (2.3)
1 hour	6 (14.0)
1.5 hour	8 (18.6)
More than 1.5 hour	2 (4.7)
Frequency additional exercise (besides current SGE)	
1 extra weekly session	12 (27.9)
2 extra weekly sessions	4 (9.3)
3 extra weekly sessions	0 (0)
More than 3 extra weekly sessions	0 (0)
How much willing to pay at most for one session of additional exercise (n = 16)	
Median amount (IQR)	€7.00 (€5-€10)
Most often reported amount (no. [%])	€10.00 (5 [31])

[a] Values are the number (%) unless indicated otherwise. SGE = supervised group exercise; SpA = spondyloarthritis; IQR = interquartile range.

Discussion

The present study examined both the satisfaction with current SGE and the views toward potential, evidence-based enhancements for patients with axial SpA. Most participants appeared to be satisfied with the current SGE, but nevertheless, the majority also agreed with most of the proposed enhancements, including periodic reassessments, heart-rate monitoring, and exercising more frequently.

The findings of the present study are highly important for a successful implementation of proposed SGE enhancements and are in line with the findings of studies by Niedermann et al (26), Curbelo Rodríguez et al (31), and O'Dwyer et al (30), which endorse the importance of education, periodic reassessments, and monitoring of exercise, as these components are needed to personalize exercise. Including such components in an SGE would require the guiding therapists to specialize in exercise for patients with axial SpA, and patients in the present study viewed this expertise by the SGE guidance as very important. However, less than half of the SGE therapists from our study had attended additional training in guiding patients with a rheumatic disease. Therefore, training on guiding patients with axial SpA who participate in SGE could be developed and offered to all SGE therapists.

A potential point of concern of the findings of the present study is that even in the regions where cardiorespiratory and strengthening exercise were not included, a majority of SGE participants viewed cardiorespiratory and strengthening exercise as receiving enough attention. This view suggests a knowledge gap regarding the health benefits of these exercise types. Therefore, a planned implementation strategy, which includes education on the importance of adequate and frequent exercise and addresses potential barriers to and facilitators for the uptake of certain SGE enhancements, is warranted (26). Such a strategy is especially important because appropriately dosed cardiorespiratory and strengthening exercises are rarely included in SGE for patients with axial SpA (18) even though these exercises have been recommended by current scientific insights (3, 5, 8, 13, 15). This implementation strategy also applies to increasing participants' exercise frequency since 37% of participants did not agree to exercising more than once a week, which is not enough for a physiologic training effect (18). The views on this subject show high variability between exercise regions, which could be explained by the varying duration of SGE. A larger proportion of participants from SGE classes with a shorter duration were willing to exercise more frequently than participants from classes with a longer duration. This is in line with other studies (26, 32, 33) that have shown that time is an important factor for exercise behavior. Since the present study and a previous study (30) have shown that most patients preferred a personally tailored exercise program in addition to SGE, it might be desirable (from a patient's perspective) to combine relatively shorter SGE with a personal (home)

exercise program. Future research should examine ways to motivate more patients to engage in more frequent and adequate exercise.

Education on important components of exercise for patients with axial SpA should not only be used to facilitate implementation of SGE enhancements but also as part of the SGE. Despite the relatively long participation in SGE and disease duration, approximately one-half of the participants still indicated a need for education on exercise and axial SpA. This is in line with findings from a study by Fontaine et al (25), which showed that less than one-half (42%) of arthritis patients report ever being advised on physical activity, and findings from a study by Curbelo Rodríguez and colleagues (31), which showed that patients with SpA demand more exercise education. Future studies should further examine educational needs. Acknowledgment of the patients' perspective might stimulate positive attitude, self-efficacy, and motivation toward group exercise among (potential) SGE participants have been shown to determine exercise behavior in patients with axial SpA (26, 32-36).

The present study had a number of limitations. First, although the survey was pilot-tested, it consisted of nonvalidated questions. Since the satisfaction and views were only questioned with a survey, the patient perspective could not be fully assessed. Additional use of qualitative methods, like semistructured interviews with patients to get insight into potential barriers and facilitators, could be of value before actual implementation. Second, despite the known effects of exercise on psychosocial well-being (10, 11), questions on perceived effects of SGE only addressed physical health. It is, however, conceivable that our observation that patients (on average) participate in SGE for many years is related to perceived positive effects that go beyond physical functioning. Furthermore, the study results might have limited generalizability. Although the study included 4 different regions spread throughout the Netherlands and a comparable sex ratio to other studies(23, 37, 38), the generalizability to other countries and the entire axial SpA population is limited. This limited generalizability is due to the fact that participants mainly represented relatively older axial SpA patients with a long disease duration and long SGE participation, and there were some dissimilarities between the SGE regions (see Supplementary Table S1). Finally, the proportion of patients with either radiographic or nonradiographic axial SpA is unknown, which made it impossible to show differences between these patient subgroups.

In future research, the perspectives of other stakeholders (health care insurance plans and SGE guidance) should also be investigated. Moreover, studies should further explore educational needs and ways to motivate patients for more frequent and adequate exercise. Lastly, after implementation of the proposed enhancements, the perspective of SGE participants should be examined again to

give insight into future possibilities to further increase SGE satisfaction and adherence.

In conclusion, although the majority of participants were satisfied with the current SGE, they would also agree with the proposed SGE enhancements. Due to the high satisfaction with the current SGE, a planned implementation strategy is warranted that would include education on the importance of the enhancements and anticipate potential barriers to and facilitators for the incorporation of enhancements. Future research should focus on the educational needs of axial SpA patients and ways to motivate them to exercise more frequently. Also, patient satisfaction and perspective should be reexamined after implementation of SGE enhancements.

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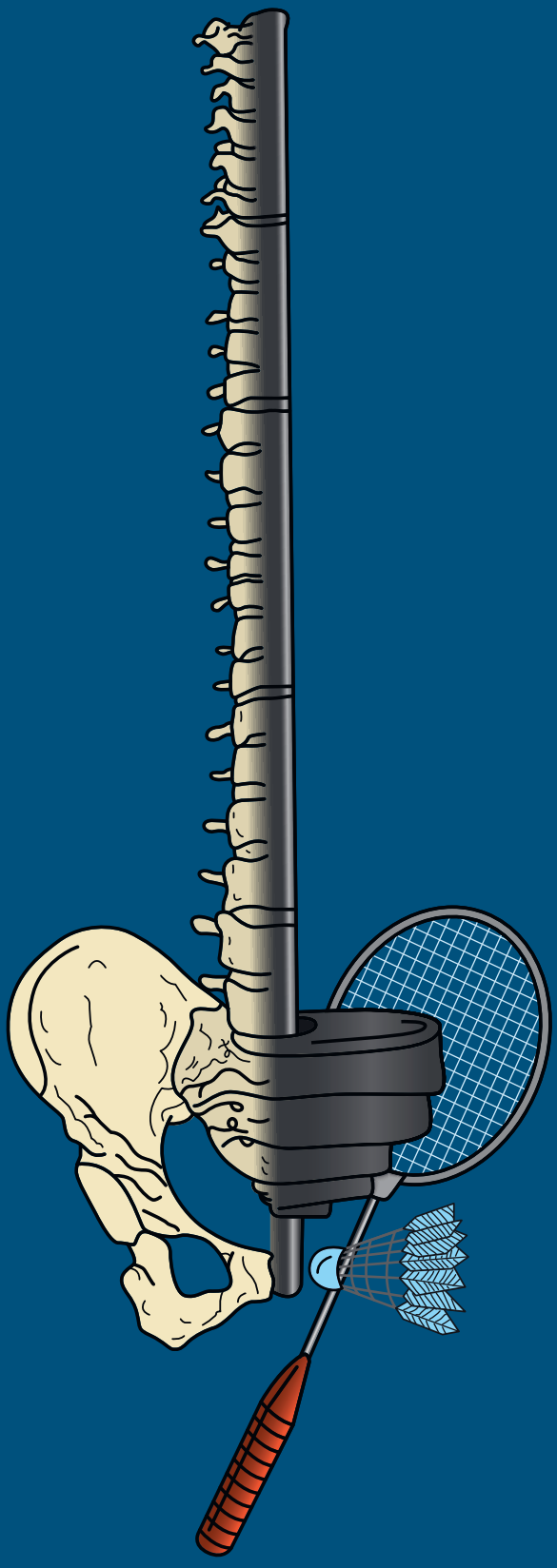
Supplementary data

Table S1. Characteristics of supervised group exercise for axial spondyloarthritis (SpA) patients in four regions in the Netherlands

	R1	R2	R3	R4
Participants (n)	43	17	35	23
Frequency	once a week	once a week	once a week	once a week
Duration (minutes)				
Total	135	100	135	90
Exercise	90	60	90	45
Hydrotherapy	45	40	45	45
Contents				
Mobility	yes	yes	yes	yes
Strengthening	no	no	yes	yes
Cardiorespiratory	no	no	yes	no
Sports	badminton and volleyball	basketball and volleyball	badminton and volleyball	badminton and volleyball
Hydrotherapy	yes	yes	yes	yes
Opportunities personal exercises	no	no	no	no
Periodic reassessments	no	no	no	no
Heartrate monitoring	no	no	no	no
Advice home exercise	no	yes	no	no
Education axial SpA and exercise	no	no	during intake	no



Chapter 6

Implementing enhancements in supervised group exercise for people with axial spondyloarthritis: a hybrid effectiveness-implementation study

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Scandinavian Journal of Rheumatology 2021 Nov 17;1-9.

Abstract

Objective

The content of supervised group exercise (SGE) for axial spondyloarthritis (axSpA) has hardly changed in recent decades, despite new evidence-based insights to improve SGE quality. This pilot implementation study evaluated the effects and feasibility of enhancements in SGE for people with axSpA in four regions in the Netherlands.

Methods

The implemented enhancements included: 1. More high-intensity aerobic exercise; 2. Exercise personalisation with periodic assessments; 3. Patient education on home exercise. The implementation strategy included a one-day supervisors' training and bimonthly telephone support. To evaluate effects, aerobic capacity (6-Minute Walk Test (6MWT)), physical functioning (Ankylosing Spondylitis Performance-based Improvement (ASPI); improved/not improved), health status (ASAS HI-questionnaire) and home exercise engagement (SQUASH-questionnaire) were assessed at baseline and after one year among 60 participants. Changes were analysed with the Wilcoxon Signed-Rank Test. To evaluate feasibility, a survey among participants and semi-structured interviews with SGE supervisors (n=4) assessed uptake and satisfaction with the enhancements.

Results

Aerobic capacity increased significantly and 35% of participants improved functioning, whereas health status and home exercise engagement did not change. The participants' survey and the supervisors' interviews showed that high-intensity aerobic exercise was implemented successfully, exercise personalisation and periodic assessments were implemented partially and patient education was not implemented at all. Most participants were satisfied with applied changes.

Conclusion

After a one-day training for SGE supervisors and telephone support, SGE enhancements were only partially implemented. Nevertheless, aerobic capacity improved significantly and satisfaction with accomplished changes was high. A nationwide implementation requires adaptations to the implementation strategy to improve feasibility.

Introduction

Axial spondyloarthritis (axSpA) is a chronic inflammatory disease that primarily affects the axial skeleton and is characterised by inflammatory back pain and stiffness (1, 2). Exercise has proven positive effects on symptoms, spinal mobility, cardiorespiratory fitness and physical functioning

in patients with axSpA (3-9). Moreover, it was found that supervised group exercise (SGE) is more beneficial than unsupervised, individual exercise (9-12). Thus, since the early nineties of the past century, SGE for patients with axSpA was implemented in many countries, including the Netherlands, where local patient associations affiliated with the Dutch Arthritis Society currently organise 56 axSpA-specific exercise groups in 17 regions (13). It was found that the delivery of SGE has hardly changed over the past decades, still comprising once weekly sessions with a relatively long duration, mainly focusing on mobility and strengthening exercises (13-17). This is in contrast with recommendations in the literature which state that more attention should be paid to high-intensity aerobic exercise (4-9, 14, 18-22), better exercise personalisation based on periodic assessments (10, 23-27) and educating patients about home exercise and about general, health-enhancing physical activity (3-5, 10, 28, 29).

Implementing these elements could enhance the SGE effectiveness, particularly regarding aerobic capacity, functioning and weekly exercise engagement. After all, studies have shown that the addition of (high-intensity) aerobic exercise can improve functioning and aerobic capacity (4, 9, 14, 19, 21), which is beneficial for the increased cardiovascular risk in axSpA (7, 18). Furthermore, both exercise personalisation and patient education on exercise can improve the overall potential for effectiveness (3, 10, 24) and increase weekly exercise engagement (3, 23, 25-27, 29).

It seems justified to implement these enhancements, yet it appears that knowledge about the feasibility of implementing them is scanty. One recent study, described in an abstract (30), involved a pilot implementation of comparable enhancements in four axSpA-specific exercise groups in Switzerland. Satisfaction levels were high, but they suggested to make the intervention less extensive to improve feasibility (30). These findings may not be fully generalisable to the Netherlands, as implementation strategies need to be tailored to a particular context, addressing specific barriers [30,31].

In the Netherlands, it seems appropriate to focus the implementation strategy on SGE supervisors. The knowledge and skills of supervisors appear to be very important in optimising exercise behaviour of people with axSpA (20, 23, 31) and are crucial for implementing the desired SGE enhancements. However, in the

Netherlands, 75% of axSpA-specific SGE supervisors had no postgraduate training related to rheumatology (13). Successful implementation strategies in other populations, i.e. in people with rheumatoid arthritis (32) and osteoarthritis (33), have also mainly focused on training exercise supervisors.

Given the lack of knowledge, this pilot implementation aims to evaluate the effects and feasibility of implementing enhancements in axSpA-specific SGE, prior to a nationwide implementation in the Netherlands. To evaluate effectiveness, changes in various patient outcomes were assessed, and to evaluate feasibility, both the extent to which the supervisors applied the enhancements and the experiences and satisfaction of participants were examined.

Materials and Methods

Design

A hybrid effectiveness-implementation type 2 design was used, because of the dual focus on both the effectiveness and the feasibility of this pilot implementation. A hybrid study design can speed the scientific progress and facilitate the translation of research findings into routine practice (34, 35). The implementation process started in 2015 in one region where axSpA-specific SGE was delivered, followed by three more regions in 2017. After a baseline survey among the participants, all involved SGE supervisors participated in a training and were urged to apply the proposed enhancements to their SGE. After one year, in 2018, an evaluation survey among participants and interviews with supervisors were used.

The guidelines of the Standards for Reporting Implementation Studies (StaRI) initiative have been followed for the reporting of this pilot implementation study (36).

Intervention and implementation strategy

The intervention to be implemented included: 1) More focus on high-intensity aerobic exercise during SGE, including intensity monitoring (e.g. by heartrate or BORG-scale); 2) Better exercise personalisation by performing periodic physical assessments, which provide insight in personal limitations; 3) Patient education during SGE about home exercise and physical activity (e.g. promotion of an axSpA-specific exercise app, called ´Bewegen met Bechterew´). To implement these enhancements, a strategy was tailored to the context of axSpA-specific SGE in the Netherlands (13) and therefore targeted the SGE supervisors. They received a one-day training, a manual for the physical assessments and bimonthly telephone support and a helpdesk (telephone or e-mail) was available on request. During the

training, supervisors were educated on why and how to implement the enhancements. The training equally consisted of theoretical and practical parts, focussing on axSpA education, exercise recommendations, intensity monitoring, physical assessments and corresponding exercise personalisation. There was some permissiveness as to how and to what extent each enhancement should be implemented by supervisors.

Setting and subjects

Six local patient associations organising axSpA-specific SGE in the Netherlands were invited for this pilot implementation project: eventually, four associations accepted the invitation (after much effort from the researchers). These associations organised nine axSpA-specific SGE classes for 130 patients with axSpA with involvement of 16 supervisors in total. Classes were once a week, combining training on land including sports activities (45-90 minutes) with hydrotherapy (45 minutes), mainly focusing on mobility and strengthening exercises and without any intensity monitoring, periodic physical assessments or patient education (15).

The inclusion criteria for SGE participants in this study were: 1) being willing and able to participate in this study; 2) completion of the baseline survey; 3) either having two physical assessments and/or completing the evaluation survey. A package of numbered surveys and patient information letters was sent to the four local patient associations that organised the SGE. To ensure anonymity, only they had a file with the link between the numbered surveys and the participants' information. The associations were responsible for inviting the SGE participants to the survey and for arranging the distribution, collection and return of the surveys.

Measurements

Effects were evaluated in three ways. First, in the evaluation survey, participants rated the changes they experienced in their functioning after the implementation (*improved*, *no change* or *worsened*). Second, the periodic physical assessments included the 6-Minute Walk Test (6MWT), measuring aerobic capacity (37), the Ankylosing Spondylitis Performance-based Improvement (ASPI), measuring physical functioning with three performance-based tests (38), and three spinal mobility tests, namely lateral spinal flexion, tragus-to-wall distance and chest expansion (39-41). Third, both the evaluation and baseline survey included the ASAS Health Index (ASAS HI), which measures participants' health status (42), and the Short Questionnaire to Assess Health-enhancing physical activity' (SQUASH), which measures the participants' weekly physical activity (43).

To evaluate the feasibility, semi-structured interviews with supervisors and an evaluation surveys among individual participants were conducted. The interviews were conducted by telephone with the coordinating supervisor from each region

(n=4), lasting approximately 45 minutes per interview. Supervisors were asked to what extent each enhancement was implemented, how they experienced its feasibility and its added value and if they had future needs. The answers were used to analyse the uptake of enhancements and compare regions. The evaluation survey examined participants' experiences with the program changes (one 5-point Likert scale and two open questions for positive and negative feedback), with each SGE enhancement (ten multiple choice questions) and with the program's intensity, options for personalisation and amount of mobility, strengthening and aerobic exercise (five multiple choice questions). Finally, to evaluate the feasibility of implementing the physical assessments, it was also analysed which assessment data were collected in the four SGE regions.

Statistical analyses

Descriptive statistics were used for the patient characteristics and the results on the evaluation survey, which were reported as frequency (and percentage) or median (and interquartile range), where appropriate. From the SQUASH, the weekly frequency and duration of aerobic exercise were calculated. Changes between two timepoints in 6MWT, ASPI, the spinal mobility tests, ASAS HI and SQUASH were analysed with the Wilcoxon Signed-Rank Test. In addition, it was calculated how many participants (numbers and percentage) did and did not improve on the ASPI (if at least one item improved with ≥20%, whereas none of the items worsened ≥20%, it was classified as improved (38)) and how many improved, had no change and worsened on the 6MWT with at least 30 meters, its minimal clinically important difference (37). Differences in age and durations of disease and SGE participation between the participants who were and were not included and between the four regions were analysed with the Median test, a non-parametric test comparing medians across two or more independent samples, and differences in gender between these subgroups were analysed with the Chi-square test.

Analyses were performed using IBM SPSS Statistics for Windows, version 23.0 (IBM Corp., Armonk, NY, USA).

Results

Patients

Of the 130 axSpA-specific SGE participants, 118 completed the baseline survey. Of these, a total of 89 were included, of which 62 had at least two physical assessments and 60 completed the evaluation survey, as shown in Figure 1. In Region 3, the assessment was organised only once and in Region 4, the evaluation survey was not sent to the participants due to a delayed start of the implementation project in that region.

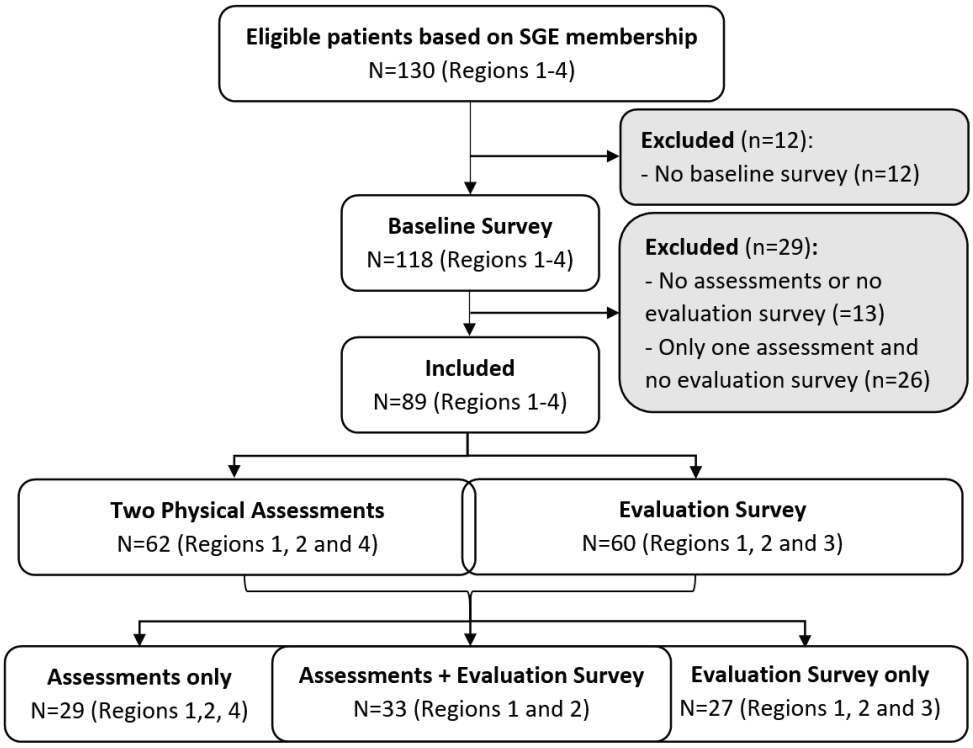

Figure 1. Inclusion flowchart of axial spondyloarthritis patients participating in the pilot implementation of supervised group exercise enhancements.

The Chi-square test showed that the proportion of males was higher among the included participants than among the excluded patients ($p < .05$), whereas there were no significant differences in age, disease duration or SGE participation according to the Median test.

Of the 89 participants, 71% was male and the median (IQR) age was 61 (55;69) years. The median (IQR) disease duration and SGE participation were 28 (14;36) and 21 (7;25) years, respectively. Table 1 presents the differences in baseline characteristics between the different subgroups; none reached statistical significance with the Chi-square or Median tests.

Table 1. Characteristics of the axial spondyloarthritis patients included in this study and the different study subgroups.

	Total (n=89)	Assessments (n=62)	Evaluation (n=60)	Region 1 (n=33)	Region 2 (n=27)	Region 3 (n=16)	Region 4 (n=13)
Age, years, Med (IQR)	61 (55;69)	62 (52;70)	60 (55;68)	59 (51;70)	62 (57;71)	60 (55;64)	62 (54;70)
Gender, male, n (%)	63 (71)	45 (73)	43 (72)	25 (76)	18 (67)	9 (56)	11 (85)
Disease duration, years, Med (IQR)	28 (14;36)	29 (12;38)	26 (16;35)	28 (10;40)	29 (17;34)	26 (23;30)	30 (14;40)
SGE Participation, years, Med (IQR)	22 (9;25)	21 (9;25)	23 (11;27)	19 (8;25)	25 (9;28)	23 (20;27)	21 (13;25)
Medication use, n (%)							
Painkiller [a]	19 (22)	11 (18)	15 (25)	6 (18)	5 (20)	6 (38)	2 (15)
NSAID	47 (54)	35 (58)	31 (52)	21 (64)	15 (60)	4 (25)	7 (54)
Biological DMARD	8 (9)	5 (8)	6 (10)	1 (3)	3 (12)	2 (13)	2 (15)
Synthetic DMARD	13 (15)	7 (12)	9 (15)	5 (15)	4 (16)	3 (19)	1 (8)
None	20 (23)	14 (23)	13 (22)	6 (18)	4 (16)	5 (31)	5 (39)

[a] Acetaminophen or opioid painkillers.

SGE = supervised group exercise; Med = median; IQR = interquartile range; NSAID = nonsteroidal anti-inflammatory drug; DMARD = disease-modifying antirheumatic drug.

Evaluation of effects

In the evaluation survey, 20 of 60 participants (33%) reported to experience improved functioning, 38 (63%) no change and 2 (3%) a negative change since the implementation. In addition, the ASPI qualified 20 of 58 participants (35%) as improved and 38 (65%) as not improved and on the 6MWT, 20 of 56 participants (36%) improved (≥30 meters), whereas 28 (50%) had no clinically significant change and 8 (14%) worsened (≥30 meters). This is presented in Figure 2. Furthermore, Table 2 shows a statistically significant improvement in the 6MWT and a small but statistically significant worsening in tragus-to-wall distance; both *p*-values < .05. No statistically significant changes over time were found in the other two spinal mobility tests, in the ASPI performance-based tests, in health status (ASAS HI) and in frequency and duration of aerobic exercise; all *p*-values > .05.

Table 2. Baseline and follow-up scores and the change over time of measurements evaluating the implementation effects.

	Baseline Med (IQR)	Follow-up Med (IQR)	Change in score Med (IQR)	*P*
Aerobic capacity: 6MWT, meters	552 (481;595)	569 (513;626)	10 (-19;60)	0.019 [a]
Physical functioning: ASPI				
Picking up pens, sec	12.0 (10.0;15.8)	11.8 (9.8;14.3)	-0.2 (-2.2;1.7)	0.321
Putting on socks, sec	12.0 (8.6;18.2)	11.5 (8.6;14.3)	-0.4 (-6.0;1.8)	0.249
Getting up from floor, sec	4.9 (3.4;6.7)	4.3 (3.4;6.2)	0 (-1.1;0.5)	0.389
Spinal mobility				
Lateral flexion, cm	9.5 (5.0;14.3)	9.5 (5.8;14.3)	0 (-1.3;1.0)	0.900
Tragus-to-wall, cm	15.7 (11.9;21.5)	17.5 (13.4;23.3)	0.7 (-0.5;2.6)	0.011 [a]
Chest expansion, cm	2.5 (1.5;4.0)	2.5 (1.5;4.0)	0 (-0.5;0.5)	0.838
Health status: ASAS HI, score	5.0 (3.0;8.0)	5.0 (3.0;8.5)	0 (-1, 1.9)	0.157
Exercise frequency: SQUASH, sessions/week	6 (3;10)	6 (3;9)	0 (-1;2)	0.357
Aerobic exercise: SQUASH, minutes/week	375 (225;555)	405 (245;555)	0 (-120;175)	0.560

[a] Significant improvement with a p value < .05 by the Wilcoxon Signed-Rank Test.
Med = Median. IQR = interquartile range. 6MWT = 6-Minute Walk Test. ASPI = Ankylosing Spondylitis Performance-based Improvement. Sec = seconds. Cm = centimetres. ASAS HI = ASAS Health Index. SQUASH = Short Questionnaire to Assess Health-enhancing physical activity.

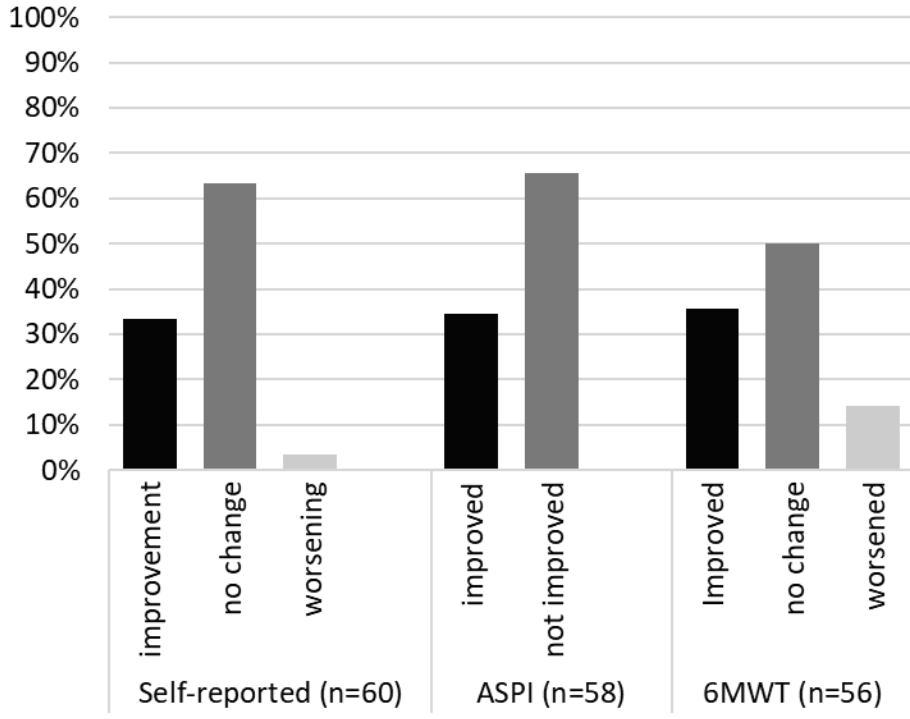

Figure 2. Proportion of participants with (and without) improvement in self-reported functioning, in the Ankylosing Spondylitis Performance-based Improvement (ASPI; improvement = one item improving ≥20% and none worsening ≥20% (38)), and in the 6-Minute Walk Test (6MWT; change = ≥30 meters difference (37)).

Implementation activities

It proved difficult to plan the one-day training with the supervisors, which resulted in four different training days, in order for all 16 supervisors to be able to attend one training day. Regarding the execution of physical assessments, the 6MWT was used in all regions and the ASPI and mobility tests in three of four regions. The time interval between assessments differed between regions: there were twelve, six and nine months between baseline and (first) follow-up physical assessments of participants in Regions 1, 2 and 4, respectively. Region 3 organised assessments just once. During the bimonthly telephone support, supervisors mainly needed advice on personalisation of exercise and intensity monitoring. The helpdesk was only used once: Region 2 had questions about the correct use of the Borg-scale to monitor exercise intensity.

Evaluation of feasibility

Supervisors' interviews

The semi-structured interviews were performed with SGE supervisors from each region (n=4): one of four was male, they were between 28 and 56 years old, and they had between 8 and 30 years of experience with axSpA-specific SGE. All supervisors experienced an increased SGE-quality, mainly due to higher exercise intensity and more variation, especially after the initial physical assessments. Regarding the three enhancements, the following findings were reported:

1. High-intensity aerobic exercise: All supervisors indicated that this was implemented successfully, e.g. by using more aerobic exercises in circuit training and by increasing intensity (getting more out of breath), and it was considered the most important enhancement. One supervisor noticed that the participants were more focused on the exercises. To monitor exercise intensity, heartrate monitors were implemented in one region only, aiming at a heartrate of 70% of the theoretical maximum (220 minus age); two regions used a Borg-scale due to limited availability of heartrate monitors and in one region it was not applied at all as it was considered impractical.
2. Exercise personalisation with physical assessments: All supervisors noted that they sometimes experienced difficulties tailoring the exercises to the large individual differences, e.g. in circuit training. Physical assessments were performed at least once in all regions, but only two regions continued with periodic assessments. The other two regions only performed the assessments once or twice, because it was too time consuming and required additional supervisors. The two regions that continued with the assessments reported to have sufficient supervisors and funding available for this. In all regions, an extra supervisor was employed during the assessments. All supervisors experienced that the participants were very positive about the assessments.
3. Patient education: none of the supervisors provided structural education on home exercise during SGE and two supervisors desired to implement it in the future. In Region 1, however, the importance of home exercises is discussed during yearly evaluations of the assessments.

Finally, the supervisors experienced the one-day training as helpful and suggested repeating the course for further training. As future needs, they mentioned support in educating and motivating participants to exercise at home in addition to SGE and to create a more standardised exercise program, to reduce the quality differences between supervisors.

Table 3. Evaluation of feasibility and satisfaction with implemented enhancement by supervised group exercise participants.

	Total (n=60)	Region 1 (n=19)	Region 2 (n=25)	Region 3 (n=16)
Experienced program changes, n (%)				
Much worse	0/60 (0)	0/19 (0)	0/25 (0)	0/16 (0)
A little worse	4/60 (7)	1/19 (5)	1/25 (4)	2/16 (13)
The same	21/60 (35)	4/19 (21)	11/25 (44)	6/16 (38)
A little better	24/60 (40)	9/19 (47)	9/25 (36)	6/16 (38)
Much better	11/60 (18)	5/19 (26)	4/25 (16)	2/16 (13)
Enhancement 1: High-intensity aerobic exercise				
Satisfied with exercise intensity, n (%)	44/57 (77)	16/19 (84)	23/25 (92)	5/13 (39) [a]
Satisfied with aerobic exercise, n (%)	39/56 (70)	13/19 (68)	16/23 (70)	10/14 (71)
Satisfied with mobility exercise, n (%)	49/55 (89)	16/18 (89)	21/23 (91)	12/14 (86)
Satisfied with strengthening exercise, n (%)	44/57 (77)	14/19 (74)	18/24 (75)	12/14 (80)
Heartrate monitoring is applied, n (%)	29/59 (49)	19/19 (100)	9/25 (36)	1/15 (7) [a]
Heartrate monitoring is favourable, n (%)	27/29 (93)	18/19 (95)	8/9 (89)	1/1 (100)
Heartrate monitoring disrupts exercise, n (%)	3/29 (10)	2/19 (11)	1/9 (11)	0/1 (0)

Table continues

Table 3 (Continued). Evaluation of feasibility and satisfaction with implemented enhancement by supervised group exercise participants.

	Total (n=60)	Region 1 (n=19)	Region 2 (n=25)	Region 3 (n=16)
Enhancement 2: Personalisation by assessments				
Satisfied with exercise personalisation, n (%)	51/58 (88)	16/19 (84)	21/24 (87)	14/15 (93)
Assessment is applied, n (%)	50/58 (86)	19/19 (100)	19/24 (79)	12/15 (80)
Assessment is favourable, n (%)	47/50 (94)	17/19 (89)	18/19 (95)	12/12 (100)
Assessment is physically demanding, n (%)	1/50 (2)	1/19 (5)	0/19 (0)	0/12 (0)
Assessment once yearly is sufficient, n (%)	40/50 (80)	16/19 (84)	17/19 (90)	7/12 (58)
Enhancement 3: Education on home exercise				
Known with axSpA exercise-app, n (%)	12/56 (21)	10/19 (53)*	1/24 (4)	1/13 (8)
Uses axSpA exercise-app, n (%)	1/56 (2)	0/19 (0)	1/24 (4)	0/13 (0)

[a] Significant difference between regions with a p value < .01 by the chi-square test.

Patients' evaluation survey

Table 3 shows the participants' evaluation of the enhancements. This shows that the majority of participants (58%) considered the new program an improvement. Regarding the first enhancement, the vast majority of participants was satisfied with the exercise intensity (77%) and with the amount of aerobic (70%), mobility (89%) and strengthening exercise (77%). When heartrate monitoring was used, most found it favourable (93%) and few experienced it to disrupt the exercise (10%). The results regarding the second enhancement show that in all regions, the majority of participants was satisfied with the exercise personalisation (88%). The physical assessments were applied at least once in 86% of participants and among those, the vast majority (94%) considered it favourable. The third enhancement involved the use of patient education, e.g. by promoting an axSpA-specific exercise app. It was found that only 12 of 56 participants (21%) were familiar with the axSpA-

specific home exercise app, 10 of whom from one region, and just one participant (2%) still used it for home exercise.

Regarding the responses to the open ended feedback of the 60 SGE participants who completed the evaluation survey, 34 (57%) provided positive feedback and 9 (15%) provided negative feedback. The most reported positive change was more focus on aerobic exercise (n=12/60), followed by more focus on active exercises (n=8/60) and exercising with higher intensity (n=6/60) and with more variation (n=6/60). Participants from all regions mentioned more aerobic exercise and higher intensity as positive changes, whereas only two participants mentioned personalisation as a positive change, only one mentioned the physical assessments and none of the participants mentioned anything about patient education. The most reported negative feedback was that some exercises were too heavy (n=4/60).

Discussion

During this pilot implementation of SGE enhancements, approximately one third of SGE participants improved functioning and there was a significant improvement in aerobic capacity, but also a statistically significant, yet very small worsening in one spinal mobility test. There were no significant changes in the other spinal mobility tests, in health status and in weekly aerobic exercise engagement. The interviews with the supervisors and the evaluation surveys among participants showed that not all enhancements were implemented successfully and that the majority of participants was satisfied with the changes. Whereas the supervisors perceived the exercise personalisation as difficult to execute, most participants were satisfied about this aspect. Although the implementation of high-intensity aerobic exercise appears to be successful, the implementation of the exercise personalisation and periodic assessments appeared to be more difficult and patient education about home exercise was not implemented at all.

The effects of this pilot implementation are in line with the realised uptake of enhancements. After all, implementing high-intensity aerobic exercise appeared the most feasible and, accordingly, aerobic capacity was the only outcome that significantly improved, whereas patient education about home exercise not being implemented could explain the lack of change in weekly exercise engagement. Although the median change in 6MWT did not exceed the minimal clinically important difference of 30 meters (37), 36% of participants did have a clinically significant improvement, compared to 14% that worsened (Figure 2). The improvement in aerobic capacity is promising, with potential benefits for the increased cardiovascular risk in axSpA (7, 18, 21). Even larger effects can be

expected if patient education on more frequent (high-intensity) exercise would be implemented. Furthermore, the finding that one third of participants improved functioning, while only 3% experienced a worsening, is also encouraging and important for long-term SGE engagement. The statistically significant worsening of the tragus-to-wall distance may be a concern, as greater focus on aerobic exercise may have reduced the amount of mobility exercise. However, although a minimal clinically important difference of this test is unknown (41), the change in score is very small and does not appear clinically relevant. Moreover, the other two spinal mobility tests are believed to be more responsive (40) and showed no change at all. Regardless, it is essential that supervisors personalise exercise in case a participant shows any deterioration during the assessments. In that case, linking patient education about home exercises to the assessment results could lead to more improvements and less deterioration in outcomes. Therefore, improving the feasibility of the implementation can further increase the effectiveness of SGE.

To improve feasibility, a more comprehensive implementation strategy with more stakeholders seems warranted to increase implementation success. Similar studies with successful implementation targeted more stakeholders than just supervisors, e.g. patients, rheumatologists, local patient associations and health insurance companies (30, 32, 33). The current implementation strategy focused mainly on the supervisors, as the expertise of SGE supervisors was considered an important facilitator for the enhancements (13, 15, 20, 23, 31). Prior to and during a nationwide implementation, it may be desirable to involve all stakeholders to jointly identify potential implementation barriers and possibilities to cope with them. This could also increase supervisors' willingness to participate, which appeared limited when inviting the patient associations for this pilot study.

A potential barrier of the implementation's feasibility could have been limited resources. The main implementation activity was the one-day training for SGE supervisors, whereas other studies with good feasibility used a two- or three-day training (32, 33). More extensive training could be challenging, as it was already difficult to plan a one-day training and two regions declined to participate because the supervisors believed that the compensation did not outweigh the time investment. In addition, limited resources (i.e. funding and supervisors) prevented two regions from continuing with periodic assessments and the limited resources could also be an important reason why patient education was not implemented successfully. Similar studies that successfully implemented patient education were able to organise education separately from the SGE sessions (30, 33). Thus, possibilities for more resources should be explored, as well as more cost-effective solutions, e.g. the use of physical therapy students for the assessments or the use of instruction manuals providing education on home exercise (23). Moreover, the currently used home exercise app appears outdated and has too little focus on aerobic exercise. Furthermore, with more resources, the participation of

supervisors can be better compensated, they can be better trained to implement all enhancements and there can be more demands and less permissiveness regarding the implementation, which should improve the feasibility (44).

There are a few study limitations to be mentioned. First, although the participating regions were spread well across the Netherlands and there were no differences in patient characteristics between these four regions, there may be limited generalisability. After all, among the SGE participants, males were more likely to participate, and compared to other studies (45), the participants represented relatively older axSpA patients with long disease duration and SGE participation. These characteristics may challenge the implementation of changes and it is therefore promising that even in this group there were some positive effects and satisfaction levels were high. In addition, although it is not fully clear to what extent the findings can be generalised to other countries, a Swiss study evaluating the implementation of similar enhancements in axSpA-specific SGE found comparable satisfaction levels among participants (30). Furthermore, while the hybrid study design provided useful insights by evaluating both feasibility and effects, the varying availability and time intervals between baseline and follow-up data between regions might have limited the validity of the effect evaluation. The final limitation is the absence of a control group to compare the changes in outcomes over time. Nevertheless, this study provided a lot of useful information for a possible nationwide implementation of the SGE enhancements.

In conclusion, after a one-day training for SGE supervisors and telephone support, a set of enhancements was partially implemented. Aerobic capacity improved significantly and functioning improved in about one third of the participants. Most of the participants were satisfied with the applied changes. To further increase the effects and feasibility during a nationwide implementation of the SGE enhancements, an increase of resources and a multifaceted implementation strategy also involving other stakeholders seems necessary.

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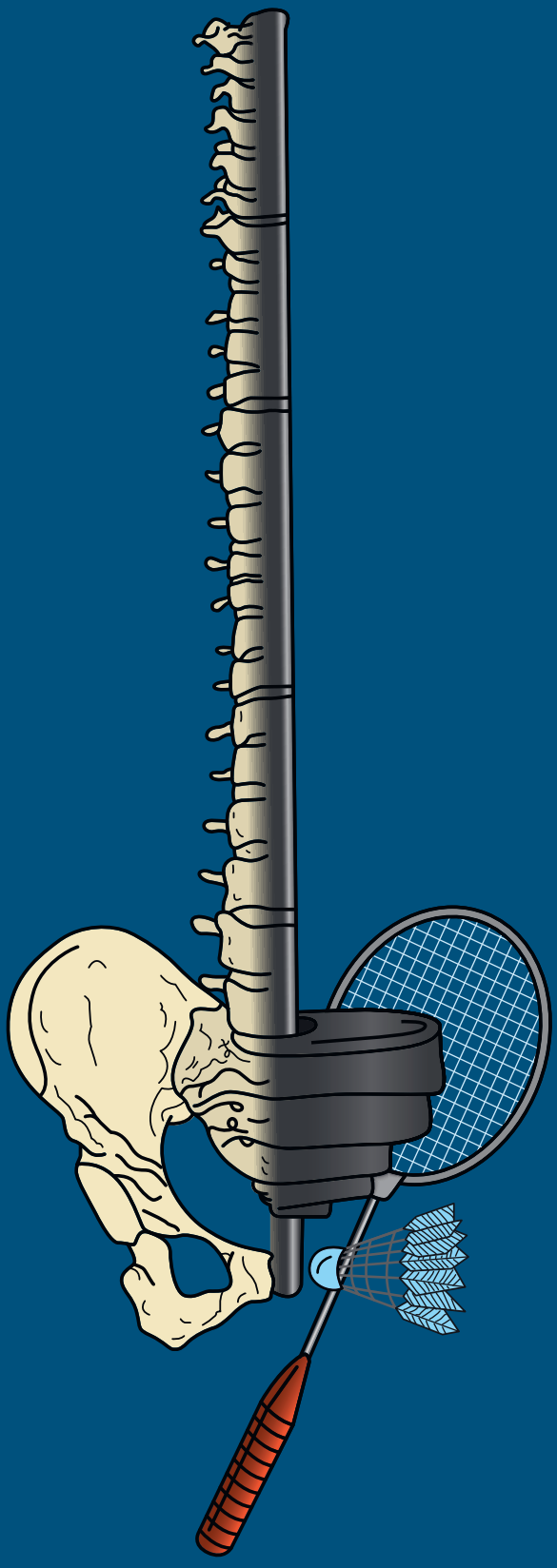

Chapter 7

How to optimize exercise behavior in axial spondyloarthritis? Results of an intervention mapping study

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Patient Education and Counseling 2020;103(5):952-959

Abstract

Objective

Many individuals with axial spondyloarthritis (axSpA) do not engage in adequate exercise, despite its proven health benefits. This study aimed to identify the intervention components needed to optimize exercise behavior in people with axSpA.

Methods

The first three steps of the Intervention Mapping protocol were used: 1) needs assessment; 2) identification of axSpA-specific exercise barriers and facilitators (´determinants'); 3) selection of effective intervention components addressing potentially modifiable determinants. All three steps included scoping reviews and semi-structured interviews with patients (n=2) and physical therapists (n=2).

Results

The scoping reviews included 28, 23 and 15 papers, respectively. Step 1 showed that only one third of axSpA patients exercise regularly, demonstrating especially a lack of strengthening and cardiorespiratory exercises. Based on eight determinants identified in Step 2, 10 intervention components were selected in Step 3: education, motivational interviewing, goal setting, action planning, monitoring, feedback, tailoring, guided practice, therapists' training and group exercise encouragement.

Conclusion

Using the Intervention Mapping method, 10 intervention components for optimizing exercise behavior in people with axSpA were identified and an intervention with behavior change guidance and a training for health professionals is proposed.

Practice Implications

This study provides a foundation for the development of an axSpA-specific exercise intervention.

Introduction

Axial spondyloarthritis (axSpA) is an inflammatory rheumatic disease primarily affecting the spine and sacroiliac joints, causing chronic back pain and stiffness (1). Exercise was found to have positive effects on functioning, disease activity, pain, stiffness, mobility, cardiorespiratory function and depressive symptoms in people with axSpA (2-8). Regular exercise is therefore included in international recommendations for the management of axSpA (1, 9).

Despite the potential beneficial effects, a considerable proportion of people with axSpA does not engage in exercise at all, engagement in exercise is not sustained, or their exercise regimens are not – or not consistently – carried out with the appropriate frequency, intensity and/or type of exercises (10-13). A potential explanation for the lack of usage of appropriately dosed exercise programs could be that the content of interventions to promote exercise in people with axSpA does not meet the requirements to achieve lasting behavioral changes. Interventions consist of 'intervention components', which are methods or techniques (e.g. 'goal setting') that aim to change certain behavior by influencing its 'determinants', which are the factors that significantly affect that behavior (e.g. 'intentions'). Ideally, interventions aiming to optimize exercise behavior of axSpA patients should use intervention components that explicitly target axSpA-specific determinants of exercise behavior (14). This is also proposed in the 2018 EULAR recommendations for physical activity in people with inflammatory arthritis and osteoarthritis (9). In that study, the importance of taking into account disease-specific barriers and facilitators when promoting physical activity in people with rheumatic and musculoskeletal diseases is underlined. In addition, it advocates the conduct of more research on how to facilitate exercise behavior change and how to address disease-specific barriers and facilitators (determinants). Identification of relevant determinants and intervention components should be based on scientific evidence from literature as well as patient values and clinical expertise of important stakeholders (i.e. health care providers) (15).

A number of studies have been published that specifically aim to optimize exercise behavior of people with axSpA (16-20). However, either the development process of the intervention was not described (16-18), relevant determinants and corresponding intervention components were not identified during the development (19) or when selecting determinants, only the patients' perspective was examined qualitatively, without reviewing the literature (20). Furthermore, various other studies examined axSpA-specific determinants of exercise, but without identifying intervention components that target these determinants (21-25). Thus, it appears that no study combined the identification of axSpA-specific exercise determinants with a selection of corresponding intervention components, while accounting for literature as well as patient values and clinical expertise.

Therefore, this study aimed to first identify axSpA-specific exercise determinants and then connect these with effective intervention components to optimize exercise behavior in people with axSpA, while combining theory, literature and the involvement of stakeholders from different ecological levels. Since other important studies have already focused extensively on the perspective of stakeholders (19-21), the current study will put more emphasis on literature reviews, while using the findings of these previous studies. The selected intervention components should be used in exercise interventions for people with axSpA, in order to increase the likelihood and magnitude of sustainable change in exercise behavior.

Methods

Study design

In order to identify intervention components targeting axSpA-specific determinants of exercise, the Intervention Mapping (IM) protocol was used (26). IM is a six-step framework for the development of theory- and evidence-based interventions, guiding the path from problem identification to solution development and using literature, stakeholders' perspectives and an ecological approach. The current study included the first three IM steps: a needs assessment (Step 1), an identification of determinants (Step 2) and a selection of intervention components (Step 3). In this study, two ecological levels were distinguished: individual axSpA patients and (physical or exercise) therapists, as most exercise interventions for patients with inflammatory arthritis are provided by physical therapists (9). Therefore, in each of the three IM steps, a scoping review of literature and semi-structured interviews with two persons with axSpA and two specialized therapists were conducted. IM Steps 4 (intervention development), 5 (implementation) and 6 (evaluation) were not performed in this study.

Scoping reviews

For all three steps, a scoping review was performed using the electronic database PubMed, searching for all types of studies, in English, Dutch or German, published between January 1990 up to May 2017. These searches combined terms related to 'axSpA', 'exercise' and the associated IM steps (Appendix A). The same author (BH) performed all scoping reviews and assessed papers for eligibility. The search strategy was extended to other databases if the PubMed search did not yield certain key references. After removing duplicates, titles and abstracts were screened for relevance: studies that did not cover axSpA, exercise and the corresponding IM Step were excluded. Reference lists of important articles were manually searched for additional studies. Full-texts were obtained and relevant data of the included studies were extracted, including first author, year of

publication, title, study type, population and the main findings relating to the research question(s) of each IM step.

Semi-structured interviews

In each step, semi-structured interviews were used to better understand the literature findings, to verify them with the Dutch situation and to rank the identified determinants and intervention components. The interviews were conducted by BH with two patients and two physical therapists, selected from an outpatient rehabilitation center in Groningen, the Netherlands (the Allied Healthcare Center for Rheumatology and Rehabilitation, PCRR). Both patients were diagnosed with ankylosing spondylitis (49 year old male with 30 years disease duration and 52 year old female with 20 years disease duration). Both therapists were experienced in treating people with axSpA (34 year old female with 11 years of experience in axSpA treatment and 51 year old male with 18 years of experience in axSpA treatment). The interviews lasted approximately one hour each and interviews were stopped if data saturation was achieved and no new information emerged. Only four interviewees were initially selected, because the stakeholders' perspective on this matter is well covered in earlier studies (19-21). This study focused more on literature reviews, which also explicitly covered the literature on the patients' perspective. However, if the interviews would yield conflicting or insufficient results, additional subjects would be included for interviews. More detailed and IM Step-specific information is provided in the following paragraphs.

IM step 1: needs assessment

With this step, three topics were addressed: (a) the potential health benefits of exercise for people with axSpA, (b) the discrepancy between current and desired exercise behavior and (c) the patients' perspective on this matter. Since this step particularly focused on current needs, the scoping review included only recent studies, published after May 2012. In addition, recommendations on the management of axSpA written in English or Dutch were used for topics a and b. In question b, exercise types recommended in at least two systematic reviews or axSpA management recommendations were linked to the proportion of people with axSpA engaging in this exercise type according to the included studies. This was done to map the discrepancy between recommended and current exercise behavior.

Semi-structured interviews with patients and therapists were used to explore the scoping review findings qualitatively. The interviewees were given summaries of the scoping review results in writing. They were asked to provide their perspective on these three questions, which were used to identify similarities and potential additions to the scoping review findings.

IM step 2: determinants identification

This step specified what should change to optimize exercise behavior in people with axSpA ('change objectives'), by identifying relevant and changeable (behavioral and environmental) exercise barriers and facilitators ('determinants') and connecting these to 'performance objectives', which are specific aspects of the desired behavior. For the scoping review in IM Step 2, the search was extended to Web of Science (in addition to PubMed), to cumulate more evidence on axSpA-specific exercise determinants. Determinants found in the included studies were only selected if they were judged as both changeable and relevant: changeability was estimated by the author (BH) and relevance was based on the strength of association with behavior in the 'Reasoned Action Approach' model (27). The Reasoned Action Approach states that behavior is predicted by one's intentions and 'self-efficacy' (perceived behavioral control), while intentions are determined by an individual's attitudes, perceived norms and self-efficacy and it will only translate to behavior given the right environmental factors, skills and abilities. This theory was used because it is often used to explain exercise behavior (27).

In the semi-structured interviews, the specified change objectives were explained by the interviewer and then scored verbally by the patients and therapists for their expected relevance in influencing exercise behavior of people with axSpA with a grade between 1 ("not relevant at all") and 10 ("absolutely essential"). Interviewees were stimulated to share their reasoning, which provided additional insight in their thought process, and they were able to either combine or split up certain change objectives. The interviewer made field notes of the interviewees' comments and their relevance grades. The grades were averaged for each change objective: if it was below a 7, it was determined whether it was justified to exclude the change objective, by re-evaluating its evidence from the scoping review and by accounting for potential reasoning of the interviewees.

IM step 3: intervention components selection

In this step, the scoping review searched for studies on interventions that included theory-based intervention components, which target the selected determinants from IM Step 2. The IM taxonomy (28) was used to determine which determinants the intervention components target and to which theories they are related. Only effective components found in at least two different studies from the scoping review were included. The selected components were translated into practical applications by linking them to the change objectives and to the I-Change Model (29, 30), a model on behavior change integrating ideas of various social cognitive theories. The I-Change Model was used because the Reasoned Action Approach model – which is used in the selection of determinants – is integrated in it as well and it organizes determinants in different successive behavior change phases (29):

awareness, motivation and action. During translation of the intervention components into practical applications, the parameters for effectiveness were also accounted for, which are the conditions under which an intervention component is more or most effective (28).

The semi-structured interviews were similar to those in IM Step 2, but in Step 3 the intervention components (instead of the change objectives) were graded.

Results

IM step 1: needs assessment

The scoping review of IM Step 1, which addressed (a) exercise benefits, (b) current and desired exercise and (c) the patients´ perspective, identified 64 abstracts, from which 28 full-text articles were selected (Figure 1). Table B.1 (Appendix B) presents the designs of the included studies.

For question a of this scoping review (exercise benefits), 22 studies were included: ten studies about effectiveness of exercise-interventions (3, 7, 8, 17, 31-36), five studies with a qualitative approach (13, 21, 22, 37, 38) and seven studies examining associations with exercise (11, 12, 23, 39-42). Reported benefits of exercise among people with axSpA are improved (physical) functioning, cardiorespiratory function, quality of life, (spinal) mobility, chest expansion and global assessment and decreased disease activity, pain, stiffness, depression, fatigue and body mass index (BMI) (3, 7, 8, 17, 31, 32, 34, 35). Due to the heterogeneity in the type of exercise used in the various interventions, it is not possible to establish which type of exercise results in which specific benefits.

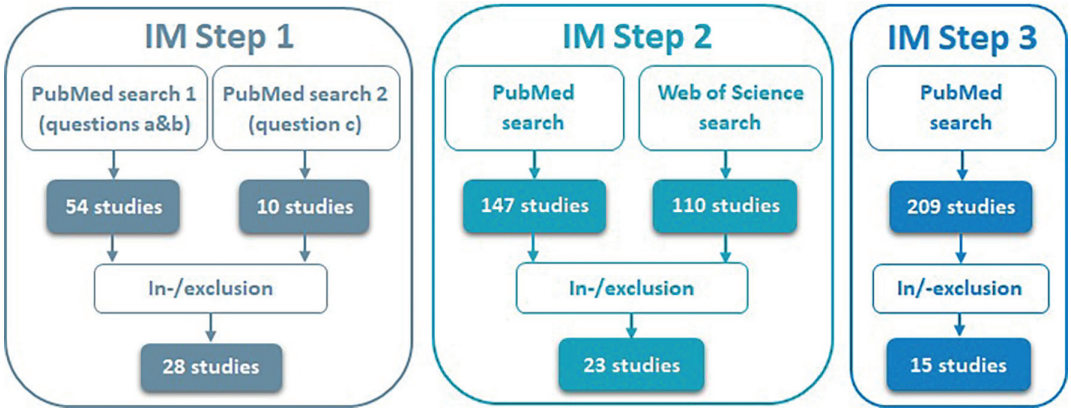

Figure 1. Flowchart of the scoping reviews of IM Steps 1, 2 and 3

Furthermore, 15 included studies covered question b (current and desired exercise). Ten of these reported on current exercise behavior (11-13, 23, 37, 39, 40, 43-45) and five studies reported on desired exercise behavior (3, 8, 19, 31, 32). In addition, six recommendation articles on the management of axSpA were obtained (1, 9, 46-49). Table 1 presents which exercise types are desired and to what extent they are currently executed by people with axSpA according to the studies found in the scoping review. These results show that about a third of the patients engage in mobility exercise, a tenth in strength exercise and a third in cardiorespiratory exercise, while these exercise types were explicitly recommended. Furthermore, it shows that few studies reported on the types of exercise people with axSpA engage in and that no study reported on current engagement in supervised group exercise, which is recommended by two systematic reviews (3, 19) and one recommendation article (47).

Table 1. Proportion of people with axSpA engaging in exercise types recommended in axSpA management (IM Step 1, question b)

Recommended Exercise Types [a]	Current Exercise Behavior [b]
Mobility exercise	In one study, 43% of patients performed home stretching weekly, of which 33% performed it at least three times per week (13). In another study, 26% of axSpA patients executed 'back exercises' (12).
Strengthening exercise	In one study, around 10% of axSpA patients engaged in strength exercise, compared to 27% among population controls (12).
Cardiorespiratory exercise	In three studies, axSpA patients engaged less in physical activities with higher intensities than the general population (39, 40, 44). In one study, 32% of the patients were exercising at vigorous intensity for at least 30 minutes 2-3 times per week (23). In another study, 58% of patients executed any form of aerobic exercise, but 30% executed it at least once a week for 30 minutes or more (37).
Supervised group exercise	No studies found
Regular physical activity	In seven studies, the amount of weekly moderate-intensity physical activity of patients was comparable to that of the general population: around half of the participants did not adhere to the recommended amount (11, 12, 23, 37, 39, 40, 44).
Interrupting sedentary time	In three studies, the total amount of weekly inactivity of axSpA patients was comparable to that of the general population (39, 40, 44).

[a] Exercise types that are recommended by at least two axSpA management recommendations or systematic reviews (3, 9, 19, 46-49).

[b] Based on the results from the scoping review of IM Step 1.

Question c of IM Step 1 (patients' perspective on exercise) was covered by eight studies (13, 20-22, 37, 38, 42, 50). These studies indicated the importance of a personally tailored exercise prescription, better monitoring, more exercise education and sufficient coherence in exercise advice.

The interviews with the patients and therapists mostly confirmed the literature findings. The therapists also expressed a need for more emphasis on exercises with higher intensity and core-stability and postural exercises. The patients indicated the importance of incorporating enjoyable activities and sufficient variation in exercise programs.

IM step 2: determinants identification

The scoping review for IM Step 2 selected 23 studies (13, 17, 18, 20-24, 37, 51-64). In total, 45 different factors influencing exercise behavior of people with axSpA were found (see Table B.2 in Appendix B), which could be clustered in 11 overarching determinants. Table 2 shows the overarching determinants and their underlying factors, supporting studies, relevance according to the Reasoned Action Approach Model (27) and expected changeability. Eight of the determinants were deemed changeable and relevant by the authors and were selected for intervention development; these are shown in Figure 2.

Table 2. Underlying factors, supporting studies, relevance and changeability for overarching exercise determinants found in the literature search (IM step 2)

Determinant	Factors	Number of supporting studies	Relevance	Changeability
Self-efficacy	Exercise self-efficacy +, trust +	6: Mattukat 2017, Mattukat 2013, Da Costa 2010, Lim 2005, Stenström 1997, Curbelo Rodríguez 2017	++	++
Attitude	Perceived exercise benefits +, perceived barriers -, attitude towards exercise +/-, experiencing exercise as tiring and hard work -	7: Mattukat 2017, Niedermann 2014, Santos 1998, O'Dwyer 2016, Da Costa 2010, Passalent 2010, Fabre 2016	+	++
Perceived Norm	Social support +, experiencing social responsibility +	3: Ward 2002, Curbelo Rodríguez 2017, O'Dwyer 2016	+	++
Intention	Motivation +, Intrinsic motivational factors (interest, enjoyment, competition) +	5: O'Dwyer 2016, Mattukat 2013, Mattukat 2014, Fongen 2015, Niedermann 2014	++	++

Table continues

Table 2 (Continued). Underlying factors, supporting studies, relevance and changeability for overarching exercise determinants found in the literature search (IM step 2)

Determinant	Factors	Number of supporting studies	Relevance	Changeability
Knowledge	Knowledge +, information and education about disease, exercise (incl. frequency and benefits) and coping +, coherent education +	6: Zangi 2015, Curbelo Rodríguez 2017, Rodríguez-Lozano 2013, Dubinina 2013, Mattukat 2013, Hammond 2008	+	++
Skills	Coping +, Self-management +, intensive training and (home) exercising +, goal setting +	6: Hammond 2008, Sweeney 2002, Mattukat 2014, Rodríguez-Lozano 2013, Dagfinrud 2008, O'Dwyer 2016	++	+
Planning	Timing in daily routine +, Time +, Regularity +	5: Niedermann 2014, Mattukat 2013, Fongen 2015, Passalent 2010, Curbelo Rodríguez 2017	++	++
Environment	Individual counselling +, tailoring exercise +, presence of exercise groups and well-educated exercise guidance +, monitoring of patients' coping and exercise behavior +, rheumatologist follow-up +, membership self-help group +	8: Zangi 2015, Fongen 2015, Mattukat 2013, Dagfinrud 2008, Curbelo Rodríguez 2017, O'Dwyer 2016, Santos 1998, Barlow 1992	++	++
Disease related variables	Symptoms -, pain -, stiffness -, fatigue -, fear -, disability -, quality of life +, disease activity -, disease stability +, perceived stress -	6: Niedermann 2014, Curbelo Rodríguez 2017, Fongen 2015, O'Dwyer 2016, Haglund 2012, Da Costa 2010	-	+
Personal factors	Sex +/-, Age +/-, education level +, being married -, employment -, past exercise behavior +, smoking -	4: Haglund 2012, Santos 1998, Stenström 1997, Fabre 2016	+	-
Fear avoidance	Fear -, Kinesiophobia -	2: Er 2017, Curbelo Rodríguez 2017	-	+

Relevance: - = no mentioning in the Reasoned Action Approach (RAA) model; + = indirectly related to exercise behavior in RAA model; ++ = directly related exercise behavior in RAA model. Changeability: - = no expected changeability; + = possible changeability on longer term; ++ = (fairly) changeable on relatively short term.

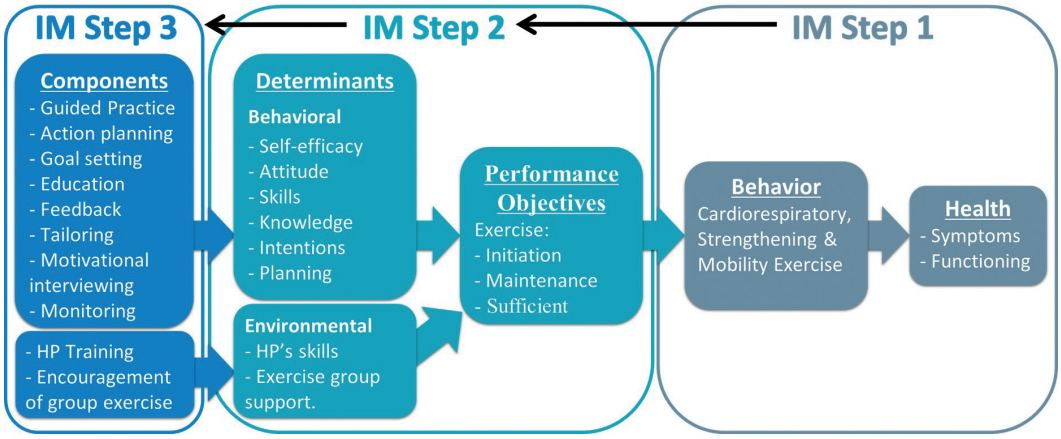

Figure 2. A model with the results of this study, demonstrating how the intervention components from IM Step 3 eventually improve health, by influencing behavioral and environmental determinants identified in IM Step 2 in order to change the desired behavior determined in IM Step 1.

The desired behavioral outcome of the intervention (optimized exercise behavior) was split into three performance objectives: (1) initiating exercise, (2) exercising sufficiently and adequately and (3) maintaining exercise activities. These three performance objectives were linked to the eight selected determinants in a matrix of change objectives, as shown in Table B.3 (Appendix B). The resulting 40 formulated change objectives specify what should change in which of the two ecological levels (individual patients and therapists) for an intervention to be successful.

During the semi-structured interviews, change objectives were clustered and eventually 23 were scored by the patients and therapists for their relevance: Table B.4 (Appendix B) shows the relevance grades. Four change objectives were rated lower than a 7 on average and were rejected after re-evaluating the supporting literature and the reasoning of the interviewees, namely: experiencing support from family and friends, experiencing social responsibility, planning coping with barriers and participating in a support group.

IM step 3: intervention components selection

The scoping review of IM Step 3 included 15 studies (16-21, 52, 53, 65-71). As shown in Table B.5 (Appendix B), 32 intervention components can be effective in improving exercise behavior in people with axSpA. Only intervention components

reported in at least two different studies were selected: therefore, 11 intervention components were excluded. The 21 remaining intervention components were graded for their expected relevance by the patients and therapists (see Table B.6 in Appendix B). Three intervention components were scored lower than a 7 on average: coping planning, mobilizing social support and providing social comparison. These three were all excluded after re-evaluating evidence and interviewee rational. When linking the 18 remaining intervention components to the selected determinants and change objectives, 11 of them were combined into three components. This finally resulted in 10 intervention components relevant for optimizing exercise behavior in axSpA by targeting identified behavioral and environmental determinants, which are shown in Figure 2.

The selected intervention components were translated into practical applications, as shown in Table 3, by accounting for the two ecological levels, the intervention's context and the components' parameters for effectiveness (28) and by sorting them to the different factors and behavior change stages of the I-Change Model (30). Consequently, the intervention should consist of (1) behavior change guidance (through counseling or an instruction manual), including individualized education, motivational interviewing, goal setting, action planning, monitoring and feedback, (2) a training for therapists on how to tailor, practice and guide exercise and (3) encouragement to exercise in a group.

Table 3. Change objectives with corresponding determinants, intervention components and practical applications, sorted by I-Change factors (IM step 3)

Change objectives and determinants (italic) sorted by I-Change factors (bold)	Intervention components	Practical application
Awareness		
Knowledge: Patients describe the consequences of axSpA, the importance of initiation and maintenance of exercise and the optimal frequency, intensity, duration and type of exercise.	Education (incl. Elaboration, Consciousness raising and Persuasive communication)	Education by instruction manual and/or health professional on disease and exercise (importance and guidelines)
Attitude: Patients explain the benefits and their positive outcome expectations of initiation and of sufficient and adequate execution of exercise.	Education (incl. Individualization)	Help patients translate education to personal situation
Motivation		
Intentions: Patients indicate that they want to initiate their exercise program and keep executing it sufficiently and adequately.	Motivational interviewing; Goal setting	Individual counselling with motivational interviewing and goal setting

Table continues

Table 3 (Continued). Change objectives with corresponding determinants, intervention components and practical applications, sorted by I-Change factors (IM step 3)

Change objectives and determinants (italic) sorted by I-Change factors (bold)	Intervention components	Practical application
Self-efficacy: Patients express confidence in ability to initiate and maintain execution of their personal exercise program, the right way and often, intense and long enough.	Guided practice; Tailoring	Tailor exercise program to patients' level and needs and practice with guidance
Attitude: Patients acknowledge that they enjoy (certain) exercise.	Tailoring	Tailor exercise to patients' preferences
Attitude: After 3 months, patients describe their perceived benefits of exercise and the realization of their positive outcome expectations.	Goal setting; Feedback (during follow-up)	Help patients set goals and provide feedback over time on goal attainment
Social norm: Patients indicate that they experience support from exercise group members and health care providers to keep executing their exercise program.	Group setting; Monitoring	Monitor and encourage patients over time to continue their exercise program
Ability		
Skills: Patients demonstrate that they are able to execute their exercise program and they demonstrate self-management and self-regulation skills to fully adhere to their exercise program (despite barriers or relapses).	Guided practice; Education (on pain- and stress-management, joint protection and self-regulation)	Practice exercise program with specialized therapist and education on self-management and self-regulation
Planning: Patients make specific plans for when, where and how to carry out their exercise program, with the right frequency and duration and linked to routine daily activities and they adjust their plans as soon as they are unable to comply with them.	Action planning	Help patients make weekly, specific, personal action plans, prompt them to create routine and re-plan when needed
Environment		
Environment: Specialized therapists tailor personal exercise programs, provide individual counselling and provide (follow-up) monitoring of exercise, outcomes and coping responses.	Educate environmental agents; Monitoring; Feedback.	Train therapists on how to tailor and practice exercise and how to provide counselling, monitoring and feedback
Environment: Patients are able to partake in exercise groups.	Education on available resources	Encourage and inform patients on (axSpA-specific) exercise groups

Discussion and conclusion

Discussion

This study combined literature reviews with theories on exercise behavior and the perspective of important stakeholders of two ecological levels (individual patients and therapists) to identify the effective intervention components required to optimize (determinants of) exercise behavior of people with axSpA. Incorporating these components in an intervention should increase the likelihood and magnitude of sustainable change in exercise behavior of people with axSpA. It was found that in order to optimize exercise behavior in people with axSpA, an intervention should include (1) behavior change guidance, including individualized education, motivational interviewing, goal setting, action planning, monitoring and feedback, (2) a training for therapists on how to tailor and practice an exercise program and provide behavior change guidance and (3) encouragement to exercise in a group.

As far as we know, this is the first study on the development of an exercise intervention for people with axSpA in which prior to selecting effective intervention components, relevant determinants were identified using both literature and stakeholders´ perspective. The use of the Intervention Mapping protocol ensured that the steps preceding behavior change were examined using theories, literature and interviews with important stakeholders from two ecological levels. Two prior studies on the effects of an intervention on axSpA patients' exercise behavior, that did not first examine which determinants to target, only found small effects (17, 18). The contents of these existing interventions deviate from the current intervention proposal; one of these interventions (17) only used one (extensive) education-session, which might be insufficient for a sustainable behavior change (72), whereas the other intervention (18) put quite some emphasis on anticipating barriers (coping planning). Coping planning was excluded in the present study as it might decrease self-efficacy when applied during exercise initiation by focusing too much on barriers instead of opportunities (73, 74). The intervention contents of the current intervention are fairly similar to the other existing interventions aimed at exercise behavior of people with axSpA (16, 19, 20). They appear most similar to the intervention studied by O'Dwyer et al. (16), which consists of various counseling sessions with a physiotherapist and also puts a large emphasis on tailoring, goal setting, feedback, monitoring and motivational interviewing principles. Their study showed promising intervention effects, but the intervention group only consisted of 20 participants. Therefore, in a future study examining the effectiveness of the current intervention (after further development), a larger population should be used.

In order to further develop, implement and evaluate the proposed intervention, IM Steps 4, 5 and 6 should be executed in a future study. The comparable intervention

by O´Dwyer et al. (16) then might serve as a suitable example, together with the different stages from the I-Change Model (29). The intervention might exist of a training for health professionals to provide behavior change guidance, which consists of the following phases: an awareness phase with education and tailoring, a motivational phase with mainly motivational interviewing, an action phase with goal setting, action planning and practice and a maintenance phase with monitoring, feedback and potentially group exercise. The behavior change guidance could also be provided or supported by an instruction manual with various assignments.

Study limitations

This study was limited by including only two patients and two therapists to provide the perspective of important stakeholders. Their representativeness was limited as they were all selected from one rehabilitation center and both patients had a relatively long disease duration (20 and 30 years). However, eight studies on the patients' perspective were included in the search of Step 1 (question c) and in all three literature searches, multiple qualitative studies among stakeholders were included. The interviewees' responses were consistent with each other and with the findings from the included studies. Hence, no additional interviewees were included. Another limitation is that the stakeholders' interviews were mostly used for confirmatory analysis instead of exploratory analysis throughout the project, deviating slightly from the IM protocol. A final limitation is that the scoping reviews and data extraction were done by only one author and not by multiple reviewers.

Future research

It is recommended to include IM steps 4, 5 and 6 in a follow-up study. When testing the intervention's effects, preferably a large sample should be used. Furthermore, IM Step 1 showed that little research is done in exercise type engagement among people with axSpA, with no studies reporting on current participation rates regarding supervised group exercise: this should be further examined. Also, many studies argued that there is insufficient evidence to describe the most optimal exercise parameters (type, frequency, duration and intensity) for people with axSpA (3, 8, 9, 19, 47): future studies should compare exercise types and dosages regarding their (long-term) health benefits and (cost-)effectiveness to determine the best exercise regimen.

Conclusion

This study showed that in order to optimize exercise behavior of people with axSpA, patients should be offered behavior change guidance including education, motivational interviewing, goal setting, action planning, monitoring and feedback and they should be encouraged to exercise in a group. In addition, therapists should

be trained in how to tailor and practice an exercise program and how to provide behavior change guidance. This intervention proposal should be further developed using IM Steps 4, 5 and 6.

Practice implications

This study provides a foundation for an axSpA-specific exercise intervention. It demonstrates that such an intervention should consist of various intervention components aimed at behavior change guidance as well as a training for health professionals.

Appendices A and B. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi: https://doi.org/10.1016/j.pec.2019.12.017.

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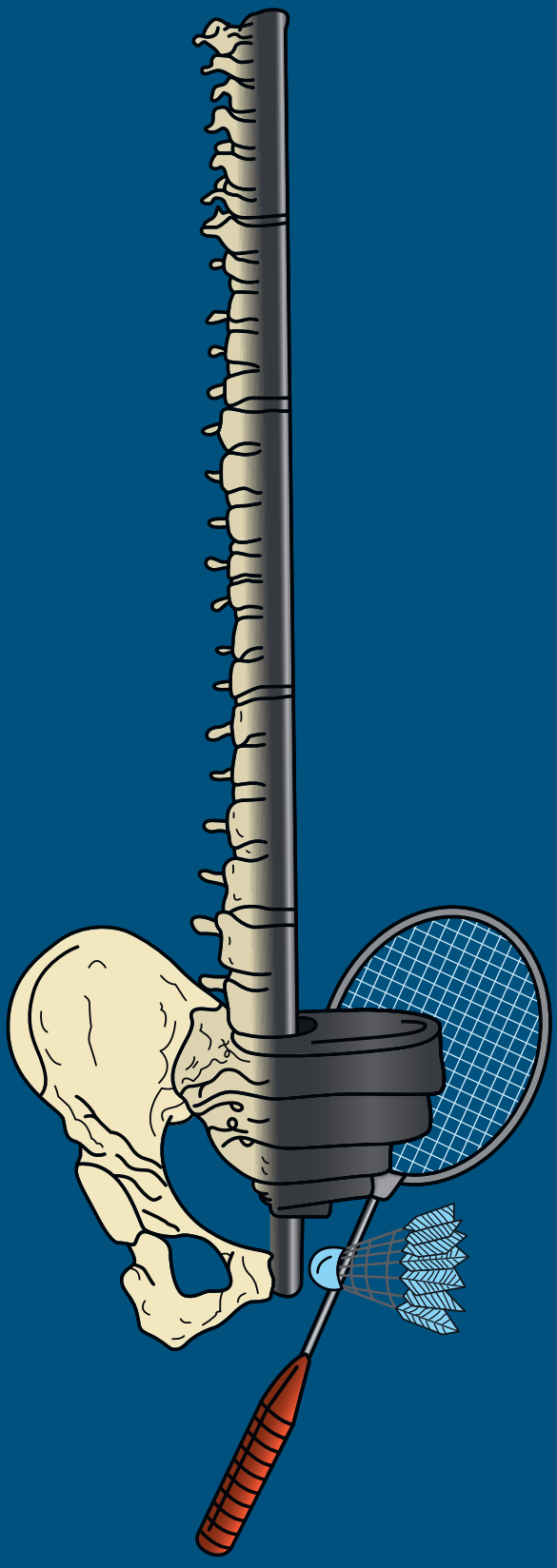

Chapter 8

Summary and general discussion

Summary

Engagement in physical activity (PA) and regular exercise is one of the cornerstones of the optimal management of axial spondyloarthritis (axSpA) and has been recommended since many years, based on solid research findings. However, there have been new scientific insights in recent years, especially on axSpA patients' engagement in PA according to public health recommendations and on the effectiveness and safety of (high-intensity) aerobic exercise. These developments are particularly relevant for people with axSpA, as a growing amount of evidence demonstrates that axSpA patients have an increased cardiovascular risk and that such PA and exercise may positively modify the consequences of axSpA.

Given these developments, a change in current practice may be warranted to optimize PA and exercise behavior of patients with axSpA. However, before any enhancements can be implemented on a large scale, more knowledge is needed. Current gaps in the evidence include the current engagement of axSpA patients in specific types and dosages of exercise and PA, the association with use of physical therapy and supervised group exercise and strategies to optimize PA and exercise. Therefore, this thesis aims to:

1. Describe the current PA and exercise engagement of patients with axSpA in the Netherlands and their relationship with physical therapy use (Chapters 2 and 3).
2. Identify the need for evidence-based enhancements in axSpA-specific group-exercise in the Netherlands and evaluate the effectiveness and feasibility of the implementation of these enhancements (Chapters 3 to 6).
3. Determine the components needed for an intervention to optimize PA and exercise of axSpA patients in general (Chapter 7).

In **Chapter 2,** axSpA patients using and not using physical therapy were compared regarding their engagement in both moderate- and vigorous-intensity aerobic PA, during work and during leisure time, of which the latter appears to have greater health benefits. In this cross-sectional study, a survey including questions on physical therapy use and aerobic PA (using the 'Short questionnaire to assess health-enhancing physical activity' (SQUASH)) was completed by 200 patients with axSpA from three outpatient rheumatology clinics. At the time of the study, 99 of these patients did and 101 did not use physical therapy. Among patients using and not using physical therapy, the aerobic PA recommendation was met by 75% and 61% of the participants with moderate-intensity PA (≥ 150 minutes/week), by 55% and 46% with vigorous-intensity PA (≥ 75 minutes/week) and by 89% and 75% with a combination of these intensities, respectively. The differences in proportions between these groups reached statistical significance for both moderate-intensity aerobic PA and the combination, but the difference with respect to vigorous-

intensity aerobic PA did not. When including only leisure time aerobic PA, the proportions of all participants together meeting the aerobic PA recommendation with moderate-intensity PA, vigorous-intensity PA or the combination dropped from 68%, 50% and 82% to 48%, 42% and 67%, respectively. In both groups, recreational walking and cycling were the most popular forms of aerobic PA. These results suggest that future implementation should focus on the general promotion of leisure time aerobic PA among axSpA patients not using physical therapy and on vigorous-intensity aerobic PA in physical therapy programs.

In **Chapter 3**, difference between axSpA patients with and without supervised group exercise were examined. Comparisons included general characteristics, health status and fulfilment of the recommendations for aerobic exercise (≥150 min/week moderate-intensity or ≥75 min/week vigorous-intensity) and strength and mobility exercise (≥2 sessions/week). Cross-sectional data on patient characteristics, health status and type, frequency and duration of exercise (derived from the SQUASH) were combined from three cohorts with axSpA patients in the Netherlands (two outpatient cohorts, 349 patients in total, and one supervised group exercise cohort, 128 patients). It was found that in the two outpatient cohorts 17 out of 349 patients (5%) engaged in supervised group exercise. Overall, the mean age of the supervised group exercise participants (n=145) was higher and they had a longer disease duration, were less frequently employed, used medication less frequently and had worse spinal mobility on average, compared to patients without supervised group exercise (n=332). There were no significant differences in health status. Patients participating in group exercise fulfilled the moderate-intensity aerobic (89% vs. 69%) and strength and mobility (44% vs. 29%) exercise recommendations more often than patients who did not, but they fulfilled the aerobic exercise recommendation less often with vigorous-intensity exercise (5% vs. 12%). It was concluded that few, especially older, patients with axSpA engage in supervised group exercise and that participation is related to meeting moderate-intensity aerobic and mobility and strength exercise recommendations. However, both among patients with and without group exercise, a minority engaged in vigorous-intensity exercises and/or in adequately dosed mobility and strength exercises.

The study in **Chapter 4** focused on the current organization and content of supervised group exercise for people with axSpA in the Netherlands. A survey among the 82 local patient associations affiliated with the Dutch Arthritis Society (ReumaNederland) was performed in 2016. Of every local association, a board member was asked to complete questions on the organization of group exercise and a supervisor was asked about the contents and supervision of the exercise program. It was found that axSpA-specific group exercise was provided in 17 regions. The majority consisted of a combination of land-based and aquatic exercise (16/17), once weekly with a median total duration of 100 minutes. All 17 regions

provided programs with mobility and strength exercises as well as sports activities (e.g. badminton and volleyball) and 10 of 17 included aerobic exercise. A minority of regions included monitoring of exercise intensity (e.g. by heart rate) (1/17), personalization (1/17), periodic assessments (2/17) and (structured) patient education (8/17) in their programs. Such elements are needed to optimize exercise behavior according to current scientific insights. The majority of the supervisors (38/59) lacked postgraduate education on axSpA. These findings are indicative of a need for an update of the contents of axSpA-specific group exercise and for the training of supervisors to implement this update.

In **Chapter 5**, the satisfaction with axSpA-specific group exercise programs was assessed among its participants, as well as their perspective on potential evidence-based enhancements. For that purpose, a survey was administered to 118 axSpA patients participating in supervised group exercise in four regions in the Netherlands. The results showed that a clear majority of participants was satisfied with the current contents of the group exercise, but the majority also agreed with a number of listed possible enhancements: 1) more high-intensity aerobic exercises including intensity monitoring (83%); 2) personalization of exercises based on periodic assessments (82%); and 3) patient education in particular on more frequent (home) exercise to meet the exercise recommendations (50%). These findings indicate that participants in SGE are supportive of potential adjustments to their current routine.

In **Chapter 6**, the effects and feasibility of a pilot implementation of the three aforementioned proposed enhancements for supervised group exercise were evaluated. The implementation strategy included a one-day supervisors' training (with both theory and practice) and bimonthly telephone support. A hybrid study design was used to evaluate effects and feasibility simultaneously. To evaluate effects, aerobic capacity and physical functioning were measured with performance tests (Six-Minute Walk Test (6MWT) and Ankylosing Spondylitis Performance-based Improvement (ASPI), respectively) and health status and home exercise engagement with questionnaires (ASAS Health Index and SQUASH, respectively). For this, both baseline and one year follow-up data of 60 participants were available. In addition, an evaluation survey among patients (n=60) and semi-structured interviews among group exercise supervisors (n=4) were used to assess feasibility. Regarding effectiveness, the mean aerobic capacity improved statistically significantly and a third of participants improved their physical functioning. With respect to feasibility, it was found that high-intensity aerobic exercise was implemented successfully, personalization with periodic assessments only partly and patient education not at all. Adaptations are required to improve effects and feasibility during a future nationwide implementation.

Physical therapists can play an important role in the promotion of PA and exercise in people with axSpA, but a significant proportion of axSpA patients does not use physical therapy at all or not on a regular basis. Therefore, in **Chapter 7**, the components of future interventions to optimize exercise behavior of axSpA patients either with or without support from a health professional (such as a physical therapist) were identified. For that purpose, the first three steps of the Intervention Mapping protocol were used: 1) assessment of the need to optimize exercise behavior of axSpA patients; 2) identification of axSpA-specific exercise determinants; and 3) selection of effective intervention components targeting these determinants. Each step included a scoping review and semi-structured interviews with axSpA patients (n=2) and physical therapists with expertise in axSpA (n=2). It was found that, based on the eight most relevant determinants identified, an axSpA-specific exercise intervention would ideally include patient education, motivational interviewing, goal setting, action planning, monitoring, feedback, tailoring, guided practice, therapists' training and encouragement for group exercise. These results were used for the proposition of an axSpA-specific exercise intervention with behavior change guidance and a training for health professionals. The behavior change guidance can be implemented either by a trained health professional or through an instruction manual without the interference of a therapist. Patients with more need for specialized supervision are advised to consult a physical therapist specifically trained in providing exercise therapy to axSpA patients.

General discussion

Aim 1: Describe the current PA and exercise engagement of axSpA patients in the Netherlands and the relationship with physical therapy use

Meeting PA recommendations

AxSpA patients are recommended to engage in aerobic, mobility, strength and neuromotor exercises according to public health PA recommendations (1-4).

Regarding aerobic exercise, research in this thesis found that the recommendation on aerobic PA by the World Health Organization (5) is met by a relatively high proportion of Dutch axSpA patients with moderate-intensity PA and by a relatively small proportion with vigorous-intensity PA (Chapters 2 and 3). These findings are in line with previous literature (6-9), although earlier studies did not distinguish between meeting the aerobic PA recommendation with either moderate- or vigorous-intensity PA. Evidence has shown that both moderate- and vigorous-intensity PA are beneficial for people with axSpA (10, 11), but it appears that vigorous-intensity PA is more effective in improving cardiorespiratory fitness and

reducing the cardiovascular risk (12-15). It should be noted that, irrespective of the presence of a chronic condition such as axSpA, caution with vigorous-intensity PA is required with sedentary individuals (who can experience lighter activities as more intense, because their threshold for exercises to be of vigorous intensity may be substantially lower than in active people) or individuals that have an increased risk of cardiovascular complications during exercise due to underlying conditions (15-17). Recently, a study addressed the effectiveness and feasibility of high-intensity aerobic PA specifically in inactive axSpA patients with moderate to high disease activity and showed that vigorous-intensity exercise has very promising health benefits among these patients (18). However, that study excluded patients with established cardiovascular disease, which is present in about 12% of patients with axSpA (19).

Regarding recommended exercise types other than aerobic exercise, it was found that only a minority of axSpA patients engages in activities with mobility or strength components and less than one-third with the recommended frequency of twice per week (Chapters 3 and 7). Moreover, engagement in neuromotor exercise remains to be established.

Specific exercise activities

People with axSpA are recommended to combine aerobic, mobility, strength and neuromotor exercise activities (1-4, 20), so it can be efficient to engage in activities in which all these exercise types can be performed, e.g. gym, home and aquatic exercise. However, Chapters 2 and 3 showed that only a minority engages in such activities, whereas walking and cycling, which are not suitable to improve axial mobility and muscle strength, are by far the most popular exercise activities in patients with axSpA.

Regarding engagement in therapeutic exercise, axSpA-specific group exercise was found to be performed by a relatively low proportion, i.e. 5% in the outpatient populations in Chapter 3. This is striking, as supervised group exercise was found to be particularly effective for axSpA patients (3, 4, 21-24). As opposed to participation in group exercise, the use of individual physical therapy was much higher. In the study described in Chapter 2, individual physical therapy was used by 44% of participants at the time of the study. However, according to these patients, only 53% of these therapeutic programs included any form of exercise during treatment and 61% included counseling on home exercise (Chapter 2).

These findings are relevant, as few studies so far examined which exercise types patients with axSpA engage in and no previous study reported on engagement in supervised group exercise (Chapter 7). Furthermore, most previous studies did not differentiate between leisure time and work-related (aerobic) PA, although leisure

time PA is often more easily modifiable and appears to have greater health benefits (25-29).

Associations between PA and physical therapy use

AxSpA patients using physical therapy, either individual therapy or supervised group exercise, appeared to meet public health PA and exercise recommendations more often than those not using physical therapy (Chapters 2 and 3). However, even among those patients, the majority still does not engage in vigorous-intensity aerobic exercise or in sufficiently frequent mobility or strength exercise. Although one might argue that it is obvious that patients with individual physical therapy or supervised group exercise meet exercise recommendations more often because they execute exercise as part of their therapy or group exercise, this is not necessarily the case for several reasons:

- AxSpA-specific group exercise and most individual physical therapy programs are only performed once weekly (Chapters 2 and 4), whereas the exercise recommendations for mobility and strengthening require a minimum frequency of twice weekly;
- Patients use physical therapy because they experience limitations in their physical functioning, thus they are a selected group in which limited exercise engagement and more barriers could be expected;
- The findings in Chapter 2 suggest that exercise therapy is performed during individual therapy in about half of the patients with axSpA (although 61% did receive counseling on home exercise);
- AxSpA patients without individual physical therapy or group exercise may have more time to engage in exercise activities.

To our knowledge, there are no previous studies examining the differences in PA between patients with and without individual physical therapy or supervised group exercise. More insight is relevant for future PA and exercise promotion, as physical therapists are in a very suitable position to provide this through patient education and guidance (2). This is especially the case for individual physical therapy, as almost all axSpA patients were found to ever use physical therapy during the course of their disease (30) and 44% of the patients used individual physical therapy during the study in Chapter 2. Moreover, behavioral interventions provided by physical therapists have shown to have a major effect on PA level in a variety of patient populations (10, 31-33). However, it appeared that both within the individual physical therapy (Chapter 2) and the group exercise setting (Chapter 4), patient education on PA is provided in less than half of the cases.

Methodological considerations

A strength of the studies described in Chapters 2 and 3, which are related to the first aim of this thesis (about current PA and exercise engagement and the relationship with physical therapy), is that they include relatively large populations from multiple sources, which improves the generalizability of their results. Moreover, the weekly duration and frequency of each PA intensity and type could be calculated by using the SQUASH and the modified SQUASH, both validated PA questionnaires (34-37). Previous studies on PA of axSpA patients used a self-made, non-validated questionnaire to measure PA (9, 38-41) or did not distinguish between leisure time and work-related PA or between meeting the aerobic PA recommendation with either moderate- or vigorous-intensity PA (6-9, 34, 38, 39, 41-49). Furthermore, no earlier study assessed fulfillment of the recommended frequency of mobility or strength exercise in axSpA patients.

Using the SQUASH and the modified SQUASH also caused some study limitations. Firstly, the SQUASH is known to overestimate the amount of PA (34, 50). Indeed, the reported total aerobic PA levels in Chapters 2 and 3 were relatively high compared to previous studies in axSpA patients that used other PA measurements (6, 8, 43). The SQUASH has shown to be particularly valid for within group comparisons (34, 36, 37), which was also the objective in both Chapters 2 and 3.

Although the proportions meeting the aerobic PA recommendation with either moderate- or vigorous-intensity PA were relatively high, there was also an important discrepancy between the studies in Chapters 2 and 3, with 42% and 12% of the patients meeting the aerobic PA recommendation with leisure time vigorous-intensity PA, respectively. This difference can probably be attributed to the fact that the official SQUASH calculation method (36, 37) was used in the study in Chapter 2, which is based on the old (expired) Dutch PA recommendation (51) and uses different intensity-cutoffs for patients under and over 55 years. On the other hand, in the study in Chapter 3, exercise intensity was only determined by the metabolic equivalent of task (MET-value), in line with the new WHO and Dutch PA recommendations (5, 52).

Another limitation with the use of the SQUASH was that it was not always fully clear from the patients´ responses what type of activities a patient actually did: e.g. if a patient reported to go to the gym, it was not always known if aerobic, strengthening or other exercises were performed. In particular the performance of neuromotor (2-4) or breathing exercises (4, 24) was difficult to identify. These types of exercise can be complicated to perform and often require specific equipment (4), so are most likely done in a therapeutic setting. In addition, the available evidence on these exercise types is limited (4, 10, 22) and most literature on axSpA-specific exercise only takes aerobic, mobility and strength exercise into account.

Aim 2: Evaluate the effects and feasibility of evidence-based enhancements of supervised group exercise for axSpA patients

Although supervised group exercise is recommended in axSpA, its current use by axSpA patients in the Netherlands appears to be low. In Chapter 3, it was found that 5% of the participants from the two outpatient population cohorts reported to engage in supervised group exercise. This corresponds well with the 2624 total group exercise participants in the Netherlands identified in Chapter 4. That number would imply a proportion between 1% and 8% of the estimated number of axSpA patients in the Netherlands, assuming an axSpA prevalence between 0.2% and 1.4% (53-55) and 17 million inhabitants.

By the 2020s, little seems to have changed regarding the content of axSpA-specific group exercise since its implementation in the Netherlands in the early nineties of the previous century (56, 57): it still comprises relatively long, once weekly sessions with the main focus on mobility and strength exercise, combined with hydrotherapy and sports (mostly badminton and volleyball) as aerobic activities, yet without monitoring of the intensity (Chapters 4 and 5). This appears to be in line with axSpA-specific group exercise provided in Switzerland and the United Kingdom (58-60). However, recent literature suggested that, based on new scientific insights, there should be more high-intensity aerobic exercise (1, 2, 4, 11, 18, 22, 60-64), better exercise personalization based on periodic assessments (3, 4, 65-68) and patient education on more frequent (home) exercise (2-4, 20, 61, 69, 70). The need for these proposed enhancements was confirmed in Chapters 3, 4 and 5.

This need was converted into a pilot implementation. Based on implementation theories (71), the studies in this thesis preparatory to the implementation analyzed barriers and facilitators of multiple stakeholders, i.e. axSpA patients participating in group exercise (Chapters 3 and 5), group exercise supervisors (Chapter 4) and board members of the local patient associations organizing the group exercise (Chapter 4). This resulted in a planned and tailored implementation strategy, which focused mainly on the group exercise supervisors. Targeting the supervisors through a training was thought to be the most important strategy, because of various reasons:

- Implementing the enhancements particularly demands a change in the practice of the supervisors;
- The supervisors' skills appear to be very important in optimizing exercise (Chapters 5 and 7);
- Only 21 of 59 supervisors (36%) had postgraduate education on rheumatology (Chapter 4), so additional training seemed warranted;
- Successful implementation studies in other rheumatic populations also mainly focused on the exercise supervisors through training (72, 73).

In hindsight, other studies with successful implementation strategies targeted other stakeholders during the implementation as well, e.g. patients, rheumatologists, local patient associations and health insurance companies (58, 72, 73).

In order to improve implementation success in the future, it is likely that strategies would require additional resources (e.g. funding or personnel). These strategies could for example include a more extensive training, compensation of the time spent on the training for the supervisors, having more supervisors available for the assessments, being able to organize patient education separately from the exercise sessions and being able to provide better education material on home exercise for patients (Chapter 6).

Methodological considerations

A strength of the studies related to the second aim, on supervised group exercise for patients with axSpA, is that the pilot implementation included four of the 17 regions for axSpA-specific group exercise in the Netherlands, with nine exercise groups, enhancing the generalizability of the findings. Another strength is that both effectiveness and feasibility of the implementation were tested by using a hybrid study design.

A limitation of the study in Chapter 6 is that there was much variety between the four regions in data availability and in time intervals between the assessments. Another limitation to be mentioned is that no control group was used, which limited the evaluation of implementation effects.

Aim 3: Determine the intervention components needed to optimize PA and exercise of axSpA patients

As a basis for the development of an intervention to optimize PA and exercise among axSpA patients, to be executed either unsupervised with an instruction manual or with support of a health professional, the study in Chapter 7 used the first three steps of the Intervention Mapping protocol: a needs assessment, an identification of determinants and a selection of intervention components. The findings showed that such an intervention should include:

1. Behavior change guidance, either provided by a health professional or through an instruction manual (with assignments), including individualized education, motivational interviewing, goal setting, action planning, monitoring and feedback;
2. A training for therapists in order to be able to tailor and practice exercise programs and to provide behavior change guidance to patients with more need for specialized counseling;
3. Encouragement to exercise in a group.

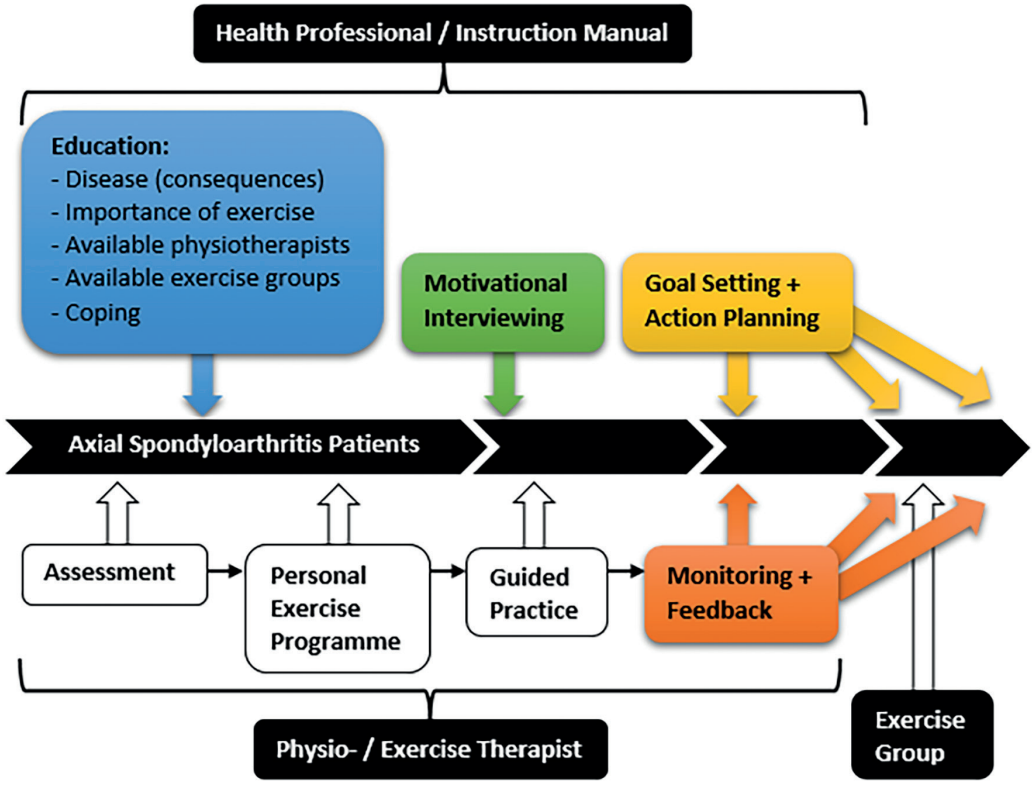

Figure 1. Conceptual model on how to optimize exercise of axSpA patients

Figure 1 visualizes how these components can influence exercise behavior of axSpA patients. This figure also shows the prominent role physical therapists and group exercise can play in this intervention.

Intervention Mapping steps 4 (intervention development), 5 (implementation) and 6 (evaluation) were not yet performed. The intervention components were most similar to an intervention studied by O'Dwyer et al. (67), in which physical therapists provided counseling including tailoring, goal setting, feedback, monitoring and motivational interviewing aspects. This intervention showed promising effects in their study and might serve as an appropriate example. It was therefore proposed in Chapter 7 that the intervention could also include a training for health professionals on how to provide such 'exercise coaching'. The process of this exercise coaching is described in more detail in Figure 2. Besides physical therapists, the exercise coaching could also be guided by other health professionals, e.g. rheumatology nurses (32), as PA promotion should be a shared responsibility among all involved health professionals (2). However, physical therapists (or certified exercise therapists) might be most suitable, especially when tailoring and supervising an exercise program is also needed (4, 74-76).

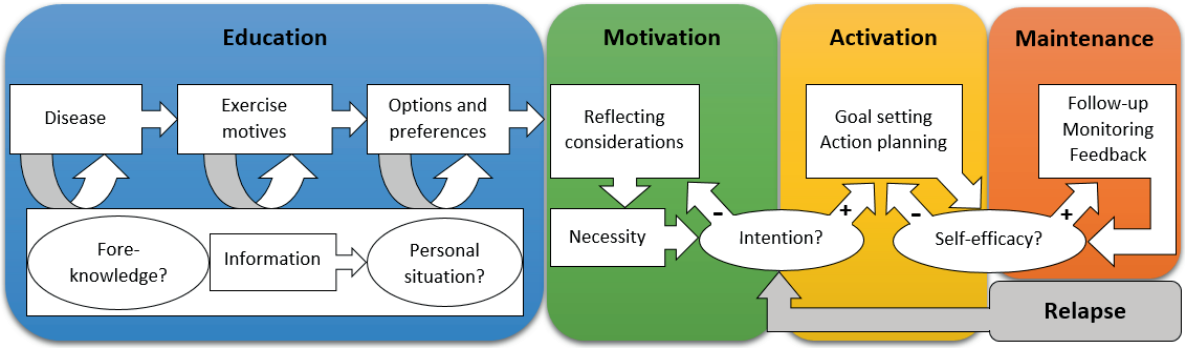

Figure 2. Detailed model of exercise coaching for axSpA by a health professional

In order to optimize exercise among axSpA patients who do not regularly consult a physical therapist, the intervention can also be provided through an instruction manual, that patients can use independent of a health professional. This manual could include patient education on different exercise types and activities and guide the process of behavior change shown in Figure 2 through various written assignments.

Methodological considerations

The study in Chapter 7 appears to be unique in the sense that it first identified relevant determinants prior to selecting effective intervention components, using both literature and the perspective of stakeholders. The use of the Intervention Mapping protocol ensured that all steps needed for behavior change were examined using theories, scoping reviews and interviews with axSpA patients (n=2) and experts (n=2).

A limitation was that there was a slight deviation from the protocol by using the interviews for confirmatory analysis of the review findings but not for exploratory analysis. Another limitation is that only four interviewees were included to analyze the stakeholders' perspectives. However, in all three steps, the literature searches included multiple qualitative studies among stakeholders, including eight studies on the patients´ perspective in the needs assessment.

Suggestions for future research

As already mentioned in Chapter 7, in which the intervention components needed to optimize exercise behavior were studied, there is a need for future research on the optimal exercise parameters for people with axSpA, by comparing the effects of different types, intensities, frequencies and durations of PA and exercise programs, as well as the influence of supervision and mode of delivery (face to face or online). This need is supported by the findings of many other studies as well (2, 3, 21, 22, 62). Future studies could for example examine if vigorous-intensity PA is indeed more beneficial than moderate-intensity PA for people with axSpA: this is expected based on studies in other populations (12-15, 77-79) and on promising results of a recent study in an axSpA population (18), but this should still be confirmed in a study comparing these intensities in patients with axSpA. It could then also be tested if it is more desirable to either encourage engagement in currently less popular vigorous-intensity exercise activities or to educate patients on how to increase intensity of already popular exercise activities, e.g. by implementing 'high-intensity interval training' during cycling (13-15). Additionally, future research may explore which specific exercises axSpA patients perform when they report to engage in home, gym or aquatic exercise. Finally, the effects and feasibility of neuromotor and breathing exercises could be studied, as the available evidence on this is limited.

Furthermore, it could also be explored which exercise activities are similarly effective as supervised group exercise. This is relevant as, although supervised group exercise was found to be more effective than home exercise, its use is very low among axSpA patients. The exercise activities found most popular in Chapters 2 and 3, recreational walking and cycling, could be suitable as a basis for aerobic exercise. However, these activities do not meet the requirements to be classified as (axial) mobility or strength exercise. Future studies could explore how to increase engagement in other exercise activities that (also) include mobility and strength components, e.g. home, gym or aquatic exercise. However, it might be that not only the contents are the reasons why it has been found so effective in the past, but especially the group setting and the presence of a supervisor, which components were found to facilitate exercise in axSpA patients (Chapter 7). These possible parameters for effectiveness should be accounted for in future studies exploring which exercise activities are particularly effective in axSpA.

Another suggestion for future research is to execute the Intervention Mapping steps 4, 5 and 6 to further develop, implement and evaluate the intervention proposed in Chapter 7. For these steps, it would be helpful to use a focus group with various stakeholders, in which an exploratory analysis is performed for each step, as this was viewed as one of the limitations from the study in Chapter 7 and because it is especially important that the intervention and implementation are

well adapted to the current situation. For the implementation and evaluation, it might be efficient to perform a pilot with a hybrid design, similar to the implementation study in Chapter 6, in order to facilitate both the scientific progress and the translation into routine practice (80, 81). The study described in Chapter 6 proved that the hybrid study design has many benefits, but it also showed that it can result in varying data availability and time intervals between baseline and follow-up. This could be prevented in a future study by using more standardization regarding assessments. In such a study, the effectiveness and feasibility of both the therapists' training and the aforementioned instruction manual for patients can be examined.

Finally, future research could also examine the possibilities to use eHealth for guiding home exercise and patient education, e.g. by digitizing the aforementioned instruction manual. This way, a broader population can be reached, including patients not using physical therapy. The COVID-19 pandemic made it all the more clear how important it is to have remote care alternatives at hand, especially because PA levels of patients with a rheumatic disease appeared to decrease more during the COVID-19 lockdown than that of the general population (82).

Implications for clinical practice

This thesis may have implications for the non-pharmacological management of axSpA and particularly for the optimization of physical activity, exercise and exercise therapy (see Figure 2 in Chapter 1). The studies in this thesis demonstrated that the majority of axSpA patients engages in sufficient moderate-intensity aerobic PA, but there appears to be a clear need for more engagement in vigorous-intensity aerobic, mobility and strength exercise. This is also the case among patients participating in axSpA-specific group exercise, as even among them, the majority does not meet the recommended exercise frequency.

Nevertheless, most room for improvement is probably among axSpA patients who are not currently using individual physical therapy or group exercise. These patients may be more difficult to reach for promotion of PA and exercise. The instruction manual guiding change in exercise behavior, described in Chapter 7, could be suitable for them. It could be disseminated through various channels, e.g. local patient associations and rheumatologists and nurses in outpatient clinics. For some patients, the education and assignments guiding behavior change in the instruction manual would suffice, but patients requiring more tailored guidance should be advised to consult a physical therapist. It should be noted that some patients could face restrictions for such consultations through limited reimbursements.

Physical therapists also play an important role within the proposed intervention, both for tailoring and supervising a personalized exercise program and for guiding change in general PA and exercise behavior. As it appears that the provision of

active treatment modalities in this patient group is suboptimal, additional education for physical therapists seems warranted. In the Netherlands, education could be provided through the professional association for physical therapy (KNGF, the Royal Dutch Society for Physical Therapy) or through 'ReumanetNL' (83), a national network for physical therapists and certified exercise therapists specialized in rheumatology.

Besides the need to promote exercise engagement among axSpA patients in general, the studies presented in Chapters 3, 4 and 5 underpinned the need for evidence-based enhancements within axSpA-specific group exercise. The implementation of these enhancements, as described in Chapter 6, was only partly successful: it appeared feasible and effective to implement high-intensity aerobic exercise, but there should be more resources to improve feasibility of implementing periodic assessments and patient education. One of those resources may be the aforementioned instruction manual (Chapter 7). This can be used to support patient education, as it requires little costs. Furthermore, to increase implementation success during a future nationwide implementation, there should be less permissiveness and more standardization regarding the implementation. Finally, in this time of individualization and the apparent aging of the axSpA-specific group exercise participants, it should be questioned whether there should be much further investments within axSpA-specific group exercise, e.g. with a future nationwide implementation. On the other hand, the social aspects of the group exercise might be particularly important for the relatively older axSpA patients. Therefore, a discussion with patients and patient associations on the future of axSpA-specific group exercise in the Netherlands appears needed.

Concluding remarks

This thesis on optimizing PA and exercise in people with axial spondyloarthritis showed that challenging and exciting times are ahead of us, both from a scientific and a clinical perspective. From a scientific standpoint, various suggestions for future research have been made, e.g. regarding the most optimal exercise regimen for axSpA patients and the further development, implementation and evaluation of the axSpA-specific exercise intervention described in Chapter 7. From a clinical standpoint, the findings have pointed out that there appears much room for improvement in optimizing exercise of axSpA patients, both in patients using and not using individual physical therapy and axSpA-specific group exercise. Hopefully, this thesis facilitates the movement for more and better movement among axSpA patients.

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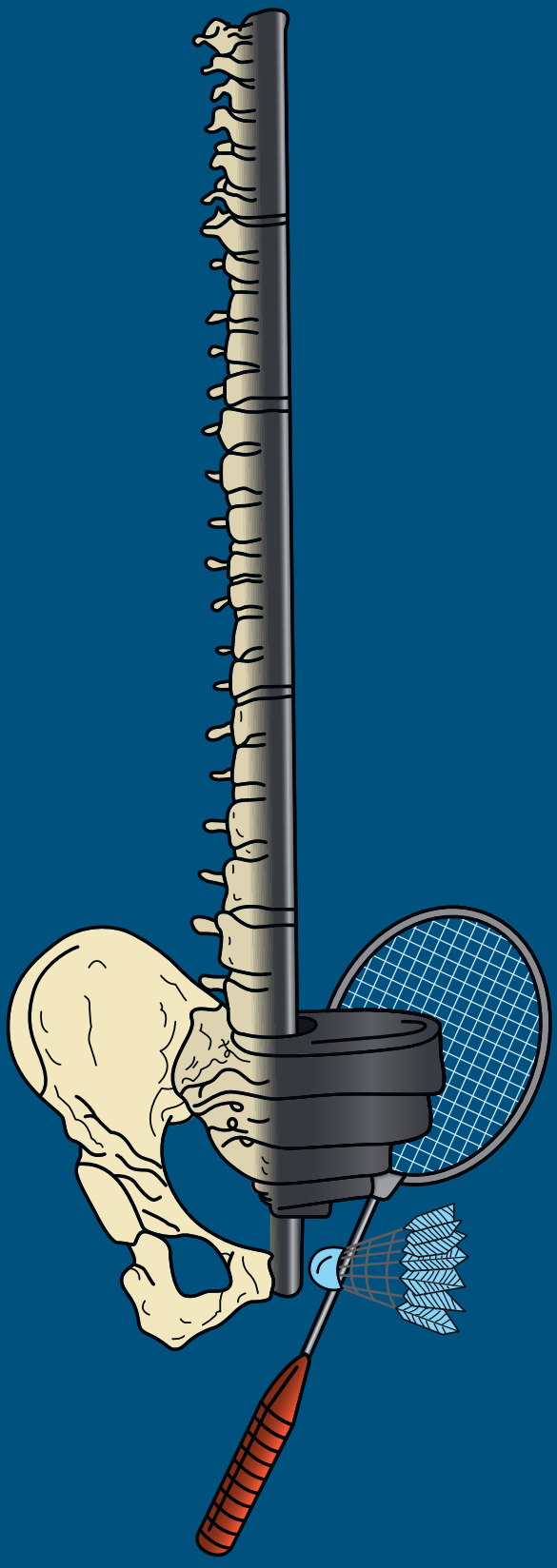


Chapter 9

Nederlandse samenvatting

Samenvatting

Axiale spondyloartritis (axSpA) is een vorm van ontstekingsreuma en treft voornamelijk de wervelkolom en de sacro-iliacale gewrichten. AxSpA wordt gekenmerkt door inflammatoire rugpijn en stijfheid. Regelmatig bewegen en oefenen is al tientallen jaren een belangrijk onderdeel van de behandeling van mensen met axSpA. Uit recent wetenschappelijk onderzoek blijkt dat de beweegrichtlijnen voor de algemene bevolking ook van toepassing zijn voor mensen met axSpA en dat ook hoog-intensieve aerobe oefeningen voor hen effectief en veilig zijn. Deze ontwikkelingen zijn relevant, omdat is gebleken dat mensen met axSpA een verhoogd cardiovasculair risico hebben. Lichamelijke activiteit met de juiste samenstelling en dosering kan deze en andere gevolgen van axSpA positief beïnvloeden.

Voordat de nieuwe inzichten op grotere schaal kunnen worden geïmplementeerd, is er op een aantal gebieden meer kennis nodig. Dit proefschrift richt zich daarom op de onderstaande drie doelen:

1. Beschrijven van de huidige beweeg- en oefenactiviteiten van mensen met axSpA in Nederland en de relatie hiervan met het gebruik van fysiotherapie (Hoofdstukken 2 en 3).

2. Inventariseren van de behoefte aan evidence-based aanpassingen in de gesuperviseerde oefengroepen voor mensen met axSpA in Nederland en evalueren van de effectiviteit en haalbaarheid van de implementatie van deze aanpassingen (Hoofdstukken 3 tot en met 6).

3. Bepalen van de interventie-componenten die nodig zijn om de beweeg- en oefenactiviteiten van mensen met axSpA in het algemeen te optimaliseren (Hoofdstuk 7).

In het onderzoek beschreven in **Hoofdstuk 2** werd de hoeveelheid matig- en hoog-intensieve aerobe lichamelijke activiteit vergeleken tussen mensen met axSpA die al dan niet gebruik maakten van fysiotherapie. In dit dwarsdoorsnede-onderzoek werd een enquête afgenomen met vragen over het gebruik van fysiotherapie en aerobe lichamelijke activiteit (met behulp van de 'Short QUestionnaire to ASsess Health-enhancing physical activity', SQUASH). Hiervoor werden 200 deelnemers met axSpA gerecruteerd in drie reumatologie poliklinieken in Zuid-Holland.

In totaal voldeed 68% aan de matig-intensieve aerobe beweegrichtlijn voor de algemene bevolking (≥ 150 minuten/week), 50% aan de hoog-intensieve aerobe beweegrichtlijn voor de algemene bevolking (≥ 75 minuten/week) en 82% aan een combinatie van beide. Wanneer alleen aerobe beweging in de vrije tijd werd meegerekend, waren deze percentages 48%, 42% en 67%.

De helft van de deelnemers (n=99) gebruikte fysiotherapie (individueel en/of in een groep). Van de deelnemers met en zonder fysiotherapie voldeden respectievelijk 75% en 61% aan de matig-intensieve aerobe beweegrichtlijn voor de algemene bevolking, 55% en 46% aan de hoog-intensieve beweegrichtlijn en 89% en 75% aan een combinatie van beide. In de groep deelnemers die wel fysiotherapie hadden waren er significant meer mensen die voldeden aan de matig-intensieve of gecombineerde aerobe beweegrichtlijn. Er was geen verschil tussen de groepen voor de hoog-intensieve beweegrichtlijn. Recreatief wandelen en fietsen waren in beide groepen de meest populaire vormen van aerobe lichaamsbeweging.

De resultaten van het onderzoek suggereren dat de implementatie van de aerobe beweegrichtlijnen voor de algemene bevolking bij mensen met axSpA die geen gebruik maken van fysiotherapie zich moet richten op het bevorderen van zowel matig- als hoog-intensieve aerobe beweging in de vrije tijd. Binnen de fysiotherapeutische behandeling lijkt vooral implementatie van hoog-intensieve aerobe oefeningen nodig.

In de studie beschreven in **Hoofdstuk 3** werden mensen met axSpA die al dan niet deelnamen aan axSpA-specifieke, gesuperviseerde oefengroepen met elkaar vergeleken. De vergelijking betrof algemene kenmerken, gezondheidstoestand en het voldoen aan de beweegrichtlijnen voor de algemene bevolking (aeroob ≥150 min/week met matige intensiteit of ≥75 min/week met hoge intensiteit en mobiliteit en spierkracht ≥2 sessies/week; gemeten met de SQUASH). In dit dwarsdoorsnede-onderzoek werden data van drie Nederlandse axSpA-cohorten gecombineerd: twee poliklinische cohorten met in totaal 349 deelnemers en één cohort met 128 deelnemers van gesuperviseerde oefengroepen.

In de twee poliklinische cohorten bleken 17 van de 349 patiënten (5%) deel te nemen aan gesuperviseerde oefengroepen. De oefengroep-deelnemers (n=145) waren gemiddeld ouder en hadden een langere ziekteduur, een slechtere mobiliteit van de wervelkolom, minder vaak betaald werk en minder medicatiegebruik dan patiënten die niet deelnamen aan gesuperviseerde oefengroepen (n=332). Er waren geen significante verschillen in gezondheidstoestand. Oefengroep-deelnemers voldeden vaker aan de beweegrichtlijnen voor de algemene bevolking ten aanzien van matig-intensieve aerobe activiteiten (89% vs. 69%) en het voldoende frequent oefenen van kracht en mobiliteit (44% vs. 29%) dan degenen die niet aan een oefengroep deelnamen, maar ze voldeden minder vaak aan de aerobe beweegrichtlijn voor hoog-intensieve oefenactiviteiten (5% vs. 12%). Deze verschillen waren statistisch significant.

De conclusie van het onderzoek was dat slechts een klein deel van de mensen met axSpA deelneemt aan gesuperviseerde oefengroepen en dat deze deelnemers vaker voldeden aan beweegrichtlijnen voor de algemene bevolking ten aanzien van

matig-intensieve aerobe, kracht- en mobiliteitsoefeningen. Echter, ongeacht deelname aan de oefengroepen, voerde slechts een minderheid hoog-intensieve aerobe oefenactiviteiten uit of voldeed aan de aanbevolen frequentie van kracht- of mobiliteitsoefeningen.

De studie beschreven in **Hoofdstuk 4** richtte zich op de huidige organisatie en inhoud van gesuperviseerde oefengroepen voor mensen met axSpA in Nederland. Hiervoor werd een enquête uitgezet onder de 82 lokale patiëntenverenigingen die in 2016 waren aangesloten bij ReumaNederland. Van elke lokale vereniging werd een bestuurslid bevraagd over de organisatie van de oefengroepen en een oefengroep-begeleider over de inhoud en begeleiding van de oefengroepen. In 17 regio's bleken axSpA-specifieke oefengroepen te worden aangeboden. In het merendeel daarvan (16/17) was de frequentie eenmaal per week en bestond deze uit een combinatie van oefeningen op het droge en in water, met een mediane totale duur van 100 minuten. In alle 17 regio's bestond het programma uit oefeningen voor kracht en mobiliteit in combinatie met sportactiviteiten (vooral badminton en volleybal). In 10 van de 17 regio's werden ook aerobe oefeningen uitgevoerd. In slechts één regio werd de oefenintensiteit gemonitord (bijvoorbeeld aan de hand van de hartslag) en werd het oefenen gepersonaliseerd (1/17). Ook periodieke metingen (2/17) en patiëntenvoorlichting (8/17) vonden in de minderheid van de regio's plaats. De meerderheid van de begeleiders (38/59) had geen nascholing gevolgd over het behandelen van mensen met axSpA.

De resultaten van dit onderzoek suggereren dat er ruimte is voor verbetering van de inhoud en vormgeving van de axSpA-specifieke oefengroepen. Verbeteringen betreffen het vaker aeroob oefenen, inclusief monitoring van de intensiteit, de personalisatie van het oefenen, het uitvoeren van periodieke metingen en het structureel aanbieden van patiëntenvoorlichting. Bij implementatie van deze bevindingen lijkt het verzorgen van bij- en nascholing voor de begeleiders, zowel over axSpA als over actuele inzichten op het gebied van oefenen bij axSpA, noodzakelijk.

In het onderzoek beschreven in **Hoofdstuk 5** werd bij deelnemers aan axSpA-specifieke oefengroepen de tevredenheid met de huidige oefengroepen en hun perspectief ten aanzien van voorgestelde evidence-based aanpassingen onderzocht. Hiervoor werd een enquête afgenomen bij 118 axSpA patiënten die deelnamen aan gesuperviseerde oefengroepen in vier regio's in Nederland. Uit de resultaten bleek dat de meerderheid weliswaar tevreden was met de huidige inhoud van de oefengroepen, maar het ook eens was met de volgende voorgestelde aanpassingen: meer aerobe oefeningen (met een hoge intensiteit), inclusief monitoring van de intensiteit (83%), personalisatie van de oefeningen op basis van periodieke metingen (82%) en structurele patiëntenvoorlichting, met

name over het vaker (thuis) oefenen om aan de beweegrichtlijnen voor de algemene bevolking te kunnen voldoen (50%).

Op basis van de resultaten van dit onderzoek werd geconcludeerd dat mensen met axSpA die deelnemen aan gesuperviseerde oefengroepen positief tegenover een aantal evidence-based aanpassingen van de inhoud en vormgeving van de gesuperviseerde oefengroepen staan.

Het onderzoek van **Hoofdstuk 6** betrof de evaluatie van de effecten en haalbaarheid van de implementatie van de hierboven genoemde evidence-based aanpassingen uit Hoofdstuk 5 in de oefengroepen voor mensen met axSpA. Deze pilot-implementatiestudie had een zogenaamd 'hybride studiedesign', waarbij tegelijkertijd de klinische effecten van de interventie en de haalbaarheid van de implementatiestrategie werden onderzocht. De pilot-implementatiestudie werd uitgevoerd in vier regio's. De implementatiestrategie bestond uit een ééndaagse training voor de begeleiders van de oefengroepen, gevolgd door tweemaandelijkse telefonische ondersteuning (en op aanvraag). Om de effecten op de gezondheidstoestand van de deelnemers te evalueren, werden bij 60 deelnemers aerobe capaciteit (met de Zes Minuten Wandeltest, 6MWT), fysiek functioneren (met de Ankylosing Spondylitis Performance-based Improvement, ASPI), de gezondheidsstatus (met de ASAS Health Index) en de hoeveelheid lichaamsbeweging (met de SQUASH) gemeten op baseline en na één jaar. Daarnaast werden voor het beoordelen van de haalbaarheid één jaar na de baseline-meting zowel een enquête onder 60 patiënten als semigestructureerde interviews onder vier oefengroep-begeleiders (van elke regio één) uitgevoerd.

Uit de metingen bleek dat er een statistisch significante verbetering van de aerobe capaciteit (6MWT) was en dat een derde van de deelnemers verbeterd was op gebied van fysiek functioneren (ASPI). Er waren daarentegen geen statistisch significante verschillen in gezondheidsstatus (ASAS Health Index) en de hoeveelheid lichamelijke activiteit (SQUASH). Wat betreft de haalbaarheid bleek uit de enquête en interviews dat de implementatie van het vaker aeroob oefenen (met hoge intensiteit) succesvol was (n=4/4 regio's), de personalisatie van de oefeningen en het uitvoeren van periodieke metingen slechts ten dele (n=2/4) en de patiëntenvoorlichting helemaal niet (n=0/4).

De resultaten van deze pilot-implementatiestudie suggereren dat voor landelijke opschaling een aantal aanpassingen van de implementatiestrategie nodig zijn.

Fysiotherapeuten kunnen een belangrijke rol spelen bij het bevorderen van beweeg- en oefenactiviteiten, maar een aanzienlijk deel van mensen met axSpA maakt geen of weinig gebruik van fysiotherapie. In de studie beschreven in **Hoofdstuk 7** werd daarom onderzocht welke componenten belangrijk zijn in interventies gericht op het optimaliseren van het beweeggedrag van mensen met

axSpA, óók als zij geen gebruik maken van de ondersteuning van een professional. Hiertoe werden de eerste drie stappen van het Intervention Mapping protocol doorlopen: 1) beoordeling van het belang om het beweeggedrag van mensen met axSpA te optimaliseren; 2) identificatie van axSpA-specifieke determinanten van beweeggedrag; en 3) selectie van effectieve interventie-componenten gericht op deze determinanten. Elke stap bestond uit een scoping review en semigestructureerde interviews met axSpA patiënten (n=2) en fysiotherapeuten met specifieke deskundigheid op het gebied van axSpA (n=2).

Het onderzoek resulteerde in de identificatie van acht componenten die werden geïdentificeerd als meest relevant: patiëntenvoorlichting, motiverende gespreksvoering, doelen stellen, actieplannen maken, personalisatie van oefenactiviteiten, begeleiding bij het oefenen en periodieke monitoring en terugkoppeling van de uitvoering en effecten van het oefenen. Daarnaast bleek het gewenst om fysiotherapeuten bij te scholen en om patiënten te stimuleren om in een groepssetting te oefenen.

Op basis van deze resultaten werd een axSpA-specifieke beweeginterventie ontwikkeld: het beweeghandboek “Bewegen tot Beweging”. Met deze interventie kan verandering in beweeggedrag van mensen met axSpA worden gefaciliteerd. Dit kan onder begeleiding van een geschoolde zorgverlener of zelfstandig door middel van het handboek voor patiënten.

Implicaties voor toekomstig onderzoek

Het onderzoek in dit proefschrift heeft aangetoond dat een aanzienlijk deel van de mensen met axSpA niet voldoet aan de beweegrichtlijnen voor de algemene bevolking ten aanzien van hoog-intensieve aerobe activiteit en ten aanzien van het met de aanbevolen frequentie oefenen van spierkracht en mobiliteit. Dit is ook het geval bij mensen met axSpA die behandeld worden door de fysiotherapeut. Er is bij mensen met axSpA die deelnemen aan gesuperviseerde oefengroepen behoefte aan het invoeren van een aantal evidence-based verbeteringen, maar bij de grootschaliger implementatie daarvan moeten nog een aantal barrières worden genomen. Omdat slechts een minderheid van de mensen met axSpA deelneemt aan dergelijke oefengroepen, zijn ook aanpassingen van de individuele oefentherapie en meer interventies waaraan mensen zelfstandig (zonder begeleiding) kunnen deelnemen gewenst. In dit proefschrift werden een aantal componenten van dergelijke interventies geïdentificeerd.

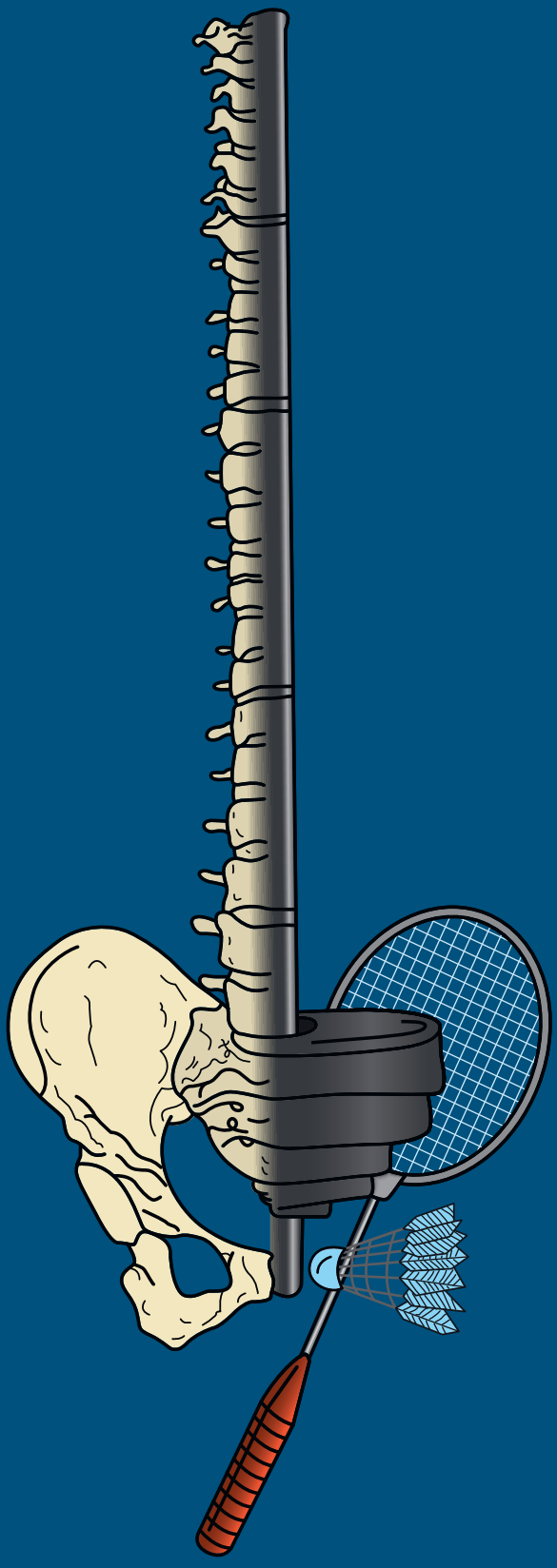
De onderzoeken in dit proefschrift hebben ook laten zien dat er meerdere kennishiaten zijn waarop toekomstig onderzoek zich zou kunnen richten:

- Het verschil in effectiviteit (ook op lange termijn en op cardiovasculaire risicofactoren) en veiligheid tussen oefenactiviteiten die verschillen in frequentie, intensiteit, tijdsduur, type oefening en supervisie. Hierbij moet ook gekeken worden hoe hoog-intensief oefenen kan worden geïntegreerd in activiteiten die al veel worden uitgevoerd in het dagelijks leven door mensen met axSpA, zoals fietsen.
- De haalbaarheid, effectiviteit en veiligheid van functionele training en ademhalingsoefeningen, omdat de bewijslast voor deze oefenvormen beperkt is.
- Bevorderende en belemmerende factoren voor deelname aan oefengroepen voor mensen met axSpA of voor alternatieven zoals individuele oefentherapie, groepstraining in de sportschool of in het zwembad of zelfstandig thuis oefenen.
- De uitvoering van stappen 4, 5 en 6 van het Intervention Mapping protocol door het beweeghandboek “Bewegen tot Beweging” verder te ontwikkelen (bijvoorbeeld op basis van focusgroeponderzoek), te implementeren en te evalueren (bijvoorbeeld door middel van een hybride studiedesign).
- De toegankelijkheid, effectiviteit en veiligheid van de inzet van eHealth in zowel de gesuperviseerde oefentherapie als in het thuis zelfstandig oefenen voor mensen met axSpA.

Implicaties voor de praktijk

De onderzoeken in dit proefschrift hebben laten zien dat een bredere inzet van nieuwe inzichten in het bewegen en oefenen van mensen met axSpA gewenst is en dat daarvoor nog een aantal stappen gezet moeten worden. Hoewel voor de verschillende doelgroepen specifieke implementatiestrategieën nodig zijn, kunnen wel een aantal algemene voorwaarden genoemd worden:

- Bij- en nascholing van fysiotherapeuten over axSpA, over de oefentherapeutische behandeling en over het stimuleren van voldoen aan beweegrichtlijnen.
- Beschikbaarheid van een beweeghandboek voor mensen met axSpA, waarmee zij onder begeleiding of zelfstandig hun beweeggedrag kunnen optimaliseren, bij voorkeur in digitale vorm en gebruikmakend van eHealth toepassingen zoals activity trackers en synchrone (video consulten) of asynchrone (app of e-mail) virtuele contacten.
- Optimale toegankelijkheid van individuele of groepsoefentherapie, onder andere door adequate vergoeding.



Chapter 10

List of publications

Curriculum vitae

Dankwoord

List of publications

Hilberdink B, Carbo M, Paap D, Arends S, Vliet Vlieland T, van der Giesen F, Spoorenberg A, van Weely S. Differences in characteristics, health status and fulfilment of exercise recommendations between axial spondyloarthritis patients with and without supervised group exercise [published online ahead of print, 2022 May 28]. *Semin Arthritis Rheum*. 2022;55:152035.

Hilberdink B, van der Giesen F, Vliet Vlieland T, van Bodegom-Vos L, Van Weely S. Implementing enhancements in supervised group exercise for people with axial spondyloarthritis: a hybrid effectiveness-implementation study [published online ahead of print, 2021 Nov 17]. *Scand J Rheumatol*. 2021;1-9.

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Hilberdink B, van der Giesen F, Vliet Vlieland T, van Gaalen F, van Weely S. Supervised Group Exercise in Axial Spondyloarthritis: Patients' Satisfaction and Perspective on Evidence-Based Enhancements. *Arthritis Care Res (Hoboken)*. 2020;72(6):829-837.

Curriculum vitae

Bas Hilberdink is geboren op 16 augustus 1989 te Groningen. In 2007 haalde hij zijn gymnasiumdiploma aan het Praedinius Gymnasium te Groningen. Na vier maanden Bewegingswetenschappen te hebben gestudeerd, besloot hij dat dit geen geschikte studie voor hem was en heeft hij de rest van dat studiejaar opgevuld door te werken als fysiotherapie-assistent in het Paramedisch Centrum voor Reumatologie en Revalidatie (PCRR Hilberdink) te Groningen, een eerstelijns fysiotherapiepraktijk die zich specifiek richt op de behandeling van mensen met een chronische aandoening. Daar is zijn passie voor het vak fysiotherapie ontstaan. In 2008 is hij begonnen met de verkorte opleiding fysiotherapie (Bachelor+) aan de Hogeschool Utrecht en in 2011 rondde hij deze bachelor af en kreeg hij de zogenaamde *Excellent Achievements – award 'Innovation and Dissemination'* volgens de criteria van de Hogeschool Utrecht.

In 2011 begon hij te werken als fysiotherapeut in het PCRR Hilberdink en in deze praktijk richtte hij destijds ook het Centrum voor Aangepast Sporten 'Ability' (CASA Hilberdink) op, een laagdrempelige sportschool waar mensen na een behandeltraject aan begeleide groepssport kunnen deelnemen. Ook begon hij in 2011 met de bachelor Psychologie aan de Open Universiteit. In 2014 startte hij met zijn master Gezondheidspsychologie, eveneens aan de Open Universiteit. De onderzoeksstage behorende bij deze master liep Bas bij de onderzoeksgroep van de afdeling Orthopedie, Revalidatie en Fysiotherapie van het Leids Universitair Medisch Centrum (LUMC) onder leiding van prof.dr. Thea Vliet Vlieland. Na het behalen van zijn masterdiploma in 2018 vervolgde Bas zijn onderzoekswerkzaamheden in deze onderzoeksgroep en startte hij zijn promotietraject bij dezelfde afdeling van het LUMC onder begeleiding van prof.dr. Thea Vliet Vlieland en dr. Salima van Weely.

Momenteel is Bas nog steeds werkzaam in PCRR Hilberdink als fysiotherapeut en kwaliteitsfunctionaris en als manager van CASA Hilberdink.

Dankwoord

Ik heb mijn promotieperiode als een erg goede tijd ervaren en daarom wil ik graag iedereen bedanken die direct of indirect heeft bijgedragen aan de totstandkoming van dit proefschrift.

Allereerst dank ik alle deelnemers van de verschillende studies: de patiënten die via de ziekenhuizen hebben deelgenomen aan het onderzoek, de patiënten en gespecialiseerde fysiotherapeuten die ik heb mogen interviewen en natuurlijk ook alle patiënten, begeleiders, coördinatoren en bestuursleden van de Bechterew Beweeggroepen, die veel tijd en energie hebben gestoken in de gehele proefimplementatie.

Ik ben mijn promotor prof.dr. Thea Vliet Vlieland en co-promotor dr. Salima van Weely erg dankbaar voor de zeer prettige en persoonlijke begeleiding tijdens het gehele promotietraject. Beste Thea, jouw efficiënte en harde werk en passie en visie voor onderzoek naar bewegen en fysiotherapie bij mensen met een reumatische aandoening zijn een enorme inspiratiebron. Beste Salima, bedankt voor al je adviezen en begeleiding bij het werken als onderzoeker, je wist het altijd leuk en gezellig te maken bij onze bijeenkomsten. Ik heb veel van jullie geleerd en vond het altijd erg fijn samenwerken.

Ook dank ik alle andere onderzoekers in de leuke onderzoeksgroep onder leiding van Thea en in het bijzonder Florus van der Giesen, Leti van Bodegom-Vos en Wilfred Peter, met wie ik in de afgelopen jaren erg prettig heb samengewerkt. Hetzelfde geldt voor de GLAS-onderzoeksgroep in het UMCG, inclusief Marlies Carbo, Suzanne Arends, Anneke Spoorenberg en Davy Paap; bedankt voor de fijne en intensieve samenwerking tijdens het laatste jaar van mijn promotieonderzoek. Ook dank ik Nique Lopuhaä van ReumaNederland voor het meedenken vanuit een patiëntperspectief bij de studies.

Lieve vrienden, familie en collegae en cliënten van het PCRR, bedankt voor jullie interesse in mijn onderzoek en voor jullie aandeel in de mooie tijd die ik heb en heb gehad ook naast mijn onderzoekswerkzaamheden. Een bijzondere dank aan Bram en Willem, die mijn paranimfen willen zijn, en aan Meike, voor het ontwerpen van de coverillustratie.

Lieve Wim en Hedi, heel erg bedankt voor jullie enorme steun en vertrouwen. Ik ben jullie enorm dankbaar voor alles, van het vele oppassen op de kinderen en alle hulp bij ons thuis (vooral ook in de zwaardere tijden), tot alles wat jullie voor mij mogelijk hebben gemaakt tijdens mijn carrière en opleidingen, zonder daarbij enige druk op mij te leggen. Bedankt dat jullie ervoor zorgden dat ik alle voorspoed niet als vanzelfsprekend ben gaan ervaren. Jullie zijn mijn grootste inspiratiebron wat

betreft jullie harde werken, het managen van de praktijk en vooral jullie zorgzaamheid.

Lieve Kimberly, bedankt voor je onvoorwaardelijke steun, al je hulp en je oneindige liefde. Ik voel mij altijd gelukkig bij jou en geniet enorm van ons leven samen. Je bent geweldig. Hetzelfde geldt voor mijn allerliefste Max en Juliette, wat maken jullie mij gelukkig en wat ben ik trots op jullie!