



**IMPLEMENTATION OF PHYSICAL
ACTIVITY RECOMMENDATIONS IN PEOPLE
WITH AXIAL SPONDYLOARTHRITIS**

Anne-Kathrin Rausch Osthoff

Implementation of physical activity recommendations in people with axial spondyloarthritis

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General introduction

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Rheumatic and Musculoskeletal Diseases (RMDs) encompass over 200 conditions of the musculoskeletal system, including osteoarthritis and inflammatory arthritis. RMDs are characterized by pain, stiffness, loss of locomotor function and, sometimes, premature death (1). About one quarter of the European population of all ages is affected by RMDs. This results in direct and indirect healthcare costs of around EUR 240 billion per year, or some 2% of the gross domestic product of European countries (2). Physical Activity (PA) is one of the most important lifestyle factors influencing human health, along with balanced diet, cessation of smoking and/or abusive substance use, and reduction of stress. PA is considered a modifiable behaviour that can reduce the risk of developing an RMD, positively influence its course and prevent some of its consequences (3-6). This thesis will in part focus on axial spondyloarthritis, a form of inflammatory arthritis.

Definition, consequences, and epidemiology of axial spondyloarthritis

Axial spondyloarthritis (axSpA), which includes both radiographic axSpA (r-axSpA) and non-radiographic axSpA (nr-axSpA), is a chronic, inflammatory RMD that predominately affects the sacroiliac joints and spine. Approximately 30% of people with axSpA have both axial and peripheral joint involvement (7). AxSpA can also present with associated musculoskeletal (e.g., arthritis, enthesitis, dactylitis) or extra-articular manifestations (e.g., uveitis, inflammatory bowel disease, cardiovascular diseases) (8, 9). In people with axSpA, the presence of disease characteristics based on the Assessment of Spondyloarthritis international Society (ASAS) classification varies significantly. These variations include, for example, radiographic or non-radiographic changes (10), or the presence of biomarkers such as the C-reactive protein, the human leukocyte antigen (HLA) B27 status, or the erythrocyte sedimentation rate (11). The chronic inflammation of the axial skeleton leads to back pain and progressive stiffness. The symptoms can be improved with exercise, but not through inactivity. The chronic inflammation may also result in functional and structural impairments (8), e.g., reduced flexibility (12), balance (13), muscle strength (14), or cardio-respiratory capacity (15). Comorbidities are common in people with axSpA. According to data from an international ASAS comorbidity study including 3'370 patients (66% male, mean \pm SD age 43 \pm 14 years), 51% of people with axSpA suffered from at least one comorbidity and 9% from three or more comorbidities (16). This study also showed that the higher the number of comorbidities (reflected by a higher score on the Rheumatic Disease Comorbidity Index (17)), the greater the impact on physical function, work ability, and quality of life (16). In Spanish, German and Dutch cohorts, the comorbidities most commonly found were hypertension, depression and obesity (18-20). It has also been demonstrated that people with axSpA have an increased risk of cardiovascular diseases (21).

The prevalence of axSpA in the general population is about 0.1%-0.6%, according to European disease prevalence data (22, 23). The male-female prevalence ratio is equal (24).

However, there are gender differences regarding radiologic prognosis (with males more affected) and burden of disease (with females more affected) (25). Characteristically, disease onset is in early adulthood and results in considerable personal burden of disease and negative economic consequences for the individual and society (26-29). Despite efforts in clinical practice to increase awareness and improve diagnostic procedures, the diagnostic delay is still 2-11 years on average, with women waiting longer than men (30-32).

The management of axSpA

The recommendations of the European Alliance of Associations for Rheumatology (EULAR) for the management of axSpA define the aim of primary treatment as: 'To maximise long-term health-related quality of life through control of symptoms and inflammation, prevention of progressive structural damage, preservation/normalisation of function and social participation' (8). This treat-to-target strategy (goal of remission or low disease activity) implies that the management of axSpA should be personalised, and a combination of pharmacological and non-pharmacological treatment modalities applied (8, 9, 33). The recommended first-line pharmacological treatment for people suffering from pain and stiffness is the prescription of nonsteroidal anti-inflammatory drugs (NSAIDs). For people with consistently high disease activity, additional biological therapies are available (8). Two groups of biological disease-modifying antirheumatic drugs (bDMARDs) and their biosimilars (drugs that are virtually identical to the original) have been approved as effective and safe: tumour necrosis factor inhibitors (TNFi) and interleukin17A inhibitors (IL17Ai) (34). The bDMARDs are used to achieve a threshold of remission or low disease activity and focus on physical function (35). The maximal reduction of symptoms by pharmacological treatment enhances the success of non-pharmacological treatment (36). The ASAS recommendations for non-pharmacological treatment include physiotherapy, education, smoking cessation, and the promotion of PA (8).

Regarding the reduction of disease activity in the management of axSpA, there is evidence to show that combining pharmacological and non-pharmacological treatment modalities through the combination of bDMARDs and physiotherapy is superior to medication alone (36-38). The effect on disease activity was established using the Bath Ankylosing Spondylitis Mobility Index (BASMI) and Bath Ankylosing Spondylitis Disease Activity Index (BASDAI) scores (37, 38).

In research specifically on the effectiveness of exercise programmes, routine pharmacological therapy was usually continued in both the intervention and the control groups. In the most recent Cochrane review from 2019, 14 randomized controlled trials investigating the effect of exercise programmes were examined. The exercise programmes had a mean duration of 12 weeks at a median frequency of three sessions per week and consisted mainly of land-based flexibility, breathing and strength exercises, in combination with standard-NSAIDs or

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DMARDs (39). The conclusions drawn from the pooled data were that these programmes slightly improve function, potentially reduce pain and, probably, slightly reduce disease activity (moderate-to-low quality evidence) in comparison with no intervention (but standard-NSAIDs) (39). The authors were uncertain about potential adverse events due to lack of evidence and insufficient reporting in the studies (39). The effectiveness of physiotherapy interventions is difficult to demonstrate because of methodological weaknesses, such as small sample sizes, heterogeneous study populations, insufficient description of the interventions and/or flaws in the assessments (39).

The studies investigated in the Cochrane review (39) represent the traditional exercise concept for people with axSpA that is commonly employed in current clinical practice. However, it has been suggested that this traditional exercise concept is no longer state-of-the-art. Recent studies, for example from Sveaas and colleagues (40), have shown that high-intensity aerobic exercise interventions have promising effects on disease activity, inflammatory markers, and symptoms such as pain, fatigue, and stiffness. A greater focus on aerobic exercises also seems to be advisable because of the growing body of knowledge on the increased cardiovascular risk in this patient group (41, 42). Patients also appear to support such a shift in the focus of axSpA exercises and concur with the inclusion of fitness-related exercises alongside to conventional disease-specific exercises (43).

Definition of physical activity and recommendations

Physical Activity (PA) is defined as ‘any bodily movement produced by skeletal muscles that results in energy expenditure above resting (basal) levels’ (44, 45). PA encompasses any exercise, sport or physical activities done as part of daily living, occupation, leisure and active transportation (46). *Exercise* is a subcategory of PA that is ‘planned, structured, and repetitive and [that] has as a final or intermediate objective to improve or maintain one or more dimensions of physical fitness’ (44). In contrast, *therapeutic exercises and exercise therapy* comprise specific exercises designed to address distinct functional health problems and are supervised by a qualified health professional, e.g., a physiotherapist.

The World Health Organisation (WHO) provides current, evidence-based public health PA recommendations on the amount (frequency, intensity, and duration) and type of regular PA necessary to offer significant health benefits and mitigate health risks. The *current PA recommendations* for adults (including elderly or people with chronic conditions) encompass four exercise dimensions: cardiorespiratory/aerobic; muscle strength; flexibility; and neuromotor exercises (3, 47). A person is advised to perform at least 150-300 minutes of moderate-intensity PA, or 75-150 minutes of vigorous-intensity aerobic PA (or combination of these) per week, plus additional muscle strengthening activities involving the major muscle groups on at least two days of the week (47). Flexibility and neuromotor exercises are additionally recommended on three or more days during the week (3, 47). Correspondingly,

sitting time should be reduced to a minimum (47).

The intensity of PA is defined through the estimation of energy demands of the metabolic system, i.e., metabolic equivalent of task (MET) (48): for example, walking at 5km/h is described by 3.2METs and classified as a moderate-intensity aerobic activity; and jogging at 9km/h is described by 8.8METs and classified as vigorous aerobic activity. The use of absolute measures may be misleading, however, because personal factors, such as weight, sex, age, and fitness level are not considered (46). For this reason, a relative *measure of intensity* (e.g., %MET_{max}, %HR_{max} or perceived exertion), which measures the energy costs relative to the individual's maximal capacity, is more appropriate. Moderate exercise is defined as 64% - 76% of the maximum heart rate (%HR_{max}) and vigorous exercise as 77% - 95%HR_{max}. Another commonly used assessment to evaluate the intensity of exercise is the Borg Rating of Perceived Exertion Scale, which measures the individual's effort and exertion, breathlessness, and fatigue during PA (49). On a numeric visual scale of 6-20, the numbers 6- 12 indicate a moderate-intensity exercise and the numbers 13-20 a vigorous-intensity exercise (49).

The dose-response relationship between daily PA and health benefits has been confirmed (50). Exceeding the minimum recommended amount of PA improves fitness, reduces the risk factors of chronic conditions, and prevents unhealthy weight gain (46). Furthermore, there is evidence that shorter vigorous-intensity exercise (e.g., 30 minutes of activity \geq 6METs) is better than longer moderate-intensity exercise (e.g., 60 minutes of activity at 3-6METs) and is associated with a greater reduction of cardiovascular risk (51) and lower mortality rate in the general population (52).

People not meeting the minimum recommendations are considered physically inactive. The WHO stresses that, when possible, people with chronic conditions should try to meet the public health PA recommendations. It also states that exercising below the recommended levels may still be beneficial to people not able or willing to fulfil the recommended amount of PA (47). The American College of Sports Medicine (ACSM) supports this statement, providing evidence on the importance of PA in the prevention and treatment of chronic conditions. It provides examples of appropriate PA programmes and guidance for the performance of exercise (3).

Physical activity and axSpA

Meeting the PA recommendations described above and incorporating the four exercise dimensions of aerobic, muscle strength, flexibility and neuromotor exercising is especially difficult for people with axSpA. They face barriers of pain, fatigue, or stiffness that healthy people do not have (53). Other aspects, such as the fear of flare-ups or the presence of comorbidities, may also hamper participation in certain types of exercise. Some physical

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consequences of the disease, such as osteoporosis (risk of fracture), severe deformities of the spine (risk of neurological complication), or extra-articular manifestations (e.g., tendons, bowels, kidney, eyes), can make an active lifestyle even more difficult to realise (54). It is therefore not surprising that people living with axSpA have been found to be generally less physically active than healthy controls (55-57). Expert support from physicians and health professionals in rheumatology (HPRs), e.g., physiotherapists, may thus be required to identify and address the individual challenges with respect to PA behaviour.

Exercise is medicine for people with axSpA: clear recommendations are needed

Despite the fact that exercise (and group exercise, in particular) is mentioned in the recommendations and guidelines for the management of axSpA (8, 58), it has been uncertain for some time whether the public health PA recommendations are applicable to people with axSpA. The public health PA recommendations focus on aerobic exercises at an appropriate dosage (moderate/vigorous intensity, and most days per week frequency) which contrasts with the content of most exercise programmes for people with axSpA found in the literature (39, 47). This is an important distinction.

In 2016, this highly relevant issue led to the initiation of an EULAR task force on the development of PA recommendations for people with RMDs, including axSpA (among others).

The first part of this thesis concerns the development process of the EULAR PA recommendations for people with RMDs, while the second part describes the lessons learned from their pilot implementation specifically in people with axSpA.

Implementation of PA recommendations in people with axSpA

After the development of a clinical innovation, it must subsequently be translated and implemented into clinical routine. Implementation is the uptake of research findings by routine health care in the clinical, organisational and policy contexts using strategies tailored to the target population, setting, and goals for improvement (59). However, the implementation of innovations into clinical routine is a great challenge (60, 61). It needs a planned, systematic approach with clear strategies. Successful implementation must be based on an analysis of the contextual factors and the knowledge-practice gap, inclusion of stakeholders, and theory-informed systematic approach (59, 62). The Grol&Wensings' model of change (63) is a theoretical approach that is commonly applied to guide and describe an implementation process. After a comprehensive analysis of current practice

and targets of change, implementation strategies and interventions can be developed, evaluated, and continuously and cyclically adapted (63).

It is known that awareness of the public health PA recommendations and their resulting benefits does not necessarily lead to behavioural changes (64-66). PA is behaviourally complex and increasing PA as a lifestyle change remains a challenge (67, 68). A successful health behaviour change can be defined as ‘the shift from risky behaviours to the initiation and maintenance of healthy behaviours and functional activities, and the self-management of chronic health conditions’ (69). Several theories have been proposed to explain PA behaviour, which is determined by individual, social, environmental, and societal factors (68). Common to many theories is the central distinction of motivation, which is conceptualised (for example) in intention, stage of change, and autonomous motivation (70). Motivation determines whether an individual will change PA behaviour over the long term. Consequently, an understanding of how PA promotion interventions can influence motivation is critical. The use of behaviour change techniques (71), such as goal-setting and self-monitoring, has been shown to be associated with beneficial changes in PA behaviour (70, 72). Fenton and colleagues (73) summarised the evidence on theory-informed interventions for people with axSpA. They emphasised that motivation and theories should be used more intensively to develop interventions and learn “how things work”. This would help to develop new strategies, optimise current interventions, and support the translation of the theory into practice process.

Physical activity promotion in people with axSpA in Switzerland

In Switzerland, 76% of the adult population is considered physically active (74). The Swiss health care system is fee-for-service and regulated by law and organised at cantonal level (75, 76). The cost of only a few PA promotion intervention programmes for people with chronic conditions is partly refunded by health insurance (77). A Swiss national agency for the development of guidelines does not exist and evidence-based interventions are often not systematically applied in clinical care (78). The Swiss Association for Rheumatology did not publish its own guidelines for the management of axSpA, but referenced those published by EULAR and the American College of Rheumatology.

The Ankylosing Spondylitis Association of Switzerland (Schweizerische Vereinigung Morbus Bechterew, SVMB, www.bechterew.ch) represents approximately 4'300 members with axSpA. The SVMB is connected to the national association Swiss League Against Rheumatism and is a member of the Ankylosing Spondylitis International Federation (ASIF) and the European Alliance of Associations for Rheumatology Patient Representatives (EULAR PARE). Since the early 1980s, the SVMB offers - among other services - physiotherapist-supervised, weekly exercise group therapy in approximately 65 locations

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across Switzerland. The concept of this exercise group therapy was, however, outdated since it was mainly based on flexibility and low-intensity strength exercising. Recent evidence indicates that greater attention should be paid to cardiovascular exercise (79-82), individual dosage of exercise intensity based on regular assessments (72, 83-85), encouragement to use exercise for self-management of disease and regular performance of individual exercise (86). Consequently, in line with the ambition of the EULAR task force, the SVMB aimed to translate the EULAR PA recommendations into a new exercise group concept that would meet both disease-specific exercising and general PA recommendations, and to subsequently implement it into routine clinical care.

Outline of this thesis

Given the lack of specific PA recommendations for people with RMDs, particularly axSpA, and their deficient implementation into clinical care, the aims of this thesis were to:

- 1) Describe the development, definition, and evidence base of the 2018 EULAR recommendations for PA in people with inflammatory arthritis and osteoarthritis.
- 2) Evaluate the pilot implementation of exercising according to the EULAR PA recommendations in exercise groups for people with axSpA in Switzerland, including the analysis of the situation, determinants of PA behaviour, and the exploration of a muscle strength assessment.

The first aim is addressed in the following chapters:

- Chapter 2 describes the development and definition of the 2018 EULAR recommendations for PA in people with inflammatory arthritis and osteoarthritis.
- Chapter 3 summarises the evidence on the effects of exercise and PA promotion, according to public health recommendations, in people with rheumatoid arthritis, spondyloarthritis, and hip/knee osteoarthritis. This meta-analysis informed the EULAR task force, defining the EULAR recommendations for PA.

The second aim is addressed in the following chapters:

- Chapter 4 evaluates patients' use of physiotherapy and their perspective on it. A quantitative analysis of the current situation in the Netherlands and Switzerland.
- Chapter 5 explores the patients' beliefs related to PA. A qualitative evaluation of the current situation in Switzerland.
- Chapter 6 describes the reliability of an adapted core strength endurance test battery. This assessment is needed to tailor individual exercises. It is a relevant component of the implementation strategy described below.
- Chapter 7 elucidates the implementation strategy and lessons learned from the pilot implementation of the PA recommendations in axSpA exercise group therapy in Switzerland.
- Chapter 8 discusses the most important findings of the studies in this thesis

and their implications for clinical care. Suggestions for further research are also presented.

- Chapter 9 summarises the thesis.

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2018 EULAR recommendations for physical activity in people with inflammatory arthritis and osteoarthritis

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Abstract

Regular physical activity (PA) is increasingly promoted for people with rheumatic and musculoskeletal diseases as well as the general population. We evaluated if the public health recommendations for PA are applicable for people with inflammatory arthritis (iA; Rheumatoid Arthritis and Spondyloarthritis) and osteoarthritis (hip/knee OA) in order to develop evidence-based recommendations for advice and guidance on PA in clinical practice.

The EULAR standardised operating procedures for the development of recommendations were followed. A task force (TF) (including rheumatologists, other medical specialists and physicians, health professionals, patient-representatives, methodologists) from 16 countries met twice. In the first TF meeting, 13 research questions to support a systematic literature review (SLR) were identified and defined. In the second meeting, the SLR evidence was presented and discussed before the recommendations, research agenda and education agenda were formulated.

The TF developed and agreed on four overarching principles and 10 recommendations for PA in people with iA and OA. The mean level of agreement between the TF members ranged between 9.8 to 8.8. Given the evidence for its effectiveness, feasibility and safety, PA is advocated as integral part of standard care throughout the course of these diseases. Finally, the TF agreed on related research and education agendas.

Evidence and expert opinion inform these recommendations to provide guidance in the development, conduct and evaluation of PA-interventions and promotion in people with iA and OA. It is advised that these recommendations should be implemented considering individual needs and national health systems.

Introduction

Physical activity (PA) is defined as 'any bodily movement produced by skeletal muscles that results in energy expenditure above resting (basal) levels. PA broadly encompasses exercise, sports and physical activities done as part of daily living, occupation, leisure and active transportation' (1, 2). Exercise is a subcategory of PA 'that is planned, structured and repetitive and [that] has, as a final or intermediate objective, the improvement or maintenance of one or more dimensions of physical fitness' (1, 2). PA-interventions can be provided or performed individually or in groups, supervised or non-supervised, in acute or chronic health states, but should always include behavioural change techniques (BCT) to promote long-term adherence (3, 4).

To promote the health benefits of PA in the general population, the WHO (5) and American College of Sports Medicine (ACSM) (2) have provided internationally accepted recommendations for PA (table 1). In this manuscript, the term PA always includes both physical activity and exercise according to the definitions above.

Inflammatory arthritis (iA, in this manuscript encompassing rheumatoid arthritis (RA) and spondyloarthritis (SpA)) and osteoarthritis (OA) (in this manuscript encompassing hip/knee OA (HOA/KOA)) are major causes of pain and disability worldwide (6). There is strong evidence for the benefits of PA on improvements on disease activity (7), activities and participation, however, people with rheumatic and musculoskeletal diseases (RMDs) are in general less active compared with healthy controls (8-10). Possible underlying reasons could be that health care providers (HCP, including rheumatology health professionals (eg, physiotherapist (PT), occupational therapist (OT), nurse, podiatrist, psychologist), physical education professions and medical doctors (rheumatologists and other specialists)) and people with iA and OA may be reluctant towards engaging in PA, fearing flare-up or joint damage by exercising (11). Furthermore, current clinical management recommendations such as the European League Against Rheumatism (EULAR) recommendations on the management of RA (12), SpA (13) or HOA/KOA (14) and the ACSM guidelines for exercise testing and prescription (15) recommend exercise and/or PA, but none of these is specific regarding the required type and dosage. Therefore, it is not clear how these recommendations should be used in routine clinical care. In particular, the evidence on the effectiveness and safety of exercise and PA to a level that meets public health (PH) recommendations has not yet been clearly examined and defined in people with RMDs. A EULAR task force (TF) was therefore set up (1) to evaluate if the PH recommendations for PA are applicable for people with iA and OA; (2) to develop evidence-based recommendations on PA-promotion and -delivery in the management of people with iA and OA and (3) formulate an educational and research agenda.

These EULAR recommendations for PA in people with iA and OA are for HCPs, patient organisations and policy makers.

Table 1 Public Health recommendations for PA

The ACSM-AHA primary physical activity recommendations*	
<ul style="list-style-type: none"> - All healthy adults aged 18-65years should participate in moderate intensity aerobic PA for a minimum of 30min on 5 days/week or vigorous intensity aerobic activity for a minimum of 20min on 3 days/week. - Combinations of moderate and vigorous intensity exercise can be performed to meet this recommendation. - Moderate intensity aerobic activity can be accumulated to total the 30min minimum by performing bouts each lasting ≥10min. - Every adult should perform activities that maintain or increase muscular strength and endurance for a minimum of 2 days/week. - Because of the dose-response relationship between PA and health, individuals who wish further improve their fitness, reduce their risk of chronic diseases and disabilities, and/or prevent unhealthy weight gain may benefit by exceeding the minimum recommended amounts of PA. 	
Cardiorespiratory ("aerobic") exercise**	
Frequency	≥5 days/week of moderate exercise, or ≥3 days/week of vigorous exercise, or a combination of moderate and vigorous exercise on ≥3–5 days/week is recommended.
Intensity	Moderate and/or vigorous intensity is recommended for most adults. Light to moderate intensity exercise may be beneficial in deconditioned persons.
Time	30–60 min/day (150 min/week) of purposeful moderate exercise, or 20–60 min/day (75 min/week) of vigorous exercise, or a combination of moderate and vigorous exercise per day is recommended for most adults. ≥20 min/day (150 min/week) of exercise can be beneficial, especially in previously sedentary persons.
Type	Regular, purposeful exercise that involves major muscle groups and is continuous and rhythmic in nature is recommended.
Volume	A target volume of ≥500–1000 MET min/week is recommended. Increasing pedometer step counts by ≥2000 steps per day to reach a daily step count ≥7000 steps per day is beneficial. Exercising below these volumes may still be beneficial for persons unable or unwilling to reach this amount of exercise.
Pattern	Exercise may be performed in one (continuous) session per day or in multiple sessions of ≥10 min to accumulate the desired duration and volume of exercise per day. Exercise bouts of ≥10 min may yield favourable adaptations in very deconditioned individuals. Interval training can be effective in adults.
Progression	A gradual progression of exercise volume by adjusting exercise duration, frequency, and/or intensity is reasonable until the desired exercise goal (maintenance) is attained. This approach may enhance adherence and reduce risks of musculoskeletal injury and adverse CHD events.
resistance exercise**	
Frequency	Each major muscle group should be trained on 2–3 days/week
Intensity	60%–70% of the 1RM (moderate to hard intensity) for novice to intermediate exercisers to improve strength. ≥80% of the 1RM (hard to very hard intensity) for experienced strength trainers to improve strength. 40%–50% of the 1RM (very light to light intensity) for older persons beginning exercise to improve strength. 40%–50% of the 1RM (very light to light intensity) may be beneficial for improving strength in sedentary persons beginning a resistance training program. ≤50% of the 1RM (light to moderate intensity) to improve muscular endurance. 20%–50% of the 1RM in older adults to improve power.
Time	No specific duration of training has been identified for effectiveness.
Type	Resistance exercises involving each major muscle group are recommended. A variety of exercise equipment and/or body weight can be used to perform these exercises.
Repetitions	8–12 repetitions are recommended to improve strength and power in most adults. 10–15 repetitions are effective in improving strength in middle aged and older persons starting exercise 15–20 repetitions are recommended to improve muscular endurance.
Sets	Two to four sets are the recommended for most adults to improve strength and power. A single set of resistance exercise can be effective especially among older and novice exercisers. ≤2 sets are effective in improving muscular endurance.
Pattern	Rest intervals of 2–3 min between each set of repetitions are effective. A rest of ≥48hours between sessions for any single muscle group is recommended.
Progression	A gradual progression of greater resistance, and/or more repetitions per set, and/or increasing frequency is recommended.

Flexibility exercise**	
Frequency	≥ 2–3 days/week is effective in improving joint range of motion, with the greatest gains occurring with daily exercise.
Intensity	Stretch to the point of feeling tightness or slight discomfort.
Time	Holding a static stretch for 10–30 s is recommended for most adults. In older persons, holding a stretch for 30–60 s may confer greater benefit. For PNF stretching, a 3- 6s contraction at 20%–75% maximum voluntary contraction followed by a 10-30s assisted stretch is desirable.
Type	A series of flexibility exercises for each of the major muscle–tendon units is recommended. Static flexibility (active or passive), dynamic flexibility, ballistic flexibility, and PNF are each effective.
Volume	A reasonable target is to perform 60s of total stretching time for each flexibility exercise.
Pattern	Repetition of each flexibility exercise two to four times is recommended. Flexibility exercise is most effective when the muscle is warmed through light to moderate aerobic activity or passively through external methods such as moist heat packs or hot baths.
Progression	Methods for optimal progression are unknown.
Neuromotor exercise training**	
Frequency	≥ 2–3 days/week is recommended.
Intensity	An effective intensity of neuromotor exercise has not been determined.
Time	≥20-30 min/day may be needed.
Type	Exercises involving motor skills (e.g., balance, agility, coordination, and gait), proprioceptive exercise training, and multifaceted activities (e.g., tai ji and yoga) are recommended for older persons to improve and maintain physical function and reduce falls in those at risk for falling. The effectiveness of neuromuscular exercise training in younger and middle-aged persons has not been established, but there is probable benefit.
Volume	The optimal volume (e.g., number of repetitions, intensity) is not known.
Pattern	The optimal pattern of performing neuromotor exercise is not known.
Progression	Methods for optimal progression are not known.

*ACSM : American College of Sports Medicine, AHA : American Heart Association, extracted from the ACSM Guidelines for Exercising Testing and Prescription, capter 1, p4 (15) ; **Extracted from ACSM position stand (2), Table 2, p1336; PA, physical activity, MET, metabolic equivalent of task; CHD, coronary heart disease; 1 RM, one-repetition maximum; PNF, proprioceptive neuromuscular facilitation.

Methods

The EULAR standardised operating procedures for the development of recommendations were followed (16). The AGREE II-instrument (17) was used to structure this manuscript.

The multidisciplinary TF consisted of a selection of 22 European PA-experts (six medical doctors, including three rheumatologists, one of them specialised in cardiovascular diseases, one GP, one orthopaedic surgeon; nine PTs, a psychologist, an OT, a nurse and a human movement scientist) and three patient representatives. A steering group managed the process (convenor KN, methodologist TVV, expert JB, fellow AR).

During the first TF meeting, definitions of exercise and PA were clarified and the TF agreed to follow the ACSM position stand (2). The TF agreed that RA and SpA as predominant iA conditions, and HOA/KOA as most relevant for PA recommendations would represent the field of iA and OA, respectively. Clinically relevant questions on the provision of advice and guidance regarding exercise and PA, from which 13 research questions were defined by consensus to guide the subsequent detailed systematic literature review (SLR) (online supplementary table S1).

Two SLRs were performed by AR with the support of two librarians and under the supervision of the convenor and methodologists. The questions were written according to the Population, Intervention, Comparison, Outcome (PICO) format (18), resulting in two PICOs: (1) on effectiveness, safety and feasibility of PA and (2) on facilitators and barriers towards PA (online supplementary table S2). For the first PICO, the fellow searched for key meta-analyses (MAs) or systematic reviews (SRs) including randomised controlled trials (RCTs) that investigated the effectiveness of PA-interventions in adults with RA/SpA/HOA/KOA. The SLR was performed in PubMed/Medline, Cochrane Library, Embase, Web of Science, Emcare and PsycInfo, using both MeSH terms and freetext, covering the time frame until 4/2017. For the second PICO, a SLR, covering the time frame until 7/2017, was performed in PubMed/Medline and Cochrane Library including qualitative studies if they described facilitators and barriers regarding PA (including exercise) in people with RA/SpA/HOA/KOA. Experts in the field of RA (EH), SpA (HD), OA (CJ) and behaviour change (KK), respectively, checked if all relevant titles and abstracts were included.

Based on the PICOs, the same author (AR) screened the titles and abstracts according to inclusion and exclusion criteria. Potentially relevant articles were identified and full text versions evaluated. Studies including adults (>18 years) with RA/SpA/HOA/KOA that included PA interventions that met the PH recommendations according to the ACSM principles (2) regarding frequency, intensity and duration for effective interventions were eligible for inclusion. All data extractions were checked by experts from the TF.

Studies measuring the effectiveness of PA-interventions were meta-analysed. These results and detailed descriptions of the methods are reported elsewhere (19). Studies were used for answering more than one research question if appropriate. For clinical studies evaluating the effectiveness of PA, the Cochrane Risk of Bias Assessment Tool was used to assess selection bias, performance bias, detection bias, attrition bias and reporting bias (20) by two independent assessors (AR, CH). An additional person (KN) helped to resolve any differences in rating between the assessors. The research evidence was categorised according to the Oxford levels of evidence (21).

During the second TF meeting, the results from the SLR were presented, and the experts developed 'overarching principles' (background statements to preface recommendations) and drafted 10 recommendations through an iterative process of discussion and consensus. After the meeting, the recommendations were collated and sent to the TF members by e-mail, to rate the level of agreement (LoA) independently and anonymously on a 0-10 point scale (0 =totally disagree, 10 =totally agree). Mean LoA >8 would be considered a 'high' LoA. Furthermore, the TF formulated a research agenda and education agenda based on identified gaps in the evidence.

Results

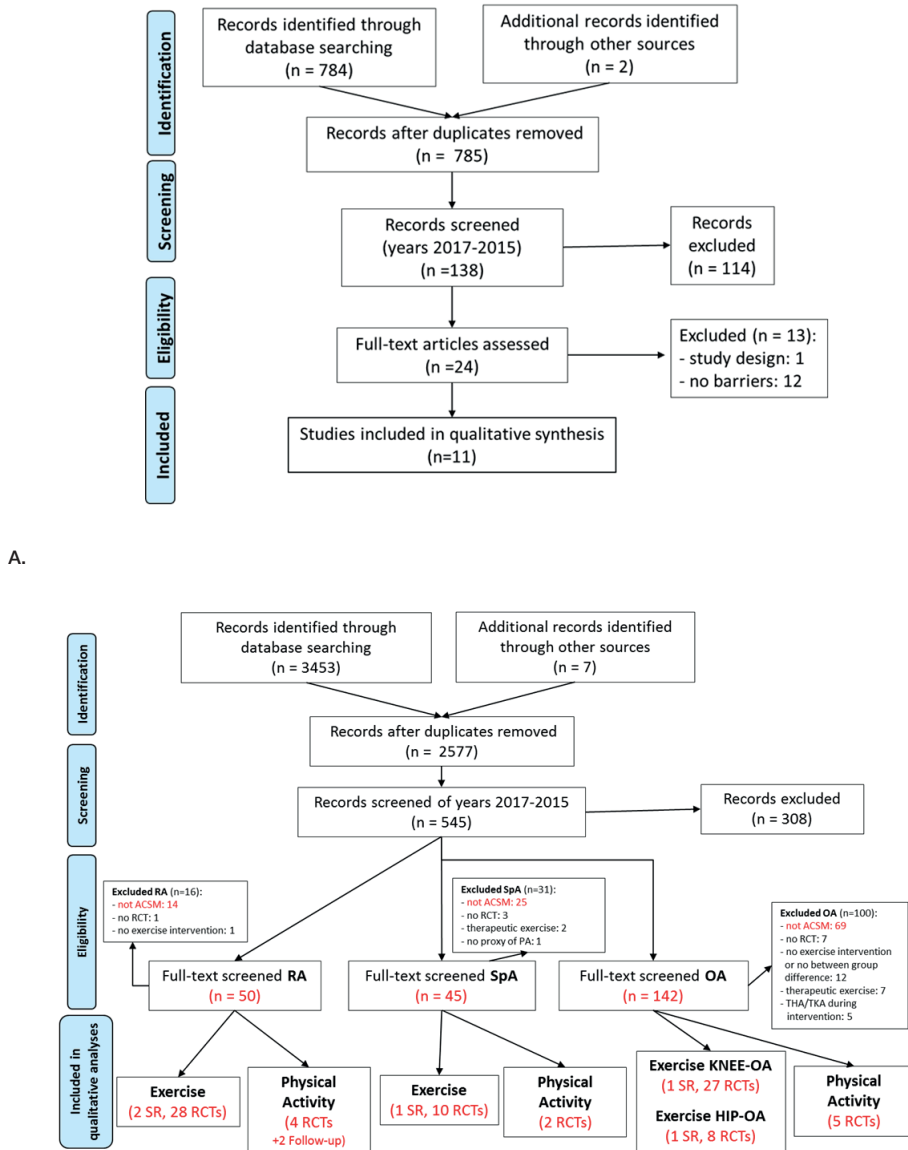
The search yielded 3471 references, 96 of which were included in the SLR: Four MA/SR (7, 22-24) and 66 RCTs (25-93) investigated the effects of exercise interventions, 11 RCTs (94-106) investigated the effects of a PA-promotion-intervention, 11 qualitative studies and literature reviews (3, 11, 107-115) described barriers and facilitators regarding PA (figure 1A, B). The included RCTs were published between 1985 and 2017. Most information is from studies with low (48%) or unclear (39%) risk of bias (online supplementary figure S1).

The TF agreed on four overarching principles and 10 recommendations for PA in people with RA/SpA/HOA/KOA based on SLR and expert opinion. High IoA was achieved for 9 out of 10 recommendations and 2 recommendations were graded as strength level A. Table 2 summarises the overarching principles and recommendations with their associated level of evidence, strength of recommendation and LoA.

Table 2 Recommendations for PA and exercise in people with inflammatory arthritis and OA

Overarching Principles			
1. PA is part of a general concept to optimize health related quality of life.			
2. PA has health benefits for people with RA/SpA/HOA/KOA.			
3. General PA recommendations, including the four domains (cardiorespiratory fitness, muscle strength, flexibility and neuromotor performance) are applicable (feasible and safe) to people with RA/SpA/HOA/KOA.			
4. The planning of PA requires a shared decision between health care providers and people with RA/SpA/HOA/KOA, which takes people's preferences, capabilities, and resources into account.			
Recommendations	Category of evidence	Strength of recommendation	Level of Agreement mean (SD) Median (Range)
1. Promoting PA consistent with general PA recommendations should be an integral part of standard care throughout the course of disease in people with RA/SpA/HOA/KOA.	1B	A	9.81 (0.39) 10 (9-10)
2. All health care providers involved in the management of people with RA/SpA/HOA/KOA should take responsibility for promoting PA, and should cooperate, including making necessary referrals, to ensure that people with RA/SpA/HOA/KOA receive appropriate PA-interventions.	4	D	9.14 (0.98) 9 (7-10)
3. PA interventions should be delivered by health care providers competent in their delivery to people with RA/SpA/HOA/KOA.	4	D	8.86 (1.48) 10 (5-10)
4. Health care providers should evaluate the type, intensity, frequency, and duration of the people's actual physical activity by means of standardized methods to identify which of the four domains of general PA recommendations can be targeted for improvement.	3	C	9.05 (1.04) 9 (6-10)
5. General and disease-specific contra-indications for PA should be identified and taken into account in the promotion of PA.	4	D	9.10 (1.41) 10 (5-10)
6. PA interventions should have clear personalized aims, which should be evaluated over time, preferably by use of a combination of subjective and objective measures (including self-monitoring when appropriate).	4	D	9.05 (1.25) 9 (5-10)
7. General and disease-specific barriers and facilitators related to performing PA, including knowledge, social support, symptom control, and self-regulation should be identified and addressed.	3	C	9.19 (1.13) 10 (6-10)
8. Where individual adaptations to general PA recommendations are needed, these should be based on a comprehensive assessment of physical, social and psychological factors including fatigue, pain, depression, and disease activity.	4	D	9.24 (0.86) 9 (7-10)
9. Health care providers should plan and deliver PA interventions that include the behavioural change techniques self-monitoring, goal setting, action planning, feedback and problem solving.	1A	A	9.48 (0.79) 10 (7-10)
10. Health care providers should consider different modes of delivery of PA (eg, supervised/not-supervised, individual/group, face-to-face/ online, booster strategies) in line with people's preferences.	4	D	9.00 (1.30) 9 (5-10)

RA, rheumatoid arthritis; SpA, Spondyloarthritis; HOA, hip osteoarthritis; KOA, knee osteoarthritis; OA, osteoarthritis; PA, physical activity



B.

Figure 1 Flowcharts of the literature search related to PICO_1 (A) and PICO_2 (B). ACSM, American College of Sports Medicine; OA, osteoarthritis; PA, physical activity; PICO, Population, Intervention, Comparison, Outcome; RA, rheumatoid arthritis; RCT, randomised controlled trial; SpA, spondyloarthritis; SR, systematic review.

Recommendation 1: PA as integral part of standard care

Given the evidence for effectiveness, feasibility and safety, the PH recommendations for PA are applicable, and thus, PA should be an integral part of standard care for people with RA/SpA/HOA/KOA. PA according to PH recommendations (2) is effective on PA level, physical fitness as well as disease-specific and general outcomes in people with RA/SpA/HOA/KOA (category I evidence (16)). Our MA including eleven RCTs (26, 35, 36, 42, 43, 50, 54, 56, 57, 61, 70) showed that cardiovascular exercises have a moderate beneficial effect on cardiovascular fitness (evaluated in VO₂ max) in all three conditions. Our MA including 25 RCTs (28, 31, 38, 39, 47, 49, 50, 62-66, 72, 75-78, 81-83, 85, 86, 88, 90, 91) showed that muscle strength exercises have a moderate beneficial effect for muscle strength in people with RA and HOA/KOA. Our MA including seven RCTs (52, 55, 58, 78, 88, 90, 116) showed that combined exercises (aerobic or strength exercises plus flexibility exercises) had no effect on flexibility in people with SpA or HOA/KOA. However, exercise conditions, assessments and outcome measures varied greatly. There is no study comparing the effect of flexibility exercises alone versus no exercises. In one RCT (48) the effect of a neuromotor-exercise programme on neuromotor performance was investigated in people with RA showing a positive effect. Eleven RCTs described the promotion of daily PA. Our MA including six RCTs (95, 98, 101, 102, 104, 117) applying BCTs for the counselling intervention showed a small beneficial effect.

Feasibility of interventions can be captured by adherence to the intervention or the study protocol (118). Adherence to interventions (number of sessions attended/total number of sessions) has been reported in 26 RCTs (35%) and the mean adherence was 69% in people with SpA, 71% in people with RA and 79% in people with HOA/KOA. However, the (self-) reported adherence to intervention might be over-estimated due to recall bias or social desirability. In 68 RCTs (94%) protocol violations were reported, with approximately 10% of these being disease-related or intervention-related.

PH recommendations for PA can be considered safe. No detrimental effects were reported, rather beneficial effects on disease activity and symptoms in iA (7). Forty-four percent of all included RCTs reported on adverse events (AE), of those 62% described no AE and 38% describe minor AE such as transitional exercise related joint or muscle pain.

Recommendation 2: Responsibility for PA promotion

All HCPs should have a responsibility for PA promotion and collaborative working that facilitate a close cooperation between different professions to support appropriate disease management. This statement was based on the finding that 66% of the included studies reported the profession of the HCP providing the intervention, of which 75% were PTs (25, 31, 36, 40, 44, 45, 48, 50, 53, 55, 58, 61, 64-66, 70, 73-79, 81, 84, 87, 88, 91, 94, 96, 101-105, 119, 120). However, the functions and responsibilities of HCPs vary across Europe (121, 122). Therefore, the TF agreed that PA advice should be provided by all HCPs.

Recommendation 3: Delivery of PA

The delivery of interventions should be performed by HCPs competent in the field of PA principles and rheumatic conditions. The reporting of training on PA guidelines was rare. One study (59) described a '4-hours education session on cardiovascular training', others described the instructing person as 'trained' (25, 50, 69, 70, 84, 88, 123) or 'experienced' (31, 49, 76, 77, 88). Some studies with focus on the promotion of daily PA described training sessions on behaviour change skills like Motivational Interviewing (94, 96, 104).

Recommendation 4: Evaluation of PA

The PA level (active or non-active) and the exercise domains (cardiorespiratory, muscle strength, flexibility and neuromotor) should be routinely assessed. Of 11 trials investigating the effect of PA promotion interventions, three RCTs (94, 96, 105) described baseline screening to distinguish between active and non-active persons before starting the tailored PA-intervention. Specific tools are needed to assess each domain (15)^{p 68}.

Recommendation 5: General and disease-specific contra-indications

Tools for specific contra-indications (CIs) were found (94, 15, 124), however, available general or national guidelines defining absolute or relative CIs should be followed as a priority.

Recommendation 6: Personalised aims and evaluation

The PA-interventions should be based on individual aims, which should be regularly evaluated. This can be done by PA assessments and any other assessments related to the individual aims. As PA assessments, performance-based tests, patient reported outcome-measures (eg, SQUASH (104), PASE (94)) and self-monitoring tools (eg, wearables such as Fitbit (100), pedometer (99) or accelerometer (101)) were identified. However, we did not evaluate the validity and reliability of the assessments applied.

Recommendation 7: General and disease-specific barriers and facilitators

General and disease-specific barriers (that are not CI per se) and facilitators should be addressed as described in 11 studies (11, 107-115, 125). Disease-specific barriers included lack of knowledge about the disease, lack of knowledge about safe exercising (both in people with iA/OA and HCPs,) and symptoms like pain, fatigue, stiffness, reduced mobility, fear of flare-ups or causing damage. Disease-specific facilitators included positive impact of exercise in symptoms or disease control, information about disease and correct exercising, the use medication for pain prior to exercising, using self-regulation techniques, supportive, but not controlling encouragement from HCPs and a supportive social background.

Recommendation 8: Individual adaptations to PA following individualised assessment

Adaptations to PA should be made on a comprehensive individual assessment. However, no evidence on the necessity of general adaptations in people with RA/SpA/HOA/KOA was found. In some RA studies the '24 hour-rule' was applied, that is, the exercise intensity was reduced when the increased pain persisted for more than 24 hours (23, 40, 50). ACSM

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provides adaptations to exercise testing in people with arthritis, (eg, no high-intensity testing if acute inflammation) and training such as exercising when pain is typically least severe or to train carefully in order to reduce risk of associated injuries, although no clear evidence that high-impact activities cannot be engaged during active inflammation (15)^{pp 298-301}. Individual disease-related barriers (eg, symptoms) may determine these adaptations.

Recommendation 9: Behaviour change techniques

BCTs should be an integral component of PA-interventions. Several behaviour change theories were used in PA promotion interventions in the field of RA and HOA/KOA (4, 126), but the reporting was poor. Future research based on theories in design, evaluation and interpretation of findings is needed.

A meta-analysis of six RCTs (94, 95, 98, 101, 102, 104) investigating the effects of a PA promotion intervention according to general PA recommendations (2) and based on counselling interventions that apply BCTs showed a small beneficial effect on PA level (19). Counselling interventions show a small beneficial effect if BCTs are applied (19).

Recommendation 10: Modes of delivery

HCPs should consider the whole range of modes to deliver interventions. No evidence on the superiority of specific delivery modes was found. The delivery modes of PA-interventions vary considerably and are mostly described as 'land-based and/ or water-based' and 'supervised and individualised', the latter usually applied to group settings. As booster strategies phone calls (36, 96, 98, 105), devices (eg, pedometer (98, 99), wearable (100, 101)), home visits (63, 70), log book (36, 51, 76, 98), web-based instructions (127), written material (51, 54, 103), visual instructions (eg, video (103)) were reported.

Research and education agendas

Based on the gaps identified in the literature, the TF discussed and proposed a research agenda (box 1) with the prioritised research topics and an education agenda (box 2) with topics for education and training in PA promotion for HCPs. Evidence on impact of (reducing) sedentary behaviour emerged as an important future research topic.

Box 1 Research agenda for physical activity (PA) in people with inflammatory arthritis and osteoarthritis

1. To evaluate the long-term effectiveness of PA at different intensities and types and monitoring of Adverse Events (AE).
2. To evaluate links between PA behaviour and disease-specific outcomes.
3. To evaluate the long-term effectiveness of sedentary behavior reduction, including the monitoring of AE.
4. To evaluate links between sedentary behavior and disease-specific outcomes.
5. To identify which PA-intervention strategies work best to increase PA level and adherence in various subgroups.
6. To identify markers of response and non-response to PA treatment.
7. To identify disease-specific contra-indications on different exercise domains (cardiovascular, strength, flexibility, neuromotor).
8. To further develop and evaluate strategies to reduce and monitor a change in sedentary behavior.
9. To develop PA-interventions targeting all exercise dimensions simultaneously with special focus on feasibility.
10. To evaluate and recommend valid PA assessments feasible for the use in clinical practice.
11. To study how to facilitate PA behavior change immediately from screening onwards and how to address facilitators and barriers.
12. To identify facilitators and barriers of health care providers towards applying the PA recommendations.
13. To perform long-term effectiveness trials on combined interventions including other health behaviours.

Box 2 Education agenda for physical activity (PA) in people with inflammatory arthritis and osteoarthritis

1. Increase knowledge about PA among health professionals (HPs), physicians and people with inflammatory arthritis and osteoarthritis.
2. Increase HPs' and physicians' skills in communicating the role of PA in managing general health and disease-specific issues.
3. Include knowledge and skills on PA promotion in all HPs' and physicians' undergraduate training curricula.
4. Develop a EULAR training module on PA for HPs and rheumatologists.
5. Propose a session on PA at every EULAR congress.
6. Develop education materials for people with inflammatory arthritis and osteoarthritis.

Discussion

The TF agreed on 4 overarching principles and 10 recommendations for PA in people with RA/SpA/HOA/KOA, which integrated the perspectives of the TF members from different professional, cultural and personal backgrounds. This led to a broad consensus on the principles and recommendations within the group and ought to foster its feasibility and practicability in the diverging health systems across Europe.

The LoA on the recommendations among the TF members was very high. The only exception was about the competency of HCP, which may be due to country specific differences in the availability of HCP competent in PA promotion.

Although the PH recommendations for PA are well established, the feasibility and applicability of these for people with iA and OA has not been assessed so far. Accordingly, the development of the recommendations was needed. Expectedly, they emphasise the importance of PA and will guide future PA-interventions in people with chronic rheumatic conditions.

PA promotion is a behavioural intervention and therefore BCT are central components in PA-interventions. Identifying effective and cost effective BCT within PA promotion intervention in people with chronic conditions is currently a hot topic in research and for example a research priority of the National Institute for Health and Care Excellence, UK (128).

We decided a priori to include only studies fulfilling the PH recommendations for PA according to ACSM principles (2). This was a far-reaching decision, which allowed drawing stronger conclusions on the effectiveness and especially the safety of correctly dosed PA-interventions. We followed a pragmatic search strategy with the plan to answer all RQs related to PICO 1 with findings of available SR/MA. However, there were no SR/MA on all exercise dimensions and all conditions available; this led to extracting single RCTs from high quality SR/ MA. This, however, excluded high-quality reviews (eg, Cochrane reviews) and RCTs that did not fulfil the ACSM principles and affected the potential to report 1A evidence according to Oxford levels of evidence (21). Furthermore, only one reviewer screened the abstracts and decided on unclear abstracts together with a second reviewer, which is not fully in line with standard procedures of a SR (129). However, we applied a double-check by experts to ensure that no relevant studies were missed.

A major problem for data extraction and interpretation was that the reporting of interventions in most studies was incomplete. Manuscripts that applied TIDieR (130) (Template for Intervention Description and Replication) guidelines reported more precisely the PA-interventions and substantially improved the objective evaluation of the PA-interventions. For the research questions related to the effectiveness and safety of PA-interventions and BCT the PICO scheme was applied, resulting in 1A level of evidence. All other research questions we had to answer in a descriptive way limiting the level of evidence to 3 to 4.

However, this limitation is due to the nature of the research questions. Nevertheless, the qualitative studies may provide valuable insight into important PA-related fields, such as assessments, barriers and facilitators, PA promotion strategies.

The recommendations focused on the conditions RA/SpA/HOA/KOA, the most prevalent RMD conditions to increase the generalisability and applicability of the recommendations. However, large heterogeneity between these conditions may limit the precision of the recommendations. Therefore, additional disease-specific recommendations are desirable. In addition, not all sub-conditions were considered and represented (eg, juvenile arthritis).

The research agenda highlights several areas where scientific evidence is lacking. It is a clear ambition to implement these recommendations into daily clinical routine. Due to the different health systems across Europe, development and evaluation of target group and culture-specific implementation strategies are needed and should involve all stakeholders.

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Contributions

AR and KN contributed equally. AR was the research fellow for the project, undertaking the SLR. The fellow was supervised by the steering group consisting of KN (convenor), TVV (methodologist), JB (expert). KN and TPMVV supervised the process of the SLR. KN organized and chaired the TF meetings. AR and KN drafted the manuscript with advice from TPMVV and JB. All authors have contributed to the recommendations by participating in the TF meetings; during discussion and agreement on the recommendations; revising and approving the manuscript for publication.

Competing interests

None

Additional files:

- Supplement 1: Research questions
- Supplement S2: PICOs
- Supplement S3: risk of bias assessment

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3

Effects of exercise and physical activity promotion: meta-analysis informing the 2018 EULAR recommendations for physical activity in people with rheumatoid arthritis, spondyloarthritis and hip/knee osteoarthritis

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Abstract

Objective

To evaluate the effectiveness of exercise and physical activity (PA) promotion on cardiovascular fitness, muscle strength, flexibility, neuromotor performance (eg, balance) and daily PA in people with rheumatoid arthritis (RA), spondyloarthritis (SpA) and hip/knee osteoarthritis (HOA/KOA).

Methods

Systematic review (SR) and meta-analysis (MA) were performed searching the databases PubMed/Medline, CENTRAL, Embase, Web of Science, Emcare, PsycInfo until April 2017. We included randomized controlled trials (RCTs) in adults (≥ 18 years) with RA, SpA and HOA/KOA, investigating the effects of exercise or PA promotion according to the public health PA recommendations by the American College of Sports Medicine. The time point of interest was the first assessment after the intervention period. If suitable, data were pooled in a MA using a random effects model presented as standardised mean difference (SMD).

Results

The SR included 63 RCTs, of which 49 (3909 people with RA/SpA/HOA/KOA) were included in the MA. Moderate effects were found of aerobic exercises and resistance training on cardiovascular fitness (SMD 0.56 (95% CI 0.38 to 0.75)) and muscle strength (SMD 0.54 (95% CI 0.35 to 0.72)), respectively, but no effect of combined strength/aerobic/flexibility exercises on flexibility (SMD 0.12 (95% CI -0.16 to 0.41)). PA promotion interventions produced a small increase in PA behaviour (SMD 0.21 (95% CI 0.03 to 0.38)).

Conclusion

Exercises and PA promotion according to public health recommendations for PA improved cardiovascular fitness, muscle strength, and PA behaviour, with moderate effect sizes in people with SpA, RA and HOA/KOA.

Trial registration number

CRD42017082131.

What is already known about this subject?

- There are public health recommendations for physical activity in healthy adults of all ages. Exercise is a cornerstone for the management of rheumatoid arthritis (RA), spondyloarthritis (SpA) and hip/knee osteoarthritis (HOA/KOA), but exercise interventions may not meet these recommendations.

What does this study add?

- Exercise interventions according to the public health recommendations in appropriate dose (frequency, intensity, time, type, volume, progression) is effective on cardiorespiratory fitness and muscle strength in people with RA, SpA and HOA/KOA.
- Counselling-based physical activity promotion interventions according to the public health recommendations effectively change physical activity behaviour in people with RA, SpA and HOA/KOA.
- There is a knowledge gap concerning the effects of flexibility and neuromotor exercises in people with RA, SpA and HOA/KOA.

How might this impact on clinical practice?

- Exercise and physical activity promotion according to the public health recommendations is effective and should be an integral part of standard care throughout the course of the disease in people with RA, SpA and HOA/KOA.

Introduction

Physical Activity (PA) is defined as 'any bodily movement produced by skeletal muscles that result in energy expenditure' (1, 2) above resting (basal) levels. PA encompasses exercise, sports and physical activities, done as part of daily living, occupation, leisure, and active transportation (3). Exercise is a subcategory of 'physical activity that is planned, structured, and repetitive and (that) has as a final or intermediate objective to improve or maintain one or more dimensions of physical fitness' (1). In contrast, therapeutic exercises are specific exercises meant to address particular functional health problems.

WHO recommends that adults, including elderly or people with chronic conditions, perform at least 150 min of moderate-intensity or 75 min of vigorous-intensity PA a week (or a combination of it) and additional muscle strengthening activities involving major muscle groups on at least 2 days a week (4). The American College of Sports Medicine (ACSM) recommends additional regular performance of flexibility and neuromotor activities such as balance or agility on at least 2 days a week (3). Accordingly, exercising in the four dimensions cardiovascular fitness, muscle strength, flexibility and neuromotor performance is recommended. The absolute energy demands of PA can be estimated by MET (metabolic equivalent of task) (5): PA like walking 5 km/h is described by 3.2 METs, which is classified as a moderate-intensity activity; PA like jogging 9 km/h is described by 8.8 METs. Following Garber and colleagues (3), the use of absolute measures may however be misleading because personal factors like weight, sex or fitness level are not considered. For this reason, a relative measure of intensity (ie, the energy costs relative to the individual maximal capacity) like %MET_{max}, %HR_{max} or perceived exertion are more appropriate. Moderate exercise is defined as 64 to 76% of the maximum heart rate (%HR_{max}), vigorous exercise is defined as 77% to 95 %HR_{max}. Furthermore, there is evidence that shorter (eg, 30 min) vigorous intensity (≥ 6 METs) of cardiovascular exercise is associated with a greater reduction of cardiovascular risk (6) and lower mortality rate in the general population (7) than longer (eg, 60 min) of moderate intensity (3-6 METs) cardiovascular exercise.

The dose-response relationship between daily PA and health benefits was proven; by exceeding the minimum recommended amount of PA, the results regarding improvement of fitness, reduction of risk factors of chronic conditions, and prevention of unhealthy weight gain are enhanced (3).

The evidence for the benefits of regular PA in healthy people is overwhelming (8, 9). The benefits of PA are obvious in people with rheumatoid arthritis (RA) (10), spondyloarthritis (SpA) (11) and hip/knee osteoarthritis (HOA/KOA) (12), and exercise is the cornerstone of the European League against Rheumatism (EULAR) recommendations for the non-pharmacological disease management of RA (13), axial SpA (14) and HOA/KOA (15). No specific recommendations on PA were available yet; therefore, in 2016, the EULAR project 'recommendations for PA in people with inflammatory arthritis and osteoarthritis' (16) was

started. The task force, developing the recommendations, agreed that RA and SpA as predominant inflammatory arthritis (iA) conditions, and HOA/KOA as most relevant for PA recommendations represented the field of iA and OA respectively. The resulting '2018 recommendations for PA' provide four overarching principles and 10 recommendations which suggest PA as an integral part of standard care throughout the course of disease in people with RA, SpA and HOA/KOA, given its effectiveness, safety and feasibility.

The recommendations for PA in people with RA, SpA and HOA/KOA may constitute a bridge between arthritis-specific exercises and public health recommendations for PA. They are also important because clinical practice shows that patients and clinicians may still believe that PA and exercising according to public health recommendations (3, 4) is potentially harmful and accelerate disease progression. Furthermore, the best strategy for the promotion of daily PA is still a matter of debate and a challenge for health professionals. However, there is evidence for the effectiveness of behaviour change techniques (BCTs) in PA promotion (17, 18).

The EULAR Standardized Operating Procedures (SOPs) for the development of recommendations (19) demand a systematic review (SR) of the literature with qualitative and if possible quantitative analysis, that is, a meta-analysis (MA), to inform the development of recommendations where appropriate. The aim of this paper is to report in detail on the MA that was performed to answer the question on the effectiveness of PA interventions in people with RA, SpA, HOA and KOA as basis for the EULAR PA recommendations.

This SR included only studies that met the dose for effective PA according to the public health recommendations for PA as provided by the ACSM for at least one dimension of exercise.

Methods

Design

This study was conducted following the Cochrane Guidelines (20) as requested by the EULAR SOP (19), and the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) analysis grid. The study was registered in PROSPERO (CRD42017082131; <https://www.crd.york.ac.uk/PROSPERO/>).

Selection Criteria

Included were randomised controlled trials (RCTs) on patients with RA, SpA and HOA or KOA, where the intervention of interest met the dose of the public health recommendations for effective PA as provided by ACSM for at least one dimension of exercise compared with any intervention not meeting the ACSM recommendations, such as low-dosed exercise, home exercises, attention control, usual care and waiting list. Further, for the inclusion in the SR, studies needed to investigate

- the effect of cardiovascular exercises on cardiovascular fitness,
or
- the effect of muscle strength exercise on lower limb muscle strength,
or
- the effect of flexibility exercises on flexibility,
or
- the effect or neuromotor exercise on neuromotor performance,
or
- the effect of a physical activity promotion strategy on the amount of daily PA in people with RA, SpA, HOA or KOA.

The MA involved those studies with the most frequently used proxy for cardiovascular fitness (eg, VO₂ max, watts both assessed on a treadmill/bicycle ergometer), muscle strength (of the lower limb like M.quadriceps femoris), flexibility (eg, passive/active range of motion (ROM), Bath Ankylosing Spondylitis Metrology Index) and PA (eg, questionnaire, accelerometer). The time point of interest was the first assessment after the intervention period.

Search strategy

Given the presumably high number of available literature, we chose a pragmatic approach: We first searched for key MA or SR including RCTs and, second updated the yield with recently published RCTs that investigated the effectiveness of PA interventions in adults with RA/SpA/HOA/KOA according to the inclusion criteria described before. The SR was performed in PubMed/Medline, Cochrane Library, Embase, Web of Science, Emcare, and PsycInfo, using both MeSH terms and freetext, covering the time frame until April 2017.

No language restrictions were applied. No additional search for grey literature or ongoing studies or unpublished data was conducted. Reference lists of included studies were scanned, and experts in the field of RA (EH), SpA (HD), HOA/KOA (CBJ), and behaviour change (KK) were consulted identifying relevant missing studies. The search strategy for Pubmed/Medline is provided in online supplementary file 1. A-KRO and KN screened firstly the abstracts of all identified records and secondly assessed full-text papers fulfilling the inclusion criteria.

Risk of bias Assessment

The risk of bias assessment included the methodological domains: random sequence generation (selection bias), allocation concealment (selection bias), blinding of participants (performance bias), blinding of outcome assessment (detection bias), incomplete data (attrition bias), selective bias (reporting bias,) and other potential bias. These criteria were judged as 'high risk', 'low risk' or 'unclear risk' as described by the Cochrane Handbook for Systematic Reviews of Interventions (20). Due to the vast number of studies included, we used a pragmatic approach. If a previous SR or MA had coded included studies for risk of bias, then these ratings were used here, after being spot-checked by the first author (A-KRO). When no previous review or meta-analyses had assessed risk of bias with the Cochrane risk of bias assessment tool, risk of bias rating was performed by two independent assessors (A-KRO, CH). If agreement was not achieved, a third review author (KN) made a final decision. Publication bias was investigated as small study bias and assessed by visual inspection of the funnel plot asymmetry.

Data extraction and management

The data extraction was performed by one reviewer (A-KRO) and verified by double reading (CBJ). In studies with more than one intervention group, the intervention groups were pooled if there were only small differences in the intervention (eg, walking or swimming as aerobic exercise intervention). Some authors were contacted to obtain unreported data.

Synthesis of data

Applying the PRISMA procedure, this MA focused on the quantitative analysis. The effects of PA on cardiovascular fitness, muscle strength and flexibility were calculated as the standardised mean difference (SMD), allowing for pooling the results of the various outcomes assessed in individual trials. The SMD was estimated as the difference between the postintervention scores in the intervention and control groups divided by the pooled SD. The SD was extracted or estimated from the SE, the 95% CI, the p value, IQR or other methods recommended by the Cochrane Collaboration (20). The SMD was clinically interpreted as originally proposed by Cohen (21). An SMD of 0.2 was considered small, an SMD of 0.5 was considered moderate (and would be recognised as clinically important) and an SMD equal to 0.8 was considered large (20). This estimate of the effect size is slightly biased, overestimating the effect size of small studies, and a correction factor was applied to convert the effect size to Hedges's *g*. Meta-analyses using a random-

effects model were applied. Heterogeneity was tested using the Q-test and was further quantified as the I^2 statistic (22) measuring the proportion of variation (ie, inconsistency) in the combined estimates due to between study variance (23). An I^2 value of <40% means low inconsistency between the results of individual trials, and an I^2 value of 100% means maximal inconsistency. All statistical analyses were performed in <stata V.15 (Stata Corp, College Station, Texas, USA).

Results

Study selection and study characteristics

The literature search revealed 3460 records; 237 of these were screened in full text (figure 1). A total of 174 studies were excluded due to unclear or insufficient dose ($n=117$), inappropriate study design ($n=11$), therapeutic exercise intervention ($n=9$), no between-group difference reported ($n=12$), joint replacement during intervention ($n=5$) and no appropriate outcome ($n=20$). The SR comprised 63 RCTs (11, 24-87) (two RCTs were reported by two papers each (33, 49, 78, 82)) published between 1985 and 2017, of which 49 RCTs were included in the MA. The sample size of these studies ranged from 16 to 222 participants; overall, a total of 3909 participants (mean age (SD) 56.2 (9.6) years) were included in the MA (1049 people with RA, 508 people with SpA, 1855 people with KOA and 497 people with HOA). The interventions lasted between 4 and 104 weeks and all studies assessed before and after the intervention. However, further assessment time points were heterogeneous; six studies (13%) performed one or several follow-ups, up to 29 months (37, 52, 54, 66, 81, 83). No detrimental effects of PA were reported in any study. Study characteristics of all studies included in the SR are provided in online supplementary table 1; interventions with assessments and outcomes are described in online supplementary tables 2-5.

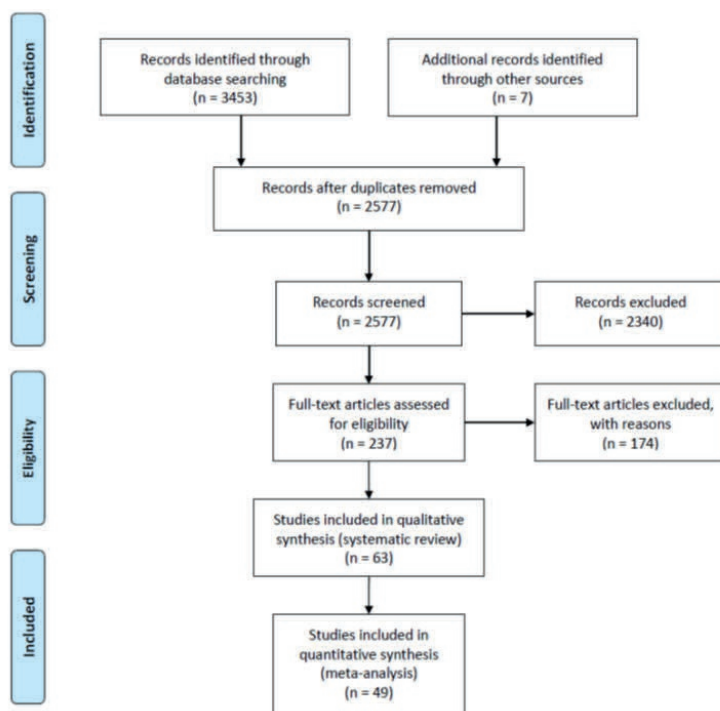


Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analysis flow chart describing the detailed selection process.

Risk of bias within studies

Online supplementary figures 6-10, describe the Cochrane risk of bias assessment. Ratings of 32 studies were adopted from existing SRs/MAs and spot-checked by the first author (12, 18, 88-90). The remaining articles were coded for risk of bias. Two RCTs were rated as low risk of bias for all items (30, 37). Randomization was performed according Cochrane criteria (20) in 44 (67%) RCTs. The allocation concealment was ensured in 31 (47%) RCTs. The blinding of participants was assured in 8 RCTs (12%), the blinding of the outcomes assessment in 30 (46%) RCTs. The risk of incomplete data was low in 49 (75%) RCTs. In 32 (48%) RCTs, a study protocol was available, with corresponding published data, resulting in a low risk for selective reporting.

Effects on cardiovascular fitness

Sixteen RCTs investigated the effect of aerobic exercise on cardiovascular fitness (online supplementary table 2), including 1326 participants with a mean (SD) age of 51.4 (7.2) years. The MA showed a moderate effect of SMD 0.56 (95% CI 0.38 to 0.75) (figure 2). The overall heterogeneity of study effects was moderate ($I^2=42.2\%$); the funnel plot (online supplementary figure 11) showed an asymmetry, indicating a risk of small study bias.

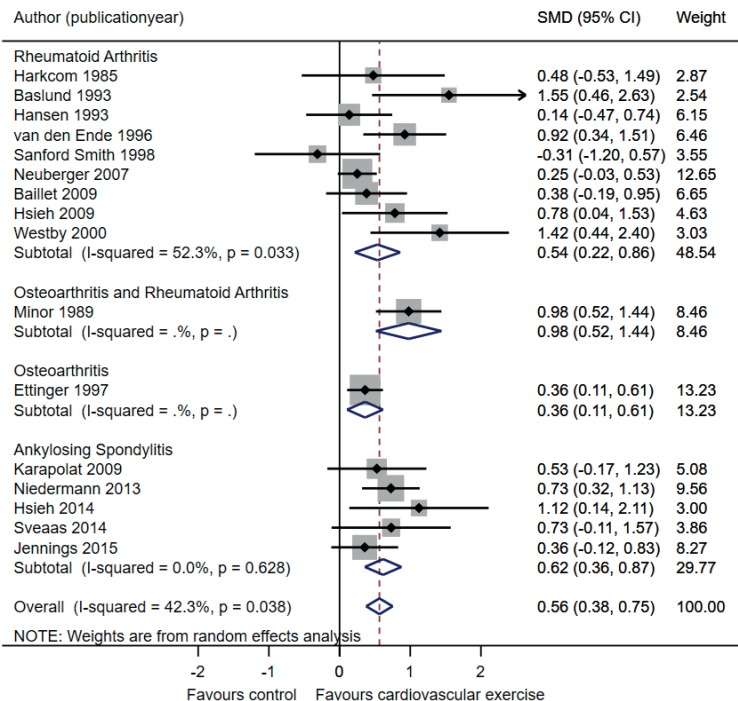


Figure 2. Forest plot showing the results of the meta-analysis on the effect of aerobic exercise on measured on VO₂max in people with rheumatoid arthritis, spondyloarthritis and hip/knee osteoarthritis. SMD, standardised mean difference.

Effects on muscle strength

Thirty-one RCTs investigated the effect of muscle strength exercises on lower limb muscle strength in people with RA or HOA/KOA (online supplementary table 3), of which 28 provided data on M.quadriceps femoris strength. The measurement (60°/sec, 90°/sec) and units (Nm, kp, kg, N, S/kg) varied between the studies; therefore, analyses were performed on SMD. Three RCTs were not included as they reported data in median and range(43, 75, 91). Although these data could be recalculated into mean and SD, this may lead to imprecise data given the small sample sizes in these studies. If strength was described for both legs, values for the affected leg/joint were included in the analysis. If strength was measured in different positions, the velocity of 60°/sec was preferred for the MA. Twenty-five RCTs, including 936 participants with a mean (SD) age of 61.5 (5.0) years, were included in the MA, which showed a moderate effect of muscle strength exercise on M.quadriceps femoris strength with a SMD 0.54 (95% CI 0.35 to 0.72; figure 3) with substantial heterogeneity ($I^2=67\%$). The funnel plot shows minor asymmetry for both RA and HOA/KOA (online supplementary figure 12), thus the analyses might slightly overestimate the effect for both RA and HOA/KOA.

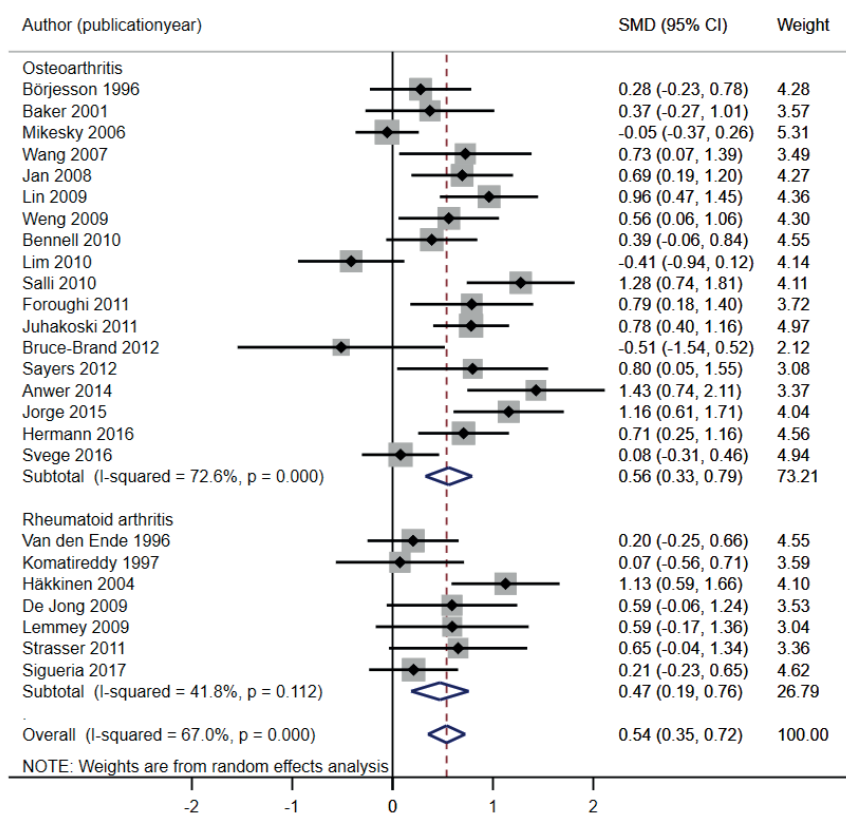


Figure 3. Forest plot showing the results of the meta-analysis on the effect of strength exercise on M.quadriceps femoris in people with rheumatoid arthritis and hip/knee osteoarthritis. SMD, standardised mean difference.

Effects on flexibility

Eight RCTs investigated the effect of flexibility exercises (ROM, stretching) combined with strength or aerobic exercises compared with no exercise or usual care, and measured the effect on ROM (passive or active) or the Bath Ankylosing Spondylitis Mobility Index. One RCT was not included in the MA as data was presented as median and range (71). None of the RCTs compared flexibility exercises alone with no exercises (online supplementary table 4). The MA of the seven RCTs, including 477 participants with a mean (SD) age of 49.3 (15.2) years, showed no effect of the exercise combination on flexibility either for RA or HOA/KOA showing an overall SMD 0.12 (95%CI, -0.16 to 0.41) (figure 4). The overall heterogeneity of study effects was moderate ($I^2=31.1\%$). Publication bias was not evaluated, due to the sparse number of included studies, especially when stratifying on patient group (HOA/KOA and SpA) in the MA (20).

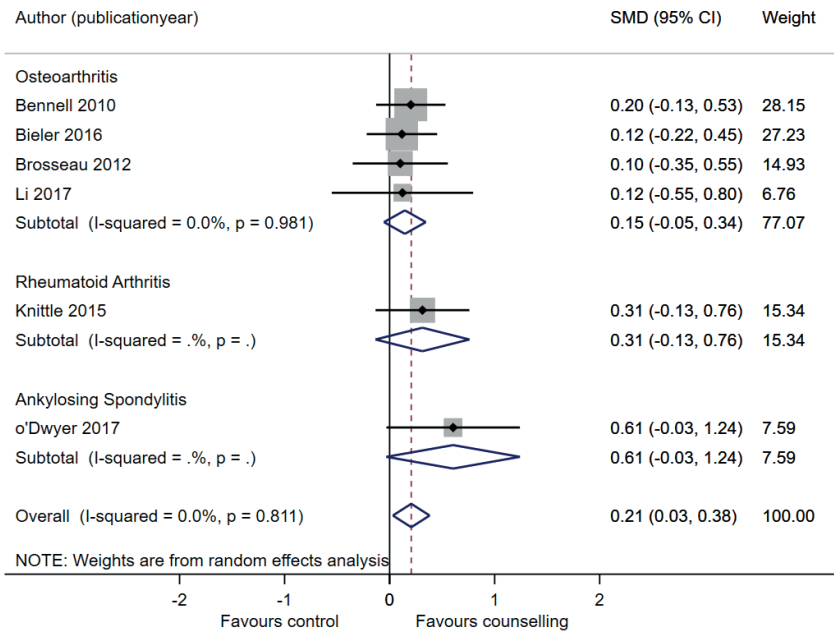


Figure 4. Forest plot showing the results of the meta-analysis on the effect of flexibility exercises combined with strength or aerobic exercises on flexibility in people with ankylosing spondylitis and hip/knee osteoarthritis. Flexibility was measured as active or passive range of motion, and using the Bath Ankylosing Spondylitis Mobility Index (BASMI). SMD, standardised mean difference.

Effects on neuromotor performance

Studies evaluating neuromotor performance were scarce. Da Silva and colleagues (36) showed that a 16-weeks neuromotor exercise programme had a statistically positive effect in neuromotor performance in 91 people with RA, evaluated with Berg Balance Scale, Tinetti Test and Timed-Up-and-Go Test. Four RCTs in people with KOA who performed

strength exercises, evaluated neuromotor performance with the step test for standing balance, reposition error of the knee, Berg Balance Scale and one leg standing time with eyes open. Two RCTs showed a positive effect (63, 92), two found no effect (74, 93). Røgind and colleagues (71) investigated the effect of a programme combining strength, stretching, mobility and balance exercises on postural sway, but found no effects.

Effects on daily PA

Eleven RCTs investigated the effect of a daily PA promotion intervention on daily PA (online supplementary table 5) evaluated by accelerometer or questionnaire. In six RCTs, counselling based on BCTs was an essential component of the intervention (30, 31, 34, 58, 61, 69). Three RCTs did not include a counselling strategy as part of the intervention (46, 56, 70) and two studies described data with percentages (33, 49, 78, 82) and were therefore excluded from the analysis. The MA of the six studies, including 694 participants with a mean (SD) age of 59.5 (9.5) years, showed a small effect SMD 0.21 (95%CI 0.03 to 0.38) (figure 5) with no heterogeneity (0%) and no small study bias (online supplementary figures 13).

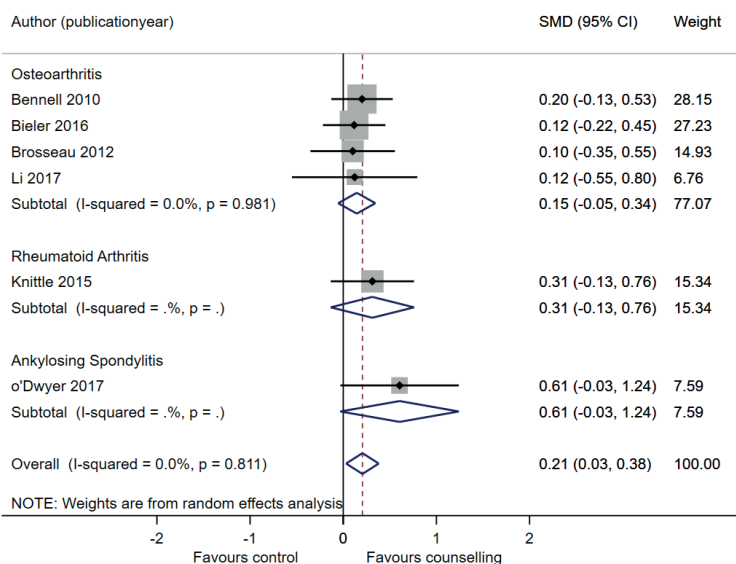


Figure 5. Forest plot showing the results of the meta-analysis on the effect of physical activity promotion strategies including counselling. SMD, standardised mean difference.

Discussion

The four MAs overall included 49 studies with 1049 people with RA, 508 people with SpA, 497 people with HOA and 1855 people with KOA. Moderate short-term effects of aerobic and muscle strength exercises on cardiovascular fitness and muscle strength in people with RA, SpA and HOA/KOA were shown. No studies on flexibility exercises alone were found, whereas flexibility exercises combined with muscle strength or aerobic exercise had no effect on flexibility. PA had no detrimental side effects like increased disease activity in any exercise dimension. PA promotion with counselling based on BCTs showed a small beneficial effect on daily PA which has been shown to be a strong mediator for further health benefits (8, 9). However, this MA did not evaluate the effects of increased daily PA on health benefits. Overall, this MA confirms the increasing evidence for the multiple benefits of exercise in people with RA, SpA and HOA/KOA, and indicates that PA promotion interventions can increase daily PA within these individuals.

In this MA, we reported the effectiveness estimates for each PA dimension over the three conditions based on the effectiveness data available in the primary studies. Exercise interventions are effective if they achieve a physiological response, such as increased flexibility, muscular strength and cardiovascular fitness, which is determined by the right intervention in its right dose, as well as patient adherence (94). Only seven RCTs, included in the MA (13%), reported (minor) adverse events related to exercise like transient increased pain (30, 38, 65, 77, 81, 85, 92). Our findings regarding the safety of exercise and PA promotion interventions are in line with the literature (3). Even a small to moderate beneficial effect of exercise on joint damage, inflammation and symptoms (pain, stiffness, joint tenderness) was found (89). Bischoff and Roos (95) showed that aerobic and strength exercise was equally effective regarding pain and function in people with HOA/KOA. Indeed, the effectiveness of interventions cannot be appraised without taking account to feasibility. The feasibility of interventions can be evaluated by adherence to the intervention or the study protocol (reported as attendance rate). However, (self-)reported adherence to intervention might be overestimated due to recall bias or social desirability (96). For aerobic exercise interventions, 75% of the MA-included studies reported an attendance rate varying between 48 and 100%; for muscle strength exercises, 60% of the MA-included studies reported an attendance rate between 49 and 96%. Attendance rate tends to decline over time (38, 42), the compliance between those with supervised and home-exercises seems to vary (47, 60). This information underlines that a low compliance rate is one of the most compelling challenges for exercise and PA interventions. Long-term adherence implies a change in lifestyle, which can be supported by interventions based on BCTs (18, 97).

This MA was based on studies that followed the public health recommendation for PA according to ACSM (3) and thus achieved the minimal dose for effective PA interventions. The ACSM (98) provide clear recommendations regarding frequency and type of exercise in people with arthritis. Cardiovascular training was performed with no-impact sports like (Nordic) walking

(68), dance (86), cycling (76) or water-based (48) exercising. The recommended intensity varies from moderate to vigorous (3), but also high intensity training up to 90% of the predicted maximal heart rate or 80% one-repetition-movement appears to be effective and feasible in people with RA (60, 83, 99). Flexibility exercises were performed as usual care or combined part of the intervention. Most included studies investigated (semi-) supervised exercise interventions. 'Booster strategies' like phone calls (33, 34, 47, 82), devices (eg, pedometer (34, 46), wearable (56, 61)), home visits (27, 38), log book (34, 47, 86, 100), web-based instructions (49), written material (48, 70, 86), visual instructions (eg, video (70)) were reported. The interventions were always provided by physiotherapists, except in three studies (pilates trainer (24), physician (76), physiatrist (80)). Only if adherence to the FITT-VP components of the intervention (frequency, intensity, time, type, volume, and progression of exercise) is given and reported the best possible training effect can be achieved and the individual goal on physical performance level can be reached (101). The initiation and maintenance of PA are both challenging and meet different general and disease-specific barriers and facilitators (102-105). This highlights the need for further development in promising strategies, such as BCTs for the promotion of a long-term active lifestyle in people with RA, SpA and HOA/KOA. However, starting and maintaining regular exercise in all four dimensions is difficult, even for healthy people. Therefore, it is important to pinpoint that the public health recommendations for PA (3) state that exercise below the recommended levels may still be beneficial for people not able or not willing to fulfil the recommended amount of PA.

Strengths and Limitations

To our knowledge, this is the first MA gathering the current evidence on the effectiveness of exercising according to the ACSM principles (3) with regard to the dimensions and dose for exercise in the three rheumatic conditions RA, SpA and HOA/KOA. The aim of this MA was to evaluate the overall effect of exercise and PA promotion, and we do not have evidence to suspect heterogeneity in treatment response among these conditions. However, a disease-specific analysis could be beneficial.

The vast variability of used assessments and scales led us to indirect comparisons. Our analysis illustrates that a consensus on assessments in the field of PA could help to launch more research with comparative outcomes and findings. Gates and colleagues (106) described a consensus how to facilitate the comparison of data between heterogeneous studies in research on PA in HOA/KOA. One of the important points was to decide on MET minutes per week as a key method to assess daily PA and defined minimal requirements for future studies. Being aware of the indirect comparisons, the analyses were a good basis for the task force to decide on PA recommendations for people with RA, SpA and HOA/KOA. More studies with a larger number of participants and similar assessments are needed to clearly decide on the long-term effects of exercise, as the overall aim of PA promotion is a change in long-term lifestyle. Long-term supervised exercises seem to be more effective than short-term exercises (88, 107); however, the intervention duration and setting was not part of this analysis.

It is a limitation that only one reviewer screened the abstracts and decided on unclear abstracts together with a second reviewer, which is not fully in line with standard procedures of a SR (108). However, we applied a double check by experts to ensure that no relevant studies were missed.

Conclusion/clinical implication

Physical activity according to public health recommendations following the ACSM principles (3) show moderate effectiveness on cardiorespiratory and muscle strength as well as PA promotion interventions based on counselling in people with RA, SpA and HOA/KOA. No evidence was found for the effects of flexibility exercises and almost no literature was available evaluating neuromotor exercises. Many studies had to be excluded due to poor reporting on the intervention. Future studies should use the TIDieR-checklist (109) (Template for Intervention Description and Replication) or CERT (110) (Consensus on Exercise Reporting Template) to improve completeness of reporting. This will enable clinicians to implement effective interventions and researchers to replicate or merge findings.

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Contributions

A-KRO performed the SR and data extraction, supervised by KN and TPVV. JS developed the search strategy for all databases. CBJ double-checked data and performed the meta-analysis. A-KRO and KN drafted the manuscript. All authors of this manuscript were members of the EULAR Task Force, except JS, who developed the recommendations for physical activity in people with inflammatory arthritis and osteoarthritis. They revised this manuscript and approved the final version for publication.

Competing interests

None

Additional Files:

- Supplement 1: Search strategy
- Supplement 2: Table study characteristics
- Supplement 3: Risk of bias assessment (one document providing legends, Figs 6-10 separately)
- Supplement 4: Tables 2-5 with description of interventions
- Supplement 5: Funnel plots (Figures 11-13)
- Supplement 6: PRISMA checklist

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4

The perspective of people with axial spondyloarthritis regarding physiotherapy: room for the implementation of a more active approach

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Abstract

Objectives

Physiotherapy is recommended in the management of people with axial spondyloarthritis (axSpA), with new insights into its preferred content and dosage evolving. The aim of this study was to describe the use and preferences regarding individual and group physiotherapy among people with axSpA.

Methods

A cross-sectional survey was conducted among people with axSpA living in The Netherlands (NL) and Switzerland (CH).

Results

Seven hundred and thirteen people with axSpA participated (56.7% male, median age 55 years, median Assessment of Spondyloarthritis International Society Health Index score 4.2). Response rates were 45% ($n=206$) in NL and 29% in CH ($n=507$). Of these participants, 83.3% of participants were using or had been using physiotherapy. Individual therapy only was used or had been used by 36.7%, a combination of individual plus land- and water-based group therapy by 29.1% and group therapy by only 5.3%. Fewer than half of the participants attending individual therapy reported active therapy (such as aerobic, muscle strength and flexibility exercises). Although the majority (75.9%) were not aware of the increased cardiovascular risk, participants showed an interest in cardiovascular training, either individually or in a supervised setting. If supervised, a majority, in CH (75.0%) more than in NL (55.7%), preferred supervision by a specialized physiotherapist.

Conclusions

The majority of people with axSpA use or have used physiotherapy, more often in an individual setting than in a group setting. The content of individual therapy should be more active; in both therapy settings, aerobic exercises should be promoted. In particular, enabling people with axSpA to perform exercises independently would meet their needs and might enhance their daily physical activity.

key messages:

- The large majority of people with axSpA uses physiotherapy.
- Individual physiotherapy in people with axSpA consists of mainly passive modalities.
- Many people with axSpA are unaware of increased cardiovascular risk but interested in aerobic exercise.

Introduction

Axial spondyloarthritis (axSpA) is a chronic, inflammatory rheumatic disease that affects the sacroiliac joints and spine, leading to structural and activity limitations (1). The prevalence in the general population is about 0.1-0.6% according to European disease prevalence data (2, 3). AxSpA affects male and female equally (1:1 ratio) (4). Disease onset usually is in the early adulthood (5), and therefore axSpA has a large impact on working ability and personal and societal costs are high (6, 7).

Drug treatment and physiotherapy, in particular exercise therapy, are the cornerstones of the appropriate management of the disease (1, 8). Especially the fact that people with axSpA have an increased risk of cardiovascular diseases (9), and evidence showing that axSpA affects flexibility (10), balance (11), muscle strength (12), and cardio-respiratory capacity (13) emphasize the need of exercise. In this respect it is important to underline that exercise is a subset of physical activity, and defined as 'planned, structured and repetitive [activity, that] has as a final or intermediate objective, the improvement or maintenance of one or more dimensions of physical activity' (14, 15). Therapeutic exercises are individual and/or disease specific, meant to improve or restore function or to prevent dysfunction.

Regarding exercise, a Cochrane systematic literature review (10) showed that exercise interventions have an effect on spinal mobility and physical function, with the most favourable results being seen with supervised group exercise. None of the 11 included studies in that systematic literature review reported harm as a result of exercising. Based on this evidence, exercise is generally recommended in professional guidelines, with the type (aerobic, muscle strengthening and flexibility), and the preferred mode of delivery [supervised, group exercise therapy (GET)] being defined (1, 16, 17). Recently, EULAR published recommendations on physical activity emphasizing the importance of adequate composition and dosage of activities according to American College of Sports Medicine (ACSM) principles (15) throughout the course of disease (18). Indeed, individual and GET meeting the frequencies, intensity, time, type, volume, progression (FITT-VP) principles described by ACSM (15) was shown to be effective in people with axSpA, by having a positive impact on disease activity, joint damage and cardiovascular risk factors (19-21). In addition, a number of trials investigated the effectiveness of cardiovascular training on disease activity and cardiovascular fitness (20-22). Despite these insights, in research and daily practice exercise may not meet the requirements described in the guidelines. It was found that only a small proportion of GET evaluated in clinical trials met the ACSM recommendations for flexibility, muscle strength or aerobic exercise capacity (23). Moreover, a small survey revealed that physiotherapists providing GET in Switzerland did not include elements of aerobic training in an adequate dose during the training sessions in people with axSpA (K.N., unpublished data). Apart from insufficient delivery, some patients may not exercise at all. The literature on barriers and facilitators to engage in exercise in patients with axSpA is, however, scanty (24).

Internationally, there are currently activities going on to develop an implementation strategy to optimize the usage and delivery of physiotherapy and exercise.

Therefore, we aimed to make an inventory of use, experiences, and preferences of people with axSpA regarding the delivery of individual physiotherapy and GET. As usage, content and preferences regarding physiotherapy may however vary among countries, the inventory was carried out in two countries, The Netherlands (NL) and Switzerland (CH).

Methods

Design and setting

This cross-sectional survey was conducted among people with axSpA living in the western region of NL and the German-speaking part of CH. The findings are reported in line with the STrengthening the Reporting of OBservational studies in Epidemiology (STROBE) guidelines (26). The study obtained ethical approval from the Leiden University Hospital Ethical committee (P14.326) and Ethics committee Canton Zurich (KEK-ZH-71-2015).

In both countries, NL and CH, supervised exercise therapy can be offered on an individual or group basis. The latter is usually water and/or land based, offered once a week, supervised by a physiotherapist, and yields an important social factor (26).

The amount of refund for both individual and group therapy differs between the two countries, because health insurance systems are different. In NL, direct access to physiotherapy was introduced in 2006, and most health-care insurers reimburse direct access therapy. However, axSpA GET is currently not reimbursed in NL. In CH, health-care insurers reimburse physiotherapy, including axSpA group exercise, but only if it is induced by a referral. In both countries, but based on different systems, patients have to pay an obligatory financial contribution. In both countries, health-care insurers have expressed the need for a proof of the effectiveness of exercise therapy.

Participants

Dutch patients

Four hundred and fifty-eight people with a confirmed diagnosis of axSpA who had visited the rheumatology outpatient clinic in the past 12 months were identified from the registries of three hospitals in The Netherlands: Leiden University Medical Center, Haga Teaching Hospital, The Hague, and Reinier de Graaf Gasthuis, Delft. Eligible patients received an invitation letter from their treating rheumatologist, an information leaflet, a paper survey and a pre-stamped envelope by regular mail. Returned questionnaires were scanned and analysed with the software Cardiff Software (CA, USA). No reminders were sent.

Swiss patients

All 1742 German-speaking members of the Schweizerische Vereinigung Morbus Bechterew (SVMB) were invited by e-mail to complete an online survey (by use of SurveyMonkey) or a paper version. Representatives of SVMB, a rheumatologist and a researcher signed the invitation. Electronic data were collected with the Internet Protocol (IP) address inactive to preserve anonymity, and all paper questionnaires were collected by the SVMB and forwarded as anonymized versions for data analysis. No reminders were sent.

Assessments

Survey on exercise use and preferences

The survey was self-developed in Dutch by a team of researchers and, at a later stage, translated into German. The survey consisted of dichotomous- or multiple-choice questions, multiple-answer options (MAOs) and some with a free text field ('other'-option). The survey consisted of the following parts:

- Demographic and clinical information: age, sex, disease duration (in years) and use of medication (pain medication, NSAIDs, DMARDs, biologicals or no drugs; MAO).
- Use of Individual physiotherapy: usage (if ever/currently; if, frequency, duration, and way of referral) and contents of physiotherapy (active and passive exercises, home exercises, hydrotherapy, education, massage, thermotherapy, kinesiotaping, electrotherapy, US, dry needling, relaxation techniques either individual or group setting; by MAO). In addition, if patients had used physiotherapy but stopped, the reasons for stopping were queried (too hard, more complaints, motivation, no positive effect, too time consuming or no refund; by MAO); Unfortunately, in the online survey for the Swiss population, the option describing the content of the individual therapy as 'I perform exercises meant to strengthen my muscles by using my own weight or free weights or machines' vanished owing to a technical problem, which led to a bias (in this case, data collection is based on the free text field option).
- Use of group physiotherapy: usage of land-based or water-based GET (ever/currently/no; frequency and duration) and, if patients had stopped it, the reasons were queried (too hard, more discomfort, motivation, no positive effect, too time consuming or no refund; by MAO).
- Patients' motivation and preferences regarding exercises: willingness/ability to exercising individually, knowledge of how to exercise without supervision, way of interaction with supervisor [e.g., (in)direct, via technology, group], preferred frequency and duration of organized activity (by MOA).

Health status

In addition, the Assessment of Spondyloarthritis International Society Health Index (ASAS HI) was included. The self-reported questionnaire evaluates 17 aspects of function and health and 9 environmental factors in patients with SpA, providing a score on the individuals' health status (27, 28). The lower the score, the better the 'functioning' (29).

Data analysis

Demographic and disease-specific data were presented as the mean and S.D. or median and associated range for continuous data or as frequencies (percentages) for categorical variables. To compare the characteristics of Dutch and Swiss patients, Student's unpaired t-tests or Mann-Whitney U-tests were used where appropriate for continuous data, and Chi Square or Fischer's exact tests for categorical data. In addition, logistic regression models with nationality as an independent variable were fitted to the data, adjusting for the effect

of age, sex, disease duration, DMARD use and current health status. For some of these analyses, some levels of the dependent variable were grouped: current or past treatment by a physiotherapist combined to 'yes' vs 'no treatment'; current or past use of GET combined to 'yes' vs 'no'; referred by rheumatologist or referred by general practitioner combined to 'referral by doctor' vs 'direct access'; duration of treatment >5 years and 1- 5 years combined to '1year+' versus <6 months and 6 months-1 year combined to '<1year'; frequency of individual therapy < once per week and once per week combined to 'once' versus twice or 3times and more per week combined to 'twice+'.

The parameters of the logistic regression models are log odds ratios (LOR): $\log O_{NL} / O_{CH} = \log O_{NL} - \log O_{CH}$ for the event given by the second level of the outcome variable, mostly 'yes'. We reported the exponentiated values (odds ratios).

The level of significance was set at $\alpha = 0.05$. The R language and environment for statistical computing (<http://www.Rproject.org>, 2018) was used for the statistical analyses.

Results

Demographics

In total, 713 people participated; 206 in NL (response rate 45%) and 507 in CH (response rate 29%; 0.5% used paper version). Approximately 57% of participants were male, with a median (range) disease duration of 16 (1-65) years and median (range) ASAS-HI score of 4.2 (0-14.2). The Dutch cohort was statistically different with regard to sex, age, disease duration, ASAS-HI score and the use of pain medication (Table 1).

Table 1. Characteristics of Dutch and Swiss people with axial spondyloarthritis participating in a survey on physiotherapy

Characteristic	Total (n=713)	NL (n=206)	CH (n=507)	p-value*
Sex, male, n (%)	404 (56.7)	142 (69.3)	262 (51.7)	<0.001
Age, years, median (range)	55.0 (21-94)	58.0 (24-94)	53.5 (21-85)	<0.001
Disease duration, years, median (range)	16 (1-65)	24 (1-58)	13 (1-65)	<0.001
Current drug treatment				
Pain medication (e.g. paracetamol), n (%)	206 (29.0)	82 (39.8)	124 (24.5)	<0.001
Anti-inflammatory pain medication				
(NSAIDs), n (%)	424 (59.5)	125 (60.7)	300 (59.2)	0.73
DMARDs, n (%)	103 (14.7)	25 (12.1)	78 (15.4)	0.26
Biologic, n (%)	270 (38.0)	81 (39.3)	189 (37.3)	0.61
No axSpA-related drugs, n (%)	94 (13.3)	16 (7.8)	78 (15.4)	0.06
ASAS Health Index, median (range)	4.2 (0-14.9)	5.7 (0-14.9)	4.3 (0-14.9)	<0.001

Abbreviations: NL=The Netherlands, CH=Switzerland, ASAS= Assessment of Spondyloarthritis International Society, NSAIDs= Nonsteroidal anti-inflammatory drugs, DMARDs= Disease modifying anti-rheumatic drug, axSpA= axial Spondyloarthritis. *p-value of Chi Square or Mann-Whitney U-Test.

More than one-third (36.7%) of participants had or had been using individual physiotherapy but never attended a GET, 29.1% had used or had been using a combination of individual plus land- or water-based GET, and 5.3% had used or had been using land- and water-based GET only (see Table 2).

Use of individual physiotherapy

In total, 83.3% of the patients were currently or had been treated by a physiotherapist individually (1:1) (Table 3). Direct access to physiotherapy was used by 17.1%. However, the chance of being referred to physiotherapy by a general practitioner or rheumatologist, in contrast to going on ones' own initiative, was 2.7 times higher in Switzerland than in NL (adjusted odds ratio 2.74, 95% CI 1.57,4.83) (Table 3).

Regarding individual physiotherapy content (Table 3) most participants receive a combination of active (70.4%) or (assisted) passive (75.2%) flexibility interventions, massage (53.6%), and instructions of home exercises (67.7%).

Table 2. Use of individual and group exercise therapy by people with axial spondyloarthritis

Setting	Total n=713 No (%)	NL n=205 ^a No (%)	CH n=506 ^a No (%)
Individual therapy only	262 (36.7)	102 (49.7)	160 (31.6)
GET only			
- Land-based GET only	14 (1.9)	3 (1.4)	11 (2.1)
- Water-based GET only	3 (0.4)	0 (0)	3 (0.5)
- combination land- and water-based GET	38 (5.3)	5 (2.4)	33 (6.5)
Combination of individual and GET			
- Combination individual with land-based GET	105 (14.7)	32 (15.6)	73 (14.4)
- Combination individual with water-based GET	19 (2.6)	9 (4.3)	10 (1.9)
- Combination individual with land and water-based GET	208 (29.1)	37 (18.0)	171 (33.7)
Never used any kind of therapy	62 (8.6)	17 (8.8)	45 (8.8)

GET= group exercise therapy, NL= the Netherlands, CH= Switzerland, ^aone individual did not answer those questions

Table 3. Use and content of individual physiotherapy by Dutch and Swiss people with axial spondyloarthritis

	Total	NL	CH	p-value*	Adjusted odds ratio (95% CI)
Current or past individual physiotherapy treatment	n=713 No (%)	n=206 No (%)	n=507 No (%)	yes vs. no	yes vs. no
• Currently	233 (32.6)	90 (43.7)	143 (28.2)	0.07	1.41 (0.86-2.39)
• In the past	362 (50.7)	90 (43.7)	272 (53.6)		
• Never	118 (16.5)	26 (12.0)	92 (18.1)		
Referral	n=437 No (%)	n=169 No (%)	n=268 No (%)	Direct vs. referral	
• Direct access	75 (17.1)	44 (26.0)	31 (11.6)	<0.001	2.74 (1.57-4.83)
• Referral by GP	130 (29.7)	32 (18.9)	98 (36.6)		
• Referral by rheumatologist or rheumatology nurse specialist	226 (51.7)	89 (52.7)	137 (51.1)		
• Other	6 (1.3)	4 (3.4)	2 (0.7)		
Duration of treatment	n=232 No (%)	n=89 No (%)	n=143 No (%)	<1y vs. 1y+	
• >5 years	132 (56.8)	67 (75.2)	65 (45.5)	0.06	0.57 (0.23-1.34)
• 1-5 years	63 (27.1)	13 (14.6)	50 (34.8)		
• 6 months- 1 year	11 (4.7)	4 (4.4)	7 (4.9)		
• < 6 months	26 (11.2)	5 (5.6)	21 (14.7)		
Frequency	n=230 No (%)	n= 89 No (%)	n=141 No (%)	≤once vs. twice+	
• < 1 per week	99 (43.0)	45 (50.5)	54 (38.3)	0.08	0.58 (0.31-1.06)
• Once per week	106 (46.0)	31 (34.8)	75 (53.2)		
• Twice per week	23 (10.0)	13 (14.6)	10 (7.1)		
• Three times or more per week	2 (0.8)	0 (0)	2 (1.4)		
Content	n=598 No (%)	n=180 No (%)	n=418 No (%)		
<i>Education</i>					
Education on coping with limitations	128 (21.4)	60 (33.3)	68 (16.3)	<0.001	2.11 (1.35-3.27)
Education on sports and physical activity	206 (34.4)	72 (40.0)	134 (32.0)	0.13	1.4 (0.99-2.19)

Table 3. Continued

	Total	NL	CH	p-value*	Adjusted odds ratio (95% CI)
Instruction on home exercises	405 (67.7)	121 (67.2)	284 (67.9)	0.51	0.87 (0.58-1.30)
<i>Exercises</i>					
Cardiovascular (Aerobic) exercises	105 (17.5)	40 (22.2)	65 (15.6)	0.08	1.26 (0.77-2.03)
Muscle strengthening exercises	262 (43.8)	76 (42.2)	186 (44.5)	0.93	0.83 (0.56-1.22)
Active range of motion / flexibility exercises	275 (70.4)	70 (38.8)	205 (49.0)	0.01	0.58 (0.39-0.85)
Balance exercises	94 (15.7)	31 (17.2)	63 (15.0)	0.62	1.09 (0.64-1.83)
Relaxation exercises	21 (3.5)	6 (3.3)	15 (3.6)	1.00	0.94 (0.32-2.45)
Passive range of motion exercises	262 (43.8)	99 (55.0)	163 (38.9)	0.00	2.13 (1.45-3.15)
Passive assisted range of motion exercises	188 (31.4)	54 (30.0)	134 (32.0)	0.50	0.98 (0.65-1.46)
<i>Other physiotherapy treatment</i>					
Heat treatment	126 (21.0)	17 (9.4)	109 (26.0)	<0.001	0.28 (0.15-0.49)
Cold treatment	13 (2.1)	3 (1.6)	10 (2.4)	0.76	0.61 (0.13-2.10)
Massage	321 (53.6)	90 (50.0)	231 (55.3)	0.11	0.80 (0.55-1.18)
Kinesiotaping	64 (10.7)	3 (1.6)	61 (15.1)	<0.001	0.14 (0.03-0.41)
US	97 (16.2)	33 (18.3)	64 (15.3)	0.47	1.19 (0.71-1.97)
Dry needling	29 (4.8)	6 (3.3)	23 (5.5)	0.30	0.67 (0.23-1.65)
Reasons for stopping (if applicable)	n=362	n= 90	n=272		
	No (%)	No (%)	No (%)		
• Not necessary anymore	73 (20.1)	16 (17.8)	57 (20.9)	0.64	0.70 (0.37-1.25)
• Being able to do the exercises at home	202 (55.8)	52 (57.7)	150 (55.1)	0.10	0.80 (0.53-1.20)
• No perceived effect	75 (20.7)	17 (18.8)	58 (21.3)	0.65	0.66 (0.34-1.23)
• More discomfort	37 (10.2)	12 (13.3)	25 (9.1)	0.32	1.04 (0.456-2.247)
• Inadequate reimbursement (any more)	65 (17.9)	17 (18.8)	48 (17.6)	1.00	0.897 (0.46-1.65)
• Other	59 (16.2)	13 (14.4)	46 (16.9)	0.40	0.41 (0.19-0.80)

NL= the Netherlands, CH= Switzerland, n= numbers, MC=multiple choice, GP = general practitioner, GET=group exercise therapy, *p-value of Mann Whitney U, Chi Square or Fischer Exact tests

Use of land- or water-based GET

Participants usually met once a week (median 4 times a month) for 60 min land-based or 45 min for water-based exercise. The most frequent reason for discontinuation was ‘too time consuming’ (22.5% for land-based and 22% for water-based GET; Table 4).

Table 4. Use and content of land- or water-based group exercise therapy by Dutch and Swiss patients with axial spondyloarthritis

	Total	NL	CH	p-value*	Adjusted odds ratio (95% CI)
Land-Based GET					
Current or past land-based GET	n=712	n=205	n =507	Yes vs. no	Yes vs. no
	No (%)	No (%)	No (%)		
• Currently	171 (24.0)	18 (8.8)	153 (30.2)	<0.001	0.28 (0.18-0.42)
• In the past	193 (27.1)	59 (28.8)	134 (26.4)		
• Never	348 (48.8)	128 (62.4)	220 (43.4)		
Frequency per months (n)	n=168	n=18	n=150		
Median (range)	4 (1-10)	4 (1-4)	4 (1-10)	0.95	n.c.

Table 4. Continued

	Total	NL	CH	p-value*	Adjusted odds ratio (95% CI)
Duration of session (minutes)	n=170	n=18	n=152		
Median (range)	60 (0-150)	90 (30-150)	60 (20-90)	<0.001	n.c.
Reasons for stopping (if applicable, MC)	n=191	n=57	n=134		
	No (%)	No (%)	No (%)		
• Too hard	28 (14.6)	17 (29.8)	11 (8.0)	<0.001	3.60 (1.42-9.36)
• More discomfort	22 (11.5)	8 (14.0%)	14 (10.3)	0.62	1.28 (0.42-3.63)
• No motivation	37 (19.3)	12 (21.0)	25 (18.4)	0.84	0.94 (0.39-2.12)
• No perceived effect	34 (17.8)	10 (17.5)	24 (17.6)	0.83	0.69 (0.26-1.69)
• Too time consuming	43 (22.5)	10 (17.5)	33 (24.3)	0.25	0.92 (0.36-2.19)
• Inadequate reimbursement (any more)	10 (5.2)	8 (14.0)	2 (1.5)	<0.001	13.48 (2.00-157.03)
Water-based GET					
Current or past water-based GET?	n=712	n=205	n=507	yes vs. no	yes vs. no
	No (%)	No (%)	No (%)		
• currently	117 (16.4)	16 (7.8)	101 (19.9)	<0.001	0.28 (0.18-0.43)
• in the past	150 (21.0)	34 (16.6)	116 (22.8)		
• never	445 (62.5)	155 (75.6)	290 (57.2)		
Frequency per months (n)	n=114	n=14	n=100		
Median (range)	4 (1-10)	4 (1-8)	4 (1-10)	0.05	n.c.
Duration of session (minutes)	n= 116	n=16	n=100		
Median (range)	45 (20-135)	45 (30-135)	45 (20-90)	0.38	n.c.
Reasons for stopping water-based GET (if applicable, MC)	n=150	n=34	n=116		
	No (%)	No (%)	No (%)		
• Too hard	17 (11.3)	9 (26.5)	8 (6.8)	<0.001	9.27 (2.57-39.09)
• More discomfort	12 (8.0)	4 (11.7)	8 (6.8)	0.47	2.16 (0.32-13.53)
• No motivation	26 (17.3)	8 (23.5)	18 (15.4)	0.29	2.22 (0.76-6.31)
• No perceived effect	25 (16.6)	11 (32.3)	14 (11.9)	<0.001	3.10 (1.09-8.77)
• Too time consuming	33 (22.0)	6 (17.6)	27 (23.0)	0.63	0.81 (0.24-2.36)
• Inadequate reimbursement (any more)	10 (6.6)	5 (14.7)	5 (4.3)	0.04	2.27 (0.42-10.64)

NL=The Netherlands, CH= Switzerland, n= numbers, GET=group exercise therapy, MC=multiple choice, n.c.= not calculated; *p-value of Mann Whitney U, Chi Square or Fischer Exact tests

Participants' motivation and preferences regarding exercise

A large proportion of participants (75.9%) were not aware of the extra risk of cardiovascular disease and osteoporosis caused by axSpA (see Table 5). However, more than two-thirds of the participants were motivated to carry out exercises to improve fitness (82.7%; see Table 5). Reasons for being unwilling or unable to exercise were 'I don't feel like it' (44.8%) for being unwilling and 'I get more discomfort' (72%) for being unable (*please Supplementary Table S1, available at Rheumatology advances in Practice online*).

The proportion of the participants who felt self-responsible and able to conduct an unsupervised program themselves was 42.4%. Of those participants preferring supervised exercising, 28% liked having an individual programme with face-to-face supervision by a

physiotherapist (see Table 5). Two-thirds of the participants (67.9%) preferred the supervising physiotherapist to be specialized in axSpA (see Table 5), with significantly more Swiss than Dutch participants finding this important. In contrast, 20.2% preferred exercising in a regular fitness club without specialized supervision. The ideal organized exercising setting would take place once per week, for a duration of about 1h, in the evening, but not at weekends (Table 5).

Table 5. Preferences of people with axial spondyloarthritis for content and design of education and exercise

Knowledge about disease and exercise	Total	NL	CH	p-value*	Adjusted odds ratio (95% CI)
Knowledge how to get information on axSpA	n=651 No (%)	n=153 No (%)	n=498 No (%)		
yes	574 (88.1)	121 (79.0)	453 (90.3)	<0.001	n.c.
no	77 (11.8)	32 (20.9)	45 (9.0)		
Awareness of extra risk of cardiovascular diseases and osteoporosis	n=708 No (%)	n=201 No (%)	n= 507 No (%)		
yes	161 (22.7)	60 (29.8)	101 (21.7)	0.025	n.c.
no	538 (75.9)	141 (70.1)	397 (78.3)		
Willingness to improve fitness	n=704 No (%)	n=197 No (%)	n=507 No (%)		
No	49 (6.9)	29 (14.7)	20 (3.9)	<0.001	n.c.
Yes, but not able to	72 (10.2)	33 (16.8)	39 (7.7)		
Yes, I do my best already	416 (59.0)	93 (47.2)	323 (63.7)		
Yes	167 (23.7)	42 (21.3)	125 (24.7)		
Preferences for delivery of unsupervised or supervised exercising? (Multiple-Answer-Option)					
Unsupervised exercises preferred (MC)	n=685 No (%)	n=199 No (%)	n=486 No (%)		
General instructions via leaflet or website	128 (18.6)	37 (18.5)	91 (18.7)	0.99	1.05 (0.66-1.66)
General instructions via DVD or APP	130 (18.9)	34 (17.0)	96 (19.7)	0.84	1.01 (0.62-1.59)
Personalized program	250 (36.4)	50 (25.1)	200 (41.1)	<0.001	0.62 (0.41-0.91)
Personal program with guidance by an expert by email, Internet or app	102 (14.8)	20 (10.0)	82 (16.8)	0.02	0.70 (0.39-1.21)
I am self-responsible and able to conduct an unsupervised exercise program	291 (42.4)	71 (35.6)	220 (45.2)	0.02	0.74 (0.51-1.06)
Supervised exercise preferred (MC)	n=670 No (%)	n=190 No (%)	n=480 No (%)		
Individual exercise programme with face-to-face supervision by PT	188 (28.0)	35 (18.4)	153 (31.2)	<0.001	0.60 (0.38-0.92)
Individual exercise with internet-based guidance (e.g. webcam)	57 (8.5)	6 (3.1)	51 (10.6)	<0.001	0.32 (0.12-0.72)
Group exercise program for axSpA patients	233 (34.7)	36 (18.9)	197 (41.0)	<0.001	0.34 (0.22-0.52)
Regular sport activities (sport club or fitness center) supervised by sports instructor	136 (20.2)	26 (13.6)	110 (22.9)	<0.001	0.54 (0.32-0.87)
Duration per session	n=445 No (%)	n= 90 No (%)	N=355 No (%)		
• <1h	47 (10.3)	11 (12.2)	36 (10.1)	n.c.	n.c.
• 1h	313 (70.3)	50 (55.5)	263 (74.0)		
• 1.5h	61 (13.7)	17 (18.9)	44 (12.4)		
• >1.5h	24 (5.3)	12 (13.3)	12 (3.3)		

Table 5. Continued

Knowledge about disease and exercise	Total	NL	CH	p-value*	Adjusted odds ratio (95% CI)
Frequency per week	n=440 No (%)	n= 85 No (%)	n=355 No (%)		
• Once	239 (54.3)	42 (49.4)	197 (55.5)	n.c.	n.c.
• Twice	151 (34.3)	34 (40.0)	117 (32.9)		
• 3 times	50 (11.3)	7 (8.2)	43 (12.1)		
• >3 times	9 (2.0)	2 (2.3)	7 (1.9)		
Time of the day	n=503 No (%)	n=84 No (%)	n= 419 No (%)		
• Morning	138 (27.4)	27 (32.1)	111 (25.9)	n. c.	n.c.
• Afternoon	61 (12.1)	12 (14.3)	49 (11.4)		
• Evening	241 (47.9)	35 (41.7)	206 (48.0)		
• Does not matter	73 (14.5)	10 (11.9)	63 (14.7)		
During Weekends	n=440 No (%)	n=84 No (%)	n= 356 No (%)		
• Yes	123 (27.9)	27 (32.1)	96 (26.9)	n.c.	n.c.
• No	239 (54.3)	50 (59.5)	189 (53.1)		
• I don't know	78 (17.7)	7 (1.2)	71 (19.9)		
Supervisor should be expert in..	n=439 No (%)	n=85 No (%)	n =354 No (%)		
• Sports	76 (17.3)	24 (28.2)	52 (14.7)	<0.001	n.c.
• Bone and joints	115 (26.1)	29 (34.1)	86 (24.3)	0.07	n.c.
• Bone and joints and rheumatic diseases	368 (83.8)	62 (72.9)	306 (86.4)	<0.001	n.c.
How important is that supervising PT is expert specifically in axSpA?	n=515 No (%)	n=159 No (%)	n=356 No (%)		
• (Very) important	350 (67.9)	83 (55.7)	267 (75.0)	<0.001	0.43 (0.28-0.67)
• Not important	165 (32.0)	76 (44.3)	89 (25.0)		

axSpA: axial spondyloarthritis; CH: Switzerland; MC: multiple choice; n.c.: not calculated; NL: The Netherlands. *p-value of Mann Whitney U, Chi Square or Fischer Exact tests, n.c.= not calculated, PT= physiotherapist

Discussion

This survey among a sample of people with axSpA found that physiotherapy was frequently used, in both individual and GET settings. Individual therapy, mostly initiated by doctoral referral, was more often used than GET. The patients in this study seemed to be motivated to exercise in either a supervised or non-supervised, individually tailored programme; for both settings, the majority of patients found that guidance by a specialist would be required. Currently, individual therapy seemed to be based on passive interventions combined with instructions for (home) exercises. If active interventions were included in the therapy sessions, which appeared to be the case in <50%, mainly muscle strengthening and flexibility exercises were used; aerobic exercises and balance exercises, which are also recommended for people with axSpA (18), were less often promoted. Counselling or advice seemed to play only a subsidiary role.

Recently, a Dutch guideline specific for physiotherapy in axSpA was launched (30) but given that this guideline is only available in Dutch, physiotherapists may work according to international general management recommendations for axSpA (1, 17, 31-33) and use experiences from other rheumatic conditions like OA (34) or RA (35). Some axSpA guidelines clearly state that active therapy is more effective than passive therapy (16) whereas RA recommendations state that passive interventions may be considered for only a limited period (35). Physiotherapy interventions with therapeutic exercises or exercise training should be structured, i.e., incorporating goals, a treatment plan, and regular assessments (36). The patients' needs and preferences and the presence of facilitators and barriers regarding exercising should be taken into account (18). Known facilitators are higher education level, belief in the benefits of exercise, and intrinsic motivation, whereas barriers are being physically inactive, fatigue, lack of time or tiring exercises (37). Therefore, priority should be given to patients' preferences in exercise choice and conditions. A Cochrane review evaluated the effect of physiotherapeutic interventions for axSpA showed that GET was superior home exercise (10). Moreover, a group setting was found to foster adherence to exercising (17). Indeed, the social aspect of GET is well-known ('moving with friends') and was also appreciated by the Dutch and Swiss participants in the survey. However, group therapy in NL was not as often attended as in CH (8.8% vs 30.2% were currently attending GET) with the numbers and sizes of the groups declining, and people in the groups ageing (oral communication). These observations could imply that in the future we need to find alternative modes to obtain the added effect of exercising in a group, e.g., by web-based physiotherapy (38) and establishment of digital communities. But costs must also be considered, because GET was not being refunded fully for many Dutch patients, or its availability was limited, unlike the situation in CH.

Irrespective of the mode of delivery, it should be ensured that the intervention is not underdosed according to ACSM principles (15). It must be emphasized that exercising once per week, i.e. usual frequency of group exercise interventions, is not enough to fulfil the

public health recommendations for physical activity. In this respect, it is noteworthy that two-thirds of the participants from both countries were not aware that regular exercising might help to reduce the extra risk of cardiovascular diseases. Although aerobic exercise is highly recommended (39), this was part of the individual physiotherapeutic intervention in only 17.5% in our study. Unfortunately, we do not know the extent to which aerobic training was performed during GET, despite the fact that this setting is ideal to promote aerobic exercises. With respect to balance exercises, these were reported by only 15.7% of patients, although people with axSpA more often have impaired balance compared with healthy controls and a higher risk of falls (11, 40).

Overall, our data underscore that the traditional focus on strength and flexibility exercises still dominates the physiotherapeutic interventions for people with axSpA and that consideration of cardiovascular and neuromotor exercises should be emphasized. Recalling the aforementioned multiplicity of physical activity recommendations, we believe that people with axSpA need more guidance to fulfil every aspect (i.e. cardiovascular, muscle strength, balance, and flexibility training). Future physiotherapy interventions should be based on physical activity recommendations in addition to patients' needs.

Regarding the patient perspective on the delivery of exercise interventions in axSpA in both countries, 67.9% of the sample thought that it is 'important' and 'very important' that the supervising physiotherapist is specialized in their condition (i.e. a specialization in rheumatic conditions/axSpA was more valued than a specialization in sports). This finding clearly underpins the need for the specialized physiotherapist.

A large proportion of the people participating in the survey in both countries signalled awareness of self-responsibility to exercise, in particular in a non-supervised setting but with tailored instructions. It should also be noted that 42.4% preferred unsupervised (non-GET setting) exercise. This need requires interventions to counsel and help a patient managing axSpA 'from a distance'. For this purpose, physiotherapists' knowledge and skills regarding counselling strategies and long-term exercise promotion need to be evaluated and, presumably, improved. Findings showed that 21% of the Dutch and 9% of the Swiss population surveyed did not know how to find information about their condition (Table 5). Physiotherapists also bear responsibility in providing information and support in disease management.

Limitations

This study has a number of limitations. One limitation was that the selection of patients was different in NL and CH, which might explain some of the differences observed between the two groups. Another limitation was that the survey questionnaire was self-developed, and we did not ask for the content of group exercise interventions, because it was assumed that standard programmes would be used.

In addition, the process of data collection differed between countries (i.e. paper vs online-survey and one question being posted differently). Nevertheless, we believe a comparison between the two nations is still useful to appraise common and different issues.

Concerning the reported differences between NL and CH in terms of the use and preferences of people with axSpA related to exercising, the comparisons were adjusted for potential confounders, such as differences in case mix or settings. However, we cannot rule out the possibility that there were other factors influencing the observed differences in habits and attitudes towards exercising.

Further research should assess the perspective of physiotherapists of the content and structure of interventions in people with axSpA. Guidelines for the physiotherapeutic management of people with axSpA, including recommendations on (long-term) exercise promotion, in addition to an implementation strategy for both nations, are needed urgently.

Conclusions

Exercises are a commonly used intervention in people with axSpA, in both the individual and the group setting. There is an international need for implementing active exercises at appropriate doses, especially with more focus on cardiovascular exercising in the individual or GET setting. Our findings may help to develop further the patient-centred services independent of insurance systems. In particular, enabling people with axSpA to perform exercises independently would meet their needs and might enhance their daily physical activity.

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Authors' contributions:

F.G. and T.P.M.V.V. initiated the project. F.G. developed the questionnaire BEVER and edited the Dutch data. A.-K.R.O. translated the questionnaire to German, edited the Swiss data and performed the data analysis. B.W. organised the data collection in Switzerland, F.A.G., Y.P.M.G.-R and A.J.P. organized the data collection in the Netherlands. T.P.M.V.V. and K.N. were involved in the study conceptualisation and supervised the study process. A.M. conducted the logistic regression analyses. A.-K.R.O. drafted the manuscript, but all authors reviewed it, provided comments on each draft and approved the final version.

Conflict of interest

The authors declare no conflict of interest.

Additional Files:

- Supplementary Table S1: Reasons of people with axSpA for not being able or willing to exercise

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5

Understanding beliefs related to
physical activity in people living with
axial spondyloarthritis
- a theory-informed qualitative study

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Abstract

Background

People living with axial spondyloarthritis (axSpA) have an increased risk of cardiovascular diseases, which can be reduced by regular physical activity (PA) and its subset of cardiorespiratory training (CRT). To fulfil their crucial role in PA promotion, physiotherapists and other health professionals need to understand the beliefs that people living with axSpA possess concerning general PA and CRT. The aim of this study is to explore these behavioural, normative and control beliefs.

Methods

A qualitative descriptive design approach was chosen. Five semi-structured focus group interviews with 24 individuals living with axSpA were performed. Data was analysed using structured thematic qualitative content analysis.

Results

People with axSpA possessed multifaceted behavioural, normative and control beliefs concerning general PA and CRT. Behavioural beliefs revealed a positive attitude towards general PA, with participants mentioning numerous physical, psychological, and social benefits and only few risks. However, the conceptual difference between general PA and CRT, and the relevance of CRT, was unclear to some participants. Normative beliefs were expressed as the beliefs of significant others that influenced their motivation to comply with such beliefs, e.g. spouses, other people living with axSpA, rheumatologists. Regarding control beliefs, general PA and CRT were both mentioned as effective self-management strategies to control the disease. From experience, a high level of self-discipline, as well as technology, were shown to be useful.

Conclusions

General PA is understood to be an important self-management strategy for people with axSpA and most participants build general PA into their daily routines. They believe that general PA beneficially impacts personal health and wellbeing. However, some participants are unaware of the difference between general PA and CRT and the important impact that this difference could have on their health. The consequences of CRT promotion for people living with axSpA should be the subject of further research.

Introduction

Axial Spondyloarthritis (axSpA) is a chronic, inflammatory rheumatic disease that leads to structural impairments and functional limitations (1). AxSpA increases the risk of cardiovascular diseases (2, 3) and has an impact on flexibility (4), balance (5), muscle strength (6) and cardio-respiratory capacity (7).

As the cornerstones of disease management, exercise and effective drug treatment are recommended (1, 8). Correspondingly, the EULAR (European Alliance of Association for Rheumatology) physical activity (PA) recommendations for individuals with rheumatic and musculoskeletal diseases (RMDs) (9) strongly emphasize the importance of PA promotion. Evidence shows that exercising, according to the public health recommendations for health-enhancing PA, is effective, safe, and feasible for individuals with RMDs (10), and that it should be performed throughout the course of the disease (9). Exercise, particularly cardio-respiratory training (CRT), can be effective medicine reducing cardiovascular risk when the dose, i.e. intensity, duration and frequency, is adequately applied (11-14). Current disease management recommendations state that patients should be continuously integrated into exercise programs, rather than taking rest or inactive periods during or after a flare up (9, 15).

Despite existing evidence, individuals with axSpA are often physically active at low-to-moderate intensity levels and spend less time performing vigorous PA than healthy people (16, 17). In Switzerland, although 88% of individuals with axSpA are willing to improve their fitness, almost 80% are unaware of the increased risk of cardiovascular diseases (18). The best facilitator of general PA is to build intrinsic motivation, guided by enjoyment and personal interest (19). The most commonly reported barriers to general PA are disease-specific symptoms, notably fatigue and pain (20). Previous research has shown that the most frequent facilitators, particularly to CRT, are knowledge, homogenous group composition, and high perceived motivation. Contrarily, the most frequent barriers to CRT are lack of motivation or information, hindering disease symptoms, and problem of timing in the daily routine (21).

The EULAR recommendations on PA state that all health professionals should provide advice on PA, however, interventions should be delivered by health professionals competent in PA principles and RMDs (9). Physiotherapists (PTs) are experts in PA promotion (22) and support people with RMDs to live an active lifestyle and exercise at a correct dose. PTs need to be precise in their instructions and use clear definitions and terms to achieve this. There is a difference between the concepts of being 'physically active' and 'exercising' (23), which often becomes blurred in communication with patients. Inconsistencies arise through the over-reporting or under-reporting of behavioural activity because the understanding of terms varies between the individuals involved (23).

PA is defined as, 'any bodily movement produced by skeletal muscles that results in energy expenditure above resting levels. PA broadly encompasses exercise, sports, and physical activities done as part of daily living, occupation, leisure, and active transportation' (24). Exercise is a subcategory of 'PA that is planned, structured, and repetitive and [that] has, as a final or intermediate objective, the improvement or maintenance of one or more dimensions of physical fitness' (25). Public health recommendations for health-enhancing PA encompass four exercise dimensions (aerobic, strength, neuromotor, flexibility) (24).

Numerous theoretical models have been applied that aim to change PA behaviour in people with RMDs (26, 27). Changes in awareness, beliefs, attitudes, motivation or knowledge may influence our PA behaviour. These psychological constructs are not open to direct observation, but models, such as the Theory of Planned Behaviour (TPB), support research in this field. The TPB has been used widely in research on PA behaviour (see Figure 1). It postulates that behaviour (e.g. PA) depends on intention (motivation) and ability (behavioural control) (28). In this respect, three constructs are relevant: (1) attitude toward the behaviour (a function of behavioural beliefs), defined as 'the psychological tendency that is expressed by evaluating a particular entity with some degree of favour or disfavour'; (2) subjective norm (arising from normative beliefs), defined as 'the beliefs of significant others and the extent that one wishes to comply with such beliefs of [other] people'; (3) perceived behavioural control (a function of control beliefs), which is 'the perceived ease or difficulty of performing behaviour' and is assumed 'to reflect past experience as well as anticipated impediments and obstacles' [all citations are obtained from (Chapter 3, (28))]. An individual's behavioural intention is determined by his or her attitude toward the behaviour, subjective norms, and perceived behavioural control. The latter is a central component in predicting behaviour: behavioural control co-determines behaviour either indirectly by shaping behavioural intention, or directly in cases where behavioural control is objectively limited by environmental circumstances.

Experience from clinical practice suggests that patients often are not aware of the distinction between PA and CRT and their specific health benefits. Therefore, the objective of this study was to explore the behavioural, normative and control beliefs concerning general PA and CRT in people living with axSpA. Understanding their beliefs would allow PTs and other health professionals to fulfil their crucial role in PA promotion.

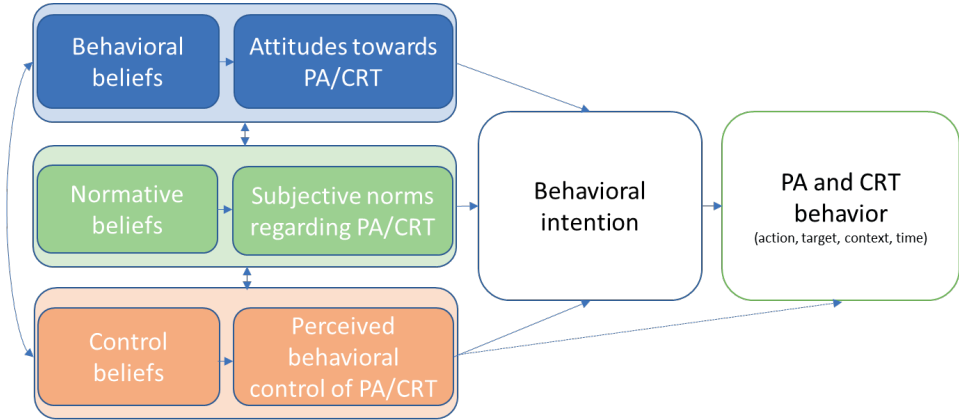


Figure 1. Adapted pathway of Theory of Planned Behaviour (29).
 Abbreviations: PA = physical activity; CRT = cardiorespiratory training.

Methods

Design

A qualitative research design with semi-structured focus groups of individuals with axSpA was chosen to explore patient beliefs concerning CRT and physical activity. The study applied a descriptive qualitative approach, as described by Sandelowski (30, 31). Focus groups are a valid qualitative method to explore people's knowledge and experiences, making use of their interaction (32, 33).

Three of the five focus groups were conceptualized primarily to learn more about the importance of PA and barriers/facilitators to CRT in individuals with axSpA (21). The other two focus groups were used to understand more about PA behaviour and technology-based CRT. All focus group interviews were performed during the early stage of a project (34) aimed at implementing PA recommendations within an axSpA exercise group concept. The data were analysed a second time with focus on beliefs.

Ethical considerations

This study was approved by the Ethics Commission of Canton Zurich (June 2016, BASEC-Nr. 2016-00316) and all participants gave their written informed consent. The principles of good clinical practice and the declaration of Helsinki were followed (35). Reporting accords with the Consolidated Criteria for Reporting Qualitative Research (COREQ, Supplement A1) (36). The characteristics of the research team are described in Supplement A2.

Procedures / patient selection / data collection

The Ankylosing Spondylitis Association of Switzerland (Schweizerische Vereinigung Morbus Bechterew, SVMB) recruited the participants of the focus groups by sending an invitation to all their members in the German-speaking part of Switzerland. For the barrier/facilitator study (21), patients were purposefully sampled based on their self-reported PA participation levels (according to the International PA Questionnaire, short version (37)) and on their participation in a SVMB exercise group. Final selection was dependent upon achieving maximum variability of group participants in terms of sex, age, and part-time or full-time employment. For two focus groups, a convenience sample of people interested in technology-based exercising participated. Demographic data of the participants are provided in Table 1.

A few days before the focus groups took place, detailed participant information and an informed consent form were sent via e-mail to the participants. The same information was explained once again verbally at the beginning of the focus group meetings and participants gave their written informed consent. The focus group interviews took place either in a meeting room at the SVMB or at the Zurich University of Applied Sciences (ZHAW). A representative of the SVMB welcomed their participant members but were not present during the conduct of the focus group interview. The researchers explained to the participants that the aim of

the study was to evaluate and further develop the SVMB exercise groups, that their opinions were of great value to the project, and that the study was independent of their engagement in the SVMB exercise groups or their current physical activity level. Furthermore, participants were assured that all data would be processed confidentially and that the transcripts of the group discussions would be anonymised. The interviewers (IN, KN, AR) were unknown to the participants prior to the study and introduced themselves, together with their professional functions at the ZHAW.

Table 1. Characteristics of focus group participants

Characteristics	Participants (n)
Total n	24 (100 %)
Gender	
<i>Male</i>	15 (62.5 %)
<i>female</i>	9 (37.5 %)
Age	
<i>mean±SD (range)</i>	53±14 (28-86)
Occupation	
<i>Employed</i>	18 (75.0 %)
<i>Retired</i>	6 (25.0 %)
Member of SVMB exercise group	8 (33.0 %)
Participation in sports club	9 (37.5 %)
Performance of regular CRT (at least 2x/week)	15 (62.5 %)

SD, standard deviation; CRT, cardiorespiratory training; SVMB, Schweizerische Vereinigung Morbus Bechterew

The semi-structured focus group interview guides are detailed in Supplement B. At the beginning, participants were invited to introduce themselves with their name and, for example, age, job, recreational activities, or onset and course of disease. The interview guide contained leading and detailed open-ended questions on the following topics: appraisal of own health; personal significance of PA; and attitudes to and thoughts on PA and CRT. Three focus groups focused on the potential barriers and facilitators to PA/CRT, while two focus groups concentrated on the use of technology for PA/CRT. In addition, SVMB group exercising and expectations on the SVMB were discussed. Each focus group lasted approximately 90 minutes.

Data analysis

Data was analysed using structured thematic qualitative content analysis, as described by Kuckartz (38). The focus group audio data was transcribed and proofread by the researchers IN (psychologist) and AR (physiotherapist). Subsequently, data was imported into the Qualitative Data Analysis Software Atlas.ti (39). Qualitative content analysis was initiated through attentive reading of the transcripts and the highlighting of important passages. Thematic main categories were defined deductively, according to the TPB's three determinants of behaviour attitudes, norms, and perceived behavioural control, as well as their associated behavioural, normative and control beliefs. In the next step, all

data were coded and quotations assigned to these three main categories. In the following step, all quotations assigned to a category were compiled. Within these, subcategories were developed inductively to describe the material within each category (IN, AR). The two researchers discussed the developed subcategories and a consensus-based detailed categorisation system was defined (Table 2). Applying this system, all the data was analysed accordingly. Finally, thematic summaries were described for all three categories of the TPB. Example quotations of patients were translated from (Swiss-)German into English.

Table 2: Detailed categorisation system

Category	Subcategories
Behavioural Beliefs	<ul style="list-style-type: none"> - Conceptualization of physical activity and cardiovascular training - Exercise benefits - Exercise associated risks
Normative Beliefs	<ul style="list-style-type: none"> - Motivation of significant others to exercise - Mutual commitment - Performance pressure - Image of people with axSpA
Control Beliefs	<ul style="list-style-type: none"> - Discipline, tricks - Key experience - Limitation due to disease - Pain control - Exercise requirements in daily living (work, leisure activities) - Exercise opportunities in daily living (work, leisure activities) - Exercise opportunities offered by the SVMB - Expectations on course instructors - Support from technology

axSpA, axial Spondyloarthritis; SVMB, Schweizerische Vereinigung Morbus Bechterew

Measures of trustworthiness

The trustworthiness of the study, as described by Steinke (38), has been strengthened by various measures taken during the study process: intersubjective comprehensibility was enhanced by stringent documentation of the research process, discussion of the results within the research group, and application and documentation of the categorisation system. Sampling, maximum variation strategy, as well as methods of data collection and analysis, have been chosen as indicated by the research question. Results are highlighted based on statements to allow empirical anchoring. Finally, memos were used to reflect on experiences, perceptions, and expectations of the topic, and the beliefs of the participants in terms of reflected subjectivity. Transcripts and findings were returned to participants for comments.

Results

Results reflect the behavioural, normative, and perceived control beliefs of individuals with axSpA concerning general PA and CRT. Table 3 (Supplement C) displays example anchor quotations that underpin the following results.

Attitudes toward behaviour: performing general PA and CRT

All participating individuals living with axSpA had a positive attitude towards PA, reporting various important benefits: physical (improving fitness, physical well-being, active control of disease); psychological (joy, self-management strategy, improvement in self-esteem, enabling a sense of achievement); and social (reinforcing exercise group, activities with healthy people or other people living with axSpA). See Table 3 Supplement C, e.g. *"I think axSpA also has advantages. You stay active."* C6 (physical benefit); *"I also feel better when I move. You have the same pain but then you know it's just a good feeling, when you don't do anything and you have pain, then it's more of a negative feeling. (..) I agree, physical activity is simply most important."* D3 (psychological); *"For us, group therapy is first and foremost a social gathering. More than anything else. That's the good thing about group therapy."* E6 (social).

Some participants also mentioned the perceived risks of PA, such as the fear of increasing symptoms (e.g. pain) or physical overload prompting an injury or flare up. Some mentioned that they had had to discontinue their preferred sport since their diagnosis (e.g. *"I'm not allowed to do contact sports anymore."* B1).

For many participants, regular PA was part of their self-concept (e.g. *"I am very sporty."* C6) and an important part of their daily routine (e.g. *"I miss something if I cannot exercise."* C5). However, the relevance of CRT was new to some participants (e.g. *"Why are people so into cardiorespiratory training, recently, it always comes up..?"* B3) and only a few participants expressed the same positive attitude towards CRT as they did towards general PA.

Those participants who were members of a SVMB exercise group reported that CRT was taken into account too little (e.g. *"I quickly realised that the exercise group neglects cardiovascular training. Quite clearly. And that is almost more important than flexibility. You have to take care of your fitness yourself."* A2).

Furthermore, the conceptual difference between general PA and CRT seemed to be unclear to some participants. If they were asked which kind of CRT they perform, answers were very diverse, covering a range from unspecific descriptions of general, often transport-related, activities (e.g. *"I just walk a lot, I don't have a car (..) I walk relatively fast."* C2) to detailed knowledge of CRT by ambitious athletes (e.g. *".. if I want to improve my fitness, then I have to go beyond this limit and see what pulse rate I train at. Otherwise, I lose fitness instead of improving it."* D2).

Normative beliefs

For normative beliefs, no distinction between general PA and CRT was observable. Participants described several beliefs of significant others (e.g. spouses, friends) who had an influence on their motivation to comply with such beliefs. Further relevant people mentioned were other patients participating in axSpA exercise groups, the rheumatologist, and the physiotherapist. Many individuals with axSpA like to be experienced by others as being positive and sportive people (e.g. *“The doctor at the hospital said that he likes axSpA people best because they are consistently nice and positive people. They can be devastated, but as soon as they can walk again, they laugh again. People with axSpA are basically positive.”* B3). This might provoke resistance in people unable to fulfil this ideal (e.g. *“And especially when I’m in pain, I can’t motivate myself to go to the gym because I’d embarrass myself. I’ll just watch the others (..) in the fitness centre, everyone is watching you.”* C3). Some made a point of being independent and competent in self-management (e.g. *“After that, I had a physiotherapist who helped very little through physical treatment, but developed exercises with me that I can do myself at home. I don’t want her doing something with her magic hands and afterwards I feel great, I want her to show me how I can help myself. And that’s the crucial thing - I don’t want to spend my whole life running after a physiotherapist or a rheumatologist.”* C1). Others saw the weekly physiotherapy session as a matter of course (e.g. *“I see my physiotherapist once a week”* E5).

Exercising together with other people was perceived as fun and motivating. Arranging joint physical activity or exercise sessions helped to overcome the “weaker self”. The competing atmosphere of an exercise group was perceived as both motivating (e.g. *“drill and fun”*, B1; *“you can compare, you can bolster each other up”*, A4) and a deterrent (e.g. *“I like more to exercise according to my possibilities without having to justify myself”*, C5). Many participants described the axSpA exercise group as socially important (e.g. *“The social component should not be underestimated”*, C1; *“We have a good group, half of it goes for a drink after exercising”*, A5). Others preferred exercise groups not specifically designed for individuals with axSpA, because they did not need to think or talk about their condition (e.g. *“When I go to handball I’m just like any other and I don’t have to deal with my back problem”*, B4).

Control beliefs

Both, general PA and CRT, were mentioned as effective self-management strategies to control their disease (e.g. *“One must have axSpA under control, not the other way around”* B1). Some reported a “key experience” that helped them to realise the importance of PA (e.g. *“There is a sequence that is firmly in my memory. I could hardly move. Nevertheless, I wanted to go horse riding... when you’re in so much pain, you can’t move. So, I somehow got my leg up and got into the saddle. I struggled onto the horse with tears in my eyes and started riding. And the longer the horse kept moving, the better the pain got. That was a key experience for me. Although everything hurt, in the end the movement did me good.”* A3). Regular PA and specific exercising (mostly CRT) were perceived as a matter of discipline,

especially when someone did not enjoy it. Many individuals with axSpA are experts in how to integrate general PA and regular exercises into their daily routine (e.g. *“I walk the stairs, I work on the 5th floor, I walk in the morning, at noon, in the evening and in between when I have to go to the construction site.”* B2). Almost all participants of the focus groups had examples (e.g. *“I was not born an athletic person, I had to acquire that. That I really do a lot and incorporate it into everyday life.”* A1; *“I have a home trainer (..) but I think riding a bike is terrible. I leave the TV on and then I know how many minutes... and then I think, that’s terrible! However, I just do it then.”* A3). A positive attitude and the perceived benefits of PA and specific exercise help individuals to create time and material resources for exercising (e.g. buying a home trainer bike). Less active individuals did not describe strategies of how to integrate general PA or specific exercises into their daily routine. Some participants underlined the importance of setting an exercise goal (e.g. *“When I have a goal, I do it. Then it’s fun. But I need a goal. If I don’t have one, I don’t do anything.”* A5). Reaching the goal reinforced their self-efficacy.

Nonetheless, the disease is associated with obstacles to exercise, since it limits the choice of sport and can also force a change in occupational career, which is sometimes hard to accept (e.g. *“I used to be an aerobics instructor (..) and had to give that up”* C3). But participants also experienced facilitators to exercise: regular participation in group exercise and the group-leading PT are often perceived as supportive (e.g. *“Physiotherapists always have a bunch of ideas [how to exercise]”* B3).

Technology-support for general PA was viewed as both motivating and demotivating. A reminder, through a tracker function that controls steps per day, was perceived as stimulating, especially for beginners or light intensity exercisers (e.g. *“I think tracking steps per day is good for a start. Everyone has a different motivation.”* D2; *“When I get up in the morning, I plan it (training), and when I remember it, it’s in the evening. In between, the day is so packed that I forget. But when I am reminded, I incorporate it more. Because I want to do it, because I know it does me good. I do it 2 times a week ... most of the time. But never without a reminder.”* E2). Others felt demotivated (e.g. *“I got a tracking watch from my wife as a birthday present. But I was so bad that I gave it back to her.”* E5).

Participants agreed that if a specific CRT goal is to be reached, technology-based pulse-control is required (e.g. *“And then there are the athletes who are training for a goal. And if you want to train properly it has to be pulse-oriented.”* D3).

Discussion

The individuals with axSpA participating in our study showed multifaceted behavioural, normative and control beliefs concerning CRT and general PA. However, the conceptual difference between general PA and CRT, and the relevance of CRT, was unclear to some. General PA is acknowledged to have a beneficial impact on personal health and wellbeing. For most participants, general PA was part of their daily routine and was understood to be an important self-management strategy. Despite the importance of CRT in reducing the increased cardiovascular risk of people with axSpA, only a small number of participants seemed to know how to perform regular CRT and did so. The engagement in CRT requires skills and empowerment, such as detailed knowledge, social support, and a strong motivation to exercise in contempt of barriers, in particular, pain or fatigue.

Some implications can be derived from this finding for clinical practice, education, and research.

PA is behaviourally complex and increasing PA as a lifestyle change is challenging (28, 40). Facilitating factors for individuals with axSpA include, but are not limited to, (intrinsic) motivation, good organisational conditions, improvement of disease symptoms and health (21, 41). Barriers to an active lifestyle include, but are not limited to, low motivation, problems with timing in the daily routine, hindering disease symptoms (notably pain or fatigue) and high disease activity (21, 41, 42). In CRT, motivation is a top facilitator and top barrier (21). PTs, but also other health professionals, need to understand the complexity of PA behaviour and learn how to promote change using appropriate (behavioural change) techniques (43). For instance, general practitioners and rheumatologists tend to have a long-term relationship with their patients. However, in the context of exercise prescription, general practitioners think that nurses or PTs are more skilled to promote PA (44). Word Physiotherapy claims that physiotherapy excellence lies in the promotion, guidance, and prescription of safe PA across the life span (45). Although this might be the case for well-informed PTs (46), there is literature describing cases of PTs with misconceptions regarding knowledge, attitudes and beliefs about PA (47), and not themselves fulfilling PA recommendations (48, 49). Rethorn and colleagues (50) highlight that addressing individual (e.g. increasing PTs' knowledge, skills) and organisational factors (e.g., touching upon perceived lack of time and increasing organizational support) may improve PTs' PA promotion interventions. Verbal information on the benefits of PA and specific exercises is not usually sufficient to change behaviour. Prior to starting an exercise intervention, a PT should explore a patient's beliefs regarding PA and exercise, detect individual barriers and define a goal, according to individual preferences and through shared decisions. Sufficient coaching, exercise guidance and correctly dosed exercise could enhance the adherence to long-term PA (51). Our data show how diverse the understanding and personal approaches to PA and CRT can be, e.g. for some patients pain is a barrier, while for others it is the main reason for exercising. Tailored goals and patient-oriented communication strategies are especially important in handling these differences.

However, as yet unpublished data on PTs working in Switzerland show that only a small number of behaviour change techniques are used, which underpins the need for the continuous training of PTs in communication and behavioural change techniques.

Patients also require further education and knowledge, since the power and effectiveness of correctly dosed exercise as medicine is still undervalued. Gossec and colleagues (52) described the belief that PA had negative effects on the disease as being associated with poor education and psychological issues, such as anxiety. Some participants in our study also mentioned their anxiety that performing PA could worsen a flare up or symptoms. However, the contrary is true. People living with axSpA benefit from both low and high intensity exercise (53-56). PA is associated with better function and greater exercise capacity, while sedentary behaviour is associated with poor quality of life and lower exercise capacity (57).

Further research should focus on the development of strategies on how to best implement educational interventions for health professionals and people living with axSpA, and thus provide the knowledge and skills on how to promote the recommended performance of general PA and CRT (9).

The lack of distinction between the concepts of PA and exercise is common, not only in individuals with axSpA (23, 58). If people cannot distinguish between these concepts, they see no need to engage in formal exercise and simply integrate more PA into their daily routine, increasing the duration rather than the intensity of PA. However, intensity matters in combatting the increased risk of cardiovascular disease. It is particularly important for individuals with axSpA to perform regular, moderate to vigorously dosed CRT. Regardless of disease activity, individuals with axSpA tend to perform less outdoor activities but with higher intensity compared to healthy controls (59). However, both aspects, outdoor activity and the intensity of PA, should be taken into account for axSpA management. Interestingly, there is some evidence to show that people are more likely to perform intense exercises outdoors, but – paradoxically – perceive it as less exhausting (60). The natural outdoor environment generally increases physical and psychological health (61), unsurprisingly, since weather conditions are associated with outdoor PA in people with arthritis (62).

The findings of our study are in line with others (63), underpinning the conclusion that group exercise is perceived as supportive in terms of motivation (encouraging) and peer reinforcement. However, there is no evidence that group exercise is more effective than individual exercise. Group supervisors need to be aware that a 'one-size fits all' approach is not useful and that the dose of exercises needs to be tailored to the fitness state of the individual (9). Independent of setting, patients report that continual guidance and acknowledgement, and receiving advice and feedback from a supervisor is important – especially during high-intensity exercising (55). Further research should consider how the promising area of technology-based counselling (64) could be integrated into axSpA

exercise groups to promote individually-tailored CRT.

A further focus of future research could be the objective assessment of daily PA in conjunction with PA/exercise beliefs to better understand behaviour patterns. The resulting information could be used to design a composite tool to measure core attitudes and beliefs to PA/exercise in people living with axSpA. This would be useful as a standardized tool for use across studies and to develop specific interventions. Finally, it is important to investigate whether changing the attitudes and beliefs of people has a positive impact on long-term PA/exercise behaviour. In this regard, other relevant behaviour change theories (27), such as self-efficacy, should also be considered.

In terms of generalisability, the results of this study should be interpreted with caution. As commonly is the case in focus groups, participants had an interest in the topic under study (65). Therefore, insight was gained only into the beliefs of those individuals who are interested in PA/CRT. The study results might not be representative for those individuals with no interest in PA/CRT. However, the study participants living with axSpA presented a wide range of PA behaviour, ranging from no regular PA engagement at all to exercising in a performance-oriented manner. Furthermore, the study covered the complete range of population, in terms of age, gender and membership of the SVMB exercise group, which is an important prerequisite for the generalisability of focus groups findings (66). Additionally, since the focus groups were conducted only in the German language, generalisability is limited for those people living with axSpA in Switzerland who are not proficient in the German language.

Although the main themes of the focus groups were the barriers and facilitators to CRT and technology-based CRT, our data revealed further interesting material on the general beliefs of participants concerning CRT and PA. During analysis of results, however, it became apparent that it was unclear whether these statements referred to CRT or to general PA. In conclusion, it can be assumed that the participants' beliefs regarding CRT and PA may differ. A detailed elaboration of these differences should be the subject of future research.

Conclusion

People living with axSpA show multifaceted behavioural, normative and control beliefs concerning CRT and general PA that underpin the beneficial impact on personal health and wellbeing (behavioural belief). For most participants, general PA is part of their daily routine and it is understood to be an important self-management strategy (control belief). However, not all participants were aware of the importance of CRT and only a few possessed the knowledge and skills to perform CRT. PTs play a key role in PA promotion and influence normative beliefs, which could be used to a greater extent in the future to promote active lifestyle competencies in people living with axSpA. Concrete training and implementation strategies at the level of patients and PTs need to be developed in the future through further research.

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Authors' contribution:

AR drafted the manuscript, both co-authors reviewed it for important intellectual content, and both co-authors approved the final version to be published. All three authors (AR, IN, KN) were involved in all stages of the study (initialisation and execution, conception and design, acquisition of data, analysis and interpretation of data).

Additional Files:

- Supplement A1: COREQ checklist
- Supplement A2: characteristics of the research team
- Supplement B: Key questions of semi-structured focus group guides
- Supplement C: Results supporting citations

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6

Reliability of an adapted core strength endurance test battery in individuals with axial spondylarthritis

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Abstract

Objectives

To adapt the core strength endurance test battery (aCSE), previously used for testing athletes, to a target group of patients with axial spondylarthritis (axSpA), to evaluate its intra-tester reliability and its associations with disease-specific factors.

Methods

A cross-sectional study was conducted at axSpA exercise therapy groups, including both axSpA patients and the physiotherapist group leaders (PTs). The aCSE was used to measure the isometric strength endurance of the ventral, lateral and dorsal core muscle chains (measured in seconds), as well as to assess the disease-specific factors of functional status, self-reported pain, and perceived strength performance. The aCSE was repeated after 7-14 days to measure intra-tester reliability for the same rater (PT group leader). Reliability was calculated as an intra-class correlation coefficient (ICC) using a nested design. The associations between ventral, lateral, and dorsal strength endurance and the disease-specific factors were calculated using Pearson correlation coefficients.

Results

Study participants were 13 PT group leaders and 62 axSpA patients. The latter were all capable of performing the aCSE, with the exception of one individual. A moderate to substantial intra-rater reliability (ICCs (95%CI)) was found for the ventral (0.54 (0.35, 0.74)), lateral (0.52 (0.33, 0.70)) and dorsal (0.71 (0.58, 0.86)) core muscle chains. None of the aCSE measures correlated with the disease-specific factors.

Conclusion

The aCSE was found to be a reliable test battery for assessing core strength endurance in axSpA patients. Interestingly, aCSE performance was not associated with any disease-specific factors.

Key points

- The adapted core strength endurance test battery measures the isometric strength of the ventral, lateral and dorsal core muscle chains.
- The adapted core strength endurance test battery showed a moderate to substantial intra-rater reliability for all three muscle chains tested in axSpA patients.
- No correlations were found between the adapted core strength endurance test battery and the disease-specific factors of self-reported pain, functional status and perceived strength performance.

Introduction

Axial spondylarthritis (axSpA) is a chronic inflammatory rheumatic condition that mainly affects the axial skeleton, iliosacral joints, and spine. It can lead to structural and functional impairments and can have a significant impact on an individual's quality of life and working ability (1, 2).

The cornerstones of non-pharmacological treatment are patient education and regular exercise (1). Current recommendations for physical activity in individuals with inflammatory arthritis emphasize that the general physical activity recommendations, comprising the four exercise domains of cardiorespiratory fitness, muscle strength, flexibility and neuromotor performance, are effective, safe and feasible for axSpA patients (3).

In addition to peripheral muscle strength, core muscle strength (sometimes referred to as the “powerhouse”) is especially important for people with axSpA (4), since inflammation and reduction in mobility affect the dynamic stabilization of the spine. A certain level of core stability is needed, in terms of strength and muscle fatigue resistance, for the activities of daily living (improved posture, enhanced balance and proprioception) and sports performance (such as correct and safe barbell-based exercising) (5). Core muscle performance is a complex and multivariable construct, with core stability not yet having been clearly defined (6, 7). Experts agreed in a Delphi-project that core stability is, “the ability to achieve and sustain control of the trunk region at rest and during precise movement” and depends on the components of muscle strength and neuromotor control (8). Three common categories to assess core muscle strength can be differentiated according to this concept: maximal strength, power (9, 10) and strength endurance, the latter defined as the ability to sustain a given level of force production over time (11).

No randomized controlled studies have been published to date investigating the effect of muscle strength exercises alone on lower limb and trunk muscle strength performance in axSpA patients (12). Training the trunk muscles does seem, however, to have a positive effect on flexibility in healthy people (13). Moreover, the combination of core strength and flexibility exercises has been found to have a positive effect on disease activity and flexibility in axSpA patients (assessed by the Bath Ankylosing Spondylitis Mobility Index, BASMI) (14). The physical activity recommendations for individuals with inflammatory arthritis (3) underline the fact that regular evaluation of physical fitness, including all afore mentioned four domains, should be part of standard care for axSpA patients (3). The assessment of strength, however, is challenging. Dagfinrud et al. found that the monitoring of muscle strength parameters in group exercise therapy (GET) studies was essentially nonexistent (15). A survey of the axSpA GET in Switzerland and the Netherlands confirmed this finding for clinical practice (16). However, there is a need to regularly assess all fitness dimensions to identify those with the potential for improvement. This could help healthcare providers and patients in the process of promoting physical activity, e.g. giving advice, setting goals,

planning and performance of exercises.

The Ankylosing Spondylitis Association of Switzerland (Schweizerische Vereinigung Morbus Bechterew, SVMB) currently has more than 4000 members and organizes more than 60 exercise groups across Switzerland. Participants exercise weekly in groups led by physiotherapists (PTs) in land-based or water-based settings. The objectives of the GET are to minimize the progressive spinal mobility restriction (17), reduce cardiovascular and biological risk factors (18), and maintain or increase muscle strength. According to the recommendations (3), annual fitness assessments are also part of the SVMB's quality concept. In clinical settings, such as the axSpA GET, the fitness dimensions should be assessed by easy-to-use and inexpensive devices. In this target group, strength assessment should focus on core muscle strength endurance rather than peripheral muscle strength.

In the absence of an existing gold standard, the isometric core strength endurance test battery (CSE), originally developed by the Swiss Olympic Medical Centers for use with athletes, seems to be the only available tool for use in an axSpA GET setting. It was found to be easy to perform, inexpensive to use and to present with good psychometric properties (19). The Biering-Sorensen test, which is part of the aCSE, showed good to excellent inter-rater and test-retest reliability (20), but no prior data on intra-rater reliability were found. The CSE was designed to evaluate the "basic" core strength of athletes, meaning the minimum strength required for the performance of sports (19). With the aid of a reference table including norm data of Swiss athletes, assessors judge whether core strength is sufficient or insufficient.

The aim of this study was to adapt the CSE for axSpA patients (aCSE), evaluate intra-tester reliability and the associations with disease-specific factors.

Methods

Design

For the analysis of reliability, a cross-sectional study with a nested design was conducted, given that across the groups, a different numbers of individuals were measured by the PTs (raters). The findings are reported in line with the GRRAS (Guidelines for Reporting Reliability and Agreement Studies) guidelines (21).

Participants

Physiotherapists (PT)

The PTs leading the GET in the German-speaking region of Switzerland (n=45) were invited to participate in this study and to perform and rate the aCSE test battery with their group participants. They were requested to attend a 2h practical training session (lead by PB). In addition, they received detailed step-by-step explanations in the form of videos, photos, and handouts. Thirteen PTs registered for the aCSE training.

AxSpA patients

An information letter was sent to the 206 participants of the SVMB exercise groups of the 13 PTs registered for the aCSE training. The letter explained the purpose and procedures of the study and described the aCSE test battery. Inclusion criteria were age of over 18 years and sufficient German language skills. Eligible individuals also had to be capable of getting down onto the floor and lying in the prone, supine and side positions. Exclusion criteria were heart diseases of class three or four, according to the New York Heart Association (22), diagnosed osteoporosis of grade two or more (23) or surgical spondylodesis performed on the entire lumbar spine.

Assessments

The aCSE test battery was performed by each axSpA patient twice with a period of 1 to 2 weeks between the tests (T0 and T1). A period of 1 week allowed for full recovery of the muscles after performing the first aCSE test battery at T0, while the maximum of 2 weeks minimized the possible effect of disease-related changes. The measurements took place during the regular GET. At T0, as well as recording patient characteristics, measurements of pain status, disease activity functional restriction, and physical fitness were made. The same group PT leader conducted the aCSE measurements at both time points with each patient. No encouragement (in terms of cheering) was allowed.

Participant characteristics

Gender, age, disease duration, and self-reported exercise hours per week were recorded for axSpA patients. Gender, age, and work experience in years were documented for the PTs.

Core strength measurements

Adaptation and performance of the core strength endurance test battery (aCSE)

Given the large number of exercise groups that could potentially implement the aCSE, the criteria for test selection were validity, reliability, and low cost. A further important criterion was feasibility, i.e. the test had to be able to be performed in sports halls with little specific equipment and by individuals with a broad range of fitness and health.

Previous field testing had shown that the CSE used with athletes (19) was too demanding for some SVMB exercise group participants. They reported joint pain while in positions of lateral and ventral muscle chains. The following adaptations were consequently made to the CSE for testing axSpA patients, resulting in an adapted version named the aCSE:

- The starting position for the ventral plane was changed from plank to quadruped position.
- Tests were performed statically instead of dynamically (24) to ensure a constant load (this modus reduced the risk of injury and was easier to standardize).
- Rods were used for standardization, i.e., the participant was asked to keep contact with the horizontal rod during the test (see supplement, Fig 1).

The time that the subject was able to remain in each of three positions was measured in seconds. Time recording stopped whenever the participant lost contact with the rod for the third time. The participant could get into the required position for a maximum of three attempts. Before the next position was measured, the participant rested for at least 30s. Detailed instructions on the performance of aCSE can be found in the Supplement.

Additional outcomes and assessments

Pain intensity

Pain intensity was measured using the Numeric Rating Scale (NRS), which is acknowledged as a reliable and valid measurement tool in clinical practice and research (25). The NRS measures pain on a scale from 0 to 10 (0 = no pain at all and 10 = worst pain ever). In this study, the tool was used to assess average pain immediately before and after the aCSE test batteries were performed.

The Bath Ankylosing Disease Activity Index (BASDAI)

AxSpA disease activity was measured using the BASDAI, which is a valid and reliable self-reporting questionnaire (26). The questionnaire consists of six items to determine pain in the peripheral joints and spine, fatigue, morning stiffness and pain sensitivity to touch (27). The BASDAI results in a mean score of 0-6 points (0= no disease activity, 6= highest disease activity) (27).

The Bath Ankylosing Spondylitis Functional Index (BASFI)

Functional limitations experienced by axSpA patients during ten everyday tasks were evaluated using the BASFI, which is a valid and reliable self-reporting questionnaire (26).

The BASFI evaluation results in a mean score between 0 and 10 (0= no handicap and 10= highest possible degree of functional limitation).

Physical fitness questionnaire (FFB-Mot.)

Self-perceived motor performance ability during everyday tasks, with regard to cardiorespiratory fitness, strength, flexibility and coordination, was evaluated using The Physical Fitness Questionnaire (FFB-Mot., German: Fragebogen zur Erfassung des motorischen Funktionsstatus) (28). It has been shown that the FFB-Mot. is a valid instrument to determine physical fitness in a healthy adult population (29). The outcome of the 28 items on the questionnaire results in a total score ranging from 5 to 140; the strength questions include seven items for which the score can range from 0 to 30. For example, a total score of 35/140 for a 58 year old healthy man would indicate a rather poor overall physical fitness status, while a score of 100/140 would indicate a rather good physical fitness status (29). It has not yet been used as an assessment for evaluation, so no reliability data are available.

Weekly exercise

Questions on weekly hours of planned exercise, together with the focus of the exercise dimension (muscle strength, cardiovascular, neuromotor or flexibility), were asked by the PT, together with the patient characteristics (age, gender, year of diagnosis and disease duration).

Sample size and statistical analysis

Sample size was estimated based on the precision of the reliability estimate following Giraudeau and Mary (30). With a targeted width of the confidence interval (two margin of errors or four standard errors) of $w = 0.3$, 57 subjects were needed for (a conservative) ICC = 0.65. For larger ICCs, the required sample size would be smaller or the precision in the analysis would be larger.

All statistical analyses were performed using the R statistical software R version 3.5.3 (31).

Reliability

Generalizability theory (32) was used as the framework to estimate the reliability of the raters' time-keeping while assessing core muscle strength. To estimate the intra-rater reliability, a linear mixed model for "(strength endurance) Time" Y_i of Subject i nested in Rater j measured at time point k was fitted to the data:

$$Y_{i(j),k} = \mu + S(R)_i + R_j + T_k + RT_{ik} + \epsilon_{i,j,k} .$$

With $Y_{i(j),k}$ representing strength endurance time, μ representing the global mean, $S(R)_i$ corresponding to $S_i + S(R)_{ij}$ which cannot be disentangled in a nested design and ϵ_{ijk} the independent and normal distributed errors.

The intra-rater reliability was calculated as the intra-class correlation coefficient

$$\text{corr} \left(Y_{i(j),k}, Y_{i(j),k'} \right) = \frac{\sigma_{S(R)}^2}{\sigma_{S(R)}^2 + \sigma_T^2 + \sigma_{RT}^2 + \sigma_\epsilon^2},$$

with the σ^2 representing the corresponding variance components. Bootstrapped confidence intervals for the intra-class correlation coefficient (ICC) were computed. Values less than 0.2 demonstrate a slight reliability, values between 0.2 and 0.39 indicate a fair reliability, values between 0.4 and 0.59 describe moderate reliability, values between 0.6 and 0.79 indicate substantial reliability, and values greater than 0.80 indicate almost perfect reliability between measurements (33). The lower limit of the 95% confidence interval of the ICC to estimate the level of reliability was used (34).

Associations between the aCSE outcomes and disease-specific factors

To evaluate the relationship between aCSE outcomes and patient-reported strength and the disease-specific outcomes, the time measurements for aCSE ventral, lateral and dorsal were correlated with the FFB-Mot. subscales of strength, NRS-measured pain, BASDAI and BASFI, using the Pearson correlation coefficient. The size of a correlation coefficient can be interpreted as negligible ($\rho < 0.3$), low ($0.3 < \rho < 0.5$), moderate ($0.5 < \rho < 0.7$), high ($0.7 < \rho < 0.9$) and very high ($\rho > 0.9$), with both positive/negative correlations (35). A priori, it was hypothesized that the following would provide evidence of an association between aCSE performance and disease-related factors: a) a positive Pearson correlation (r_s) > 0.3 between aCSE and FFB-Mot. subscale strength and/or self-reported hours exercise per week; and/or b) a negative correlation < 0.5 between aCSE and pain (NRS) and/or disease activity (BASFI, BASDAI). The lower limits of 95% confidence intervals adjusted for multiple testing were used.

Results

Thirteen PTs (28.8%) and 62 group participants (30.0%) provided informed consent and were included in the study; three of the latter could not participate at T1 (n = 2 due to acute influenza, n = 1 due to pain after the first measurement). Descriptive data for the study participants are shown in Table 1.

Intra-rater reliability of aCSE

A moderate to substantial intra-rater reliability was found for all three test positions that tested the strength of the ventral, lateral, and dorsal core muscle chains (Table 2).

Associations of aCSE outcomes with disease-specific factors

Data shown in Table 3 indicate no positive or negative associations between aCSE outcomes and any disease-specific factors measured. Thus, the a priori hypotheses were not confirmed.

Table 1. Participants' characteristics

Characteristics of axSpA patients	n=62
Gender, female, n (%)	29 (46)
Age, years	54.6 [11.2]
BASDAI (0-10)	3.5 [2]
BASFI (0-10)	1.8 [1.5]
FFB-Mot. total (0-140)	85.8 [18]
FFB subscale strength (0-35)	21.5 [5.4]
NRS pre aCSE at T0	2.2 [2.2]
NRS post aCSE at T0	1.6 [2.4]
Disease symptoms since, years	27.5 [12.9]
Disease duration since diagnosis, years	20.1 [13]
Self-reported training per week, hours	3.1 [2.9]
Characteristics of physiotherapists	n=13
Gender, female, n (%)	9 (69)
Age, years	46 [11]
Work experience, years	6.3 [3.5]
Number of participants per rater (median, range)	4 [2-9]

Data are mean (standard deviation), if not stated otherwise. BASDAI, Bath Ankylosing Disease Activity Index; BASFI, Bath Ankylosing Spondylitis Functional Index; FFB-Mot., Physical Fitness Questionnaire; NRS, Numeric Rating Scale; aCSE, adapted Core Strength Endurance test battery; T0 and T1, time point 1 (baseline) and 2, respectively; GET, group exercise therapy.

Table 2. Intra-rater reliability of the aCSEs

Test position	ICC	95% CI
aCSE ventral	0.54	0.35, 0.74
aCSE lateral	0.52	0.33, 0.70
aCSE dorsal	0.71	0.58, 0.86

aCSE, adapted Core Strength Endurance test battery; CI: Confidence Interval; ICC: Intraclass Correlation Coefficient.

Table 3. Evaluation of associations between aCSE and disease-specific factors

Association	r	95%CI*
aCSEv vs.FFB-Mot. strength	0.25	-0.19, 0.61
aCSEl vs. FFB-Mot. strength	0.34	-0.11, 0.67
aCSEd vs. FFB-Mot. strength	0.30	-0.15, 0.65
aCSEv vs. self-reported training hrs	-0.06	-0.44, 0.34
aCSEl vs. self-reported training hrs	-0.06	-0.44, 0.34
aCSEd vs. self-reported training hrs	-0.01	-0.32, 0.30
aCSEv vs. pain	-0.11	-0.50, 0.31
aCSEl vs. pain	-0.07	-0.44, 0.33
aCSEd vs. pain	0.06	-0.33, 0.43
aCSEv vs. BASFI	-0.03	-0.39, 0.33
aCSEl vs. BASFI	-0.16	-0.54, 0.27
aCSEd vs. BASFI	-0.35	-0.68, 0.10
aCSEv vs. BASDAI	-0.23	-0.59, 0.22
aCSEl vs. BASDAI	-0.26	-0.62, 0.19
aCSEd vs. BASDAI	0.03	-0.33, 0.37

r=observed correlation coefficient, CI = confidence interval (*uncertainty adjusted for multiple testing (Holm procedure)), BASDAI, Bath Ankylosing Disease Activity Index; BASFI, Bath Ankylosing Spondylitis Functional Index; FFB-Mot.strength, physical fitness questionnaire subscale strength; NRS, Numeric Rating Scale; aCSE, adapted Core Strength Endurance test battery; v,ventral; l, lateral; d, dorsal

Discussion

The aCSE values for the intra-rater reliability of the ventral, lateral, and dorsal planes show a moderate to substantial level of agreement. The results show that PTs are able to use the aCSE reliably, even with little experience of aCSE testing. Furthermore, nearly all participants were able to perform the aCSE, only one (1.6%) was unable to. In conclusion, the aCSE is a reliable assessment for people with axSpA in a group setting.

Possible associations between aCSE performance and disease-specific factors, according to the a priori hypotheses, were not confirmed. This is an interesting finding, suggesting that the aCSE can be performed by an individual with axSpA irrespective of their perceived strength performance, functional status and self-reported pain. This may be an aspect worthy of further investigation.

However, we were unable to confirm that pain did not influence aCSE performance. Pain was reported using NRS prior to and post testing, but no statistically significant negative relationship was found that would imply that more pain is related to less strength. Other than pain (36), the factors of motivation and effort are determinants of strength performance (37). Midgley and colleagues hypothesized that verbal encouragement could make a difference to test outcomes, through having a positive impact on intrinsic motivation and physical performance (38). The rating of perceived exertion together with consistent verbal encouragement should be incorporated into the future use of the aCSE. Consistent verbal encouragement could be usefully included in the GET assessment situation.

Due to the complexity of the core strength construct, there has been no gold standard for assessing core strength in the past, or core strength endurance in particular. Core strength is vital for maintaining an upright posture and is especially important for axSpA patients, who are affected by spinal inflammation and decreased spinal mobility. It is therefore appropriate to assess core strength endurance for axSpA patients. The physical position for assessing these individuals poses an additional challenge. It could be argued that to assess strength endurance of the dorsal muscle chain, the testing position described by Ito and colleague (39) (lying in prone position performing back extension) would be preferable to the testing position described by Biering Sorensen (40) (lying in prone position half of the body fixed on a treatment bench holding neutral position), because the Biering Sorensen occasionally activates more hip extensor muscles (24, 41). However, since the restricted flexibility of the spine is a major impediment in axSpA patients, the test procedure described by Biering Sorensen was considered to be more appropriate for covering the complete range of impairments from low to high. In future, it would be useful to develop a score for strength that encompasses all three planes, or to investigate whether there is a score from one plane that would serve as a sufficient proxy for all three planes. Ultimately, a database containing norm core strength values of individuals both with and without axSpA could ensure a meaningful interpretation of test results.

The original CSE is used as part of a sports performance test battery for athletes (19). With the aid of a reference table containing norm data of Swiss athletes, assessors judge whether core strength is sufficient or insufficient. Currently, no reference table including norm data of people with axSpA is available. This aspect should be taken into consideration when reporting test results to participants. However, until such a set of norm data is established, intra-individual comparisons might give an orientation.

Surprisingly, no relationship between aCSE outcomes and perceived strength performance was found, although there is evidence that people of all ages have a moderately accurate perception of their physical fitness (42). In contrast, other studies (43) provide evidence that people tend to be unrealistic in assessing their abilities, such as physical fitness or level of physical activity. A further reason for our finding could be that the aCSE measures core stability and not strength endurance. Core stability was not explicitly assessed in the patient-reported outcome measure. However, there is a consensus that core stability is dependent on the components of muscle strength and neuromotor control (8). Majewski-Schrage and colleagues (8) asked experts to provide assessment techniques that were specific to the components of core stability. The top three answers were: timed side bridge, Sorenson test, and timed prone bridge. All three of these are elements of the aCSE.

Low-cost was prioritized in our study setting. However, future projects could investigate the use of appropriate, objective, strength assessment devices, such as a hand-held dynamometer (44). This has been used previously to measure core strength indirectly (albeit maximal strength, not strength endurance) and has been found to be reliable and valid (7, 45). It might be less time-consuming to incorporate, e.g. easy to perform handgrip, instead of core strength, especially in a group setting.

This study has strengths and limitations. To our knowledge, this was the first study to evaluate the psychometric properties of a core strength assessment in axSpA patients. Movement assessment by visual observation and time-keeping appears to be feasible for PTs. However, it is a limitation of this study that reliability was tested by the clinically working usual GET PT leaders rather than by raters in a laboratory setting. Although the 2h assessment training was designed to standardize the test procedures and was appreciated by the PTs, their performance was likely to have been influenced by their motivation and understanding of the importance of performing the aCSE in a standardized way. PTs were not asked to perform the additional, disease-specific assessments, such as the Bath Ankylosing Mobility Index (BASMI), since the participants needed to receive specific instructions on how to hold the correct positions and to exert themselves. Additionally, the PTs emphasized that it was challenging to perform the assessments with each individual in the group during the usual GET sessions, in terms of time management and the planned exercise program. These factors (i.e., PTs' adherence to standardization, PTs' motivation, complexity of time-consuming tests) may have had an impact on the accuracy and reliability of the measurement outcomes. The reliability values could potentially be improved with improved test conditions.

Conclusion

Regular fitness assessment on an individual basis is part of the SVMB's concept of quality and is recommended (3). The choice of assessment used in this study was influenced mainly by feasibility criteria, such as low-cost, easy-to-use for axSpA patients, and the ability for people with different health and fitness status to perform in both land-based and water-based GET settings. Appropriate assessments with good psychometric quality are necessary. In summary, the aCSE was found to be a feasible assessment instrument to measure core strength in axSpA patients reliably. It could be potentially combined with other assessments of aerobic fitness, flexibility and neuromotor performance to establish an inexpensive and practical assessment battery, covering all exercise dimensions, for axSpA patients. Future research should establish a reference norm data table including axSpA patients, to enable an appropriate interpretation of test results. In addition, a less time-consuming alternative to implementing aCSE testing should be investigated, e.g. using only one representative plane instead of three separate planes.

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Authors' contributions

PB, AKR and KN designed the project. PB organised the data collection as part of his master's thesis. KN supervised the progress of the study. AM conducted the statistical analysis. All authors contributed significantly to the interpretation of results. AR drafted the manuscript. All authors provided comments on each draft and approved the final version.

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Conflicts of Interest

The authors declare no conflict of interest.

Compliance with ethical standards

Ethical approval and consent to participate The study obtained ethical approval from the Ethics committee of Canton Zurich (BASEC nr. 201700833). All participants (patients and PTs) gave written informed consent.

Additional Files

- Supplement A: Description of the core strength assessment battery

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7

Lessons learned from a pilot implementation of physical activity recommendations in axial Spondyloarthritis exercise group therapy

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Abstract

Background

The Ankylosing Spondylitis Association of Switzerland (SVMB) aimed to implement physical activity recommendations (PAR) within their exercise groups (EGs). The PAR promote exercise in all fitness dimensions at the correct dose. To implement the PAR within EGs, they were translated into a new EG concept with five key activities: (a) training for supervising physiotherapists (PTs), (b) correctly dosed exercises in all fitness dimensions, (c) exercise counselling, (d) bi-annual fitness assessments, and (e) individual exercise training, in addition to EG. All these activities were realized in close coordination with SVMB management.

Objectives

To analyse the implementation success by evaluating adherence/fidelity, feasibility, and satisfaction at the patient, PTs, and organisational level.

Methods

The five key activities of the new EG concept were developed, executed, and assessed after 6 months. The primary outcomes for implementation success were adherence of patients to the recommended exercise behaviour, self-reported by electronic diary; fidelity of PTs to the new concept, self-reported by diary; SVMB organisational changes. Secondary outcomes were feasibility and satisfaction with the new EG concept at all three levels. The tertiary outcome, to evaluate the effectiveness of PAR, was patient fitness, assessed through fitness assessments.

Results

30 patients with axSpA (ten women, mean age 58 ±9 years) and four PTs (three women, mean age 46 ±9 years) participated. The patients' self-reporting of adherence to the PAR was insufficient (43%), possibly due to technical problems with the electronic diary. The PTs' fidelity to the new EG concept was satisfactory. On all levels, the new concept was generally perceived as feasible and useful for supporting personalised exercise. The frequency of exercise counselling and the fitness assessments was found by patients and PTs to be too high and rigid. Patients' cardiorespiratory fitness [ES 1.21 (95%CI 0.59, 1.89)] and core strength [ES 0.61 (95%CI 0.18, 1.069)] improved over the 6 months.

Conclusions

The pilot implementation of PAR showed acceptance and satisfaction to be sufficient, thus confirming the need for evidence-based EGs, provided by a patient organisation in order to support active PA behaviour. However, adaptations are necessary to increase its feasibility for nationwide implementation.

Trial Registration

SNCTP000002880 (registered 31 May 2018)

Introduction

Patients with axial spondyloarthritis (axSpA) have an increased risk of cardiovascular diseases (1). In addition, evidence shows that axSpA has an impact on flexibility (2), balance (3), muscle strength (4), and cardio-respiratory capacity (5).

Exercise and effective drug treatment are recommended as the cornerstones of disease management (6, 7). Indeed, the promotion of physical activity (PA) and specific exercise (cardiovascular, muscle strength, flexibility, and neuromotor exercise) should be an integral part of standard care throughout the course of disease (8). Regarding cardiovascular exercise, evidence underpins that the appropriate intensity and frequency are relevant to reduce the risk of cardiovascular diseases in healthy people effectively; this might be valid for people with rheumatic and musculoskeletal diseases (RMDs) as well (9, 10). Furthermore, evidence shows that exercise according to public health recommendations for health-enhancing PA is effective, safe, and feasible in people with RMDs (11). Consequently, PA recommendations should be implemented, establishing a standard for PA and exercise promotion and education of health professionals for effectively delivering PA promotion and exercise across Europe.

The Ankylosing Spondylitis Association of Switzerland (Schweizerische Vereinigung Morbus Bechterew, SVMB) decided to implement the PA recommendations within their exercise groups. It was further decided to involve the SVMB members who currently do not participate in exercise groups at a later stage of time.

Previously, the groups, each consisting of between 5 and 25 patients with axSpA, met weekly to conduct 45-60 min of spinal flexibility and strength exercises, mostly land-based, few water-based, or combined, under the supervision of a physiotherapist (PT). Health insurers refunded the costs for the attendance of these exercise groups.

The overall aim of this implementation project was to establish the PA recommendations for patients with axSpA participating in exercise groups to perform exercises regularly and adequately dosed (12). The PA recommendations were translated into a new SVMB exercise group concept, named “moveSVMB” (an acronym for *iMplementation Of physical actiVity rEcommendations in SVMB*). It incorporated the following key implementation activities: (a) 2 days of training for supervising PTs, (b) exercises in all fitness dimensions, according to the exercise guidelines (13), (c) quarterly individual exercise counselling with a supervising PT to support more individual exercise training, (d) bi-annual fitness-assessments, and (e) individual exercise training in addition to group exercise. All implementation activities were closely coordinated by SVMB management and study staff.

It is well known that the implementation of innovations in clinical routine is a great challenge (14, 15), requiring a planned and systematic approach with clear strategies. Knowledge

does not necessarily lead to changed behaviour (16-18). In this project, the implementation process was determined following the cyclical approach of Grol & Wensing' implementation of change model (19) and included the following steps (and publications): (A) analysis of the current clinical practice and settings (as briefly outlined above, (20)); (B) exploration of facilitators and barriers towards PA and exercise from the stakeholders' perspective, i.e. patients with axSpA, PTs and rheumatologists (21), including the patients' perspective on technology-based exercise (yet unpublished data); (C) development and application of a tailored implementation strategy; (D) pilot testing and adjustment of the applied strategy, and E) nationwide implementation.

The aim of the present pilot implementation study was to perform steps (C) and (D) and evaluate the adherence to recommended exercise behaviour on the levels of patients with axSpA, the fidelity to the new concept on the level of PTs, and the feasibility and satisfaction regarding the new concept, on the levels of patients, PTs and organisation. An additional objective was to investigate the effectiveness of PA recommendations at the level of patients. Furthermore, the long-term implementation fidelity was evaluated to gain lessons learned and inform the future nationwide implementation (step E).

Methods

The Standards for Reporting Implementation Studies (STaRI) checklist (22) were followed to report the implementation steps (additional file 1), as well as the recommendations for reporting implementation strategies (23). The study was registered (SNCTP000002880) and approved by the ethical board of Canton Zurich (BASEC-Nr. 2018-00145). PTs and patients gave written informed consent.

Study design

The pilot implementation study had a hybrid type 3 design (24). It was executed from June (T0) to November 2018 (T1), with evaluations at T1 and at T2 (T2 after 1 year). An implementation strategy, nested implementation activities and evaluation procedures for each of the relevant target groups were developed, i.e. patients with axSpA, PTs, and SVMB management. For details refer to Table 1 and “implementation strategy” section below. The outcomes and assessments used to evaluate the implementation strategy and the effectiveness of the PA recommendations on the level of patients with axSpA, are described in Table 2 and below in “Evaluations” section.

Implementation strategy

Targeting patients and PTs: the new exercise group concept “moveSVMB”

A new EG concept encompassing the following key elements was introduced:

a. *Training of supervising PTs*

The supervising PTs attend a mandatory 2 days of training to learn how to apply the new concept within their exercise groups. The training consists of: gaining knowledge and awareness of the general and EULAR PA recommendations and improving exercise counselling and motivational support skills. The monitoring of quality is performed by diary and peer-involvement through regular exchange between the PTs and study staff. Besides communication and psychological theory, PTs learn the practical use of the instrument PRISM (Pictorial Representation of Illness and Self Measure, described in Additional file 2) (25) and, behavioural change techniques, such as goal setting and strengthening self-efficacy using role plays. Furthermore, study staff and PTs discuss the study processes. During the pilot intervention a refresher event and regular support is provided, e.g. “help desk” for current issues.

b. *Correctly dosed exercises in all fitness dimensions*

PTs instruct and perform exercises in all fitness dimensions during the exercise group sessions. According to the current knowledge of exercise guidelines, the dosage of exercises follows the FITT (Frequency, Intensity, Type, Time) principles (8, 13). Patients are additionally informed about the importance and elements of adequate exercise through information provided by the SVMB (website, SVMB journal). Both activities enable patients to perform exercises alone.

c. *Individual and group exercise counselling*

PTs are asked to perform three individual exercise counselling sessions with each

patient and at least three group interventions to improve patients PA behaviour.

An individual counselling session lasts about 30 min. PTs are encouraged to use an empathic, supportive, yet directive counselling style, according to the principles of Motivational Interviewing (26). PTs are asked to start each individual session by applying the PRISM, which is a visual-tactile instrument that fosters communication, collaboration and mutual confidence (25, 27). PRISM can also be used to get to know a person better, by defining dimensions relevant to his/her life and, thus, enhancing intrinsic motivation and self-management activities (28). After using PRISM and, based on the assessments of the patient's fitness and his/her personal needs, the PT discusses with the patient how he/she can integrate more exercise into his/her everyday life. The fitness assessments help to identify the exercise dimension(s) with potential for improvement. In this regard, counselling may focus on raising consciousness, reinforcing the patients' PA behaviour, avoidance of relapse, or maintenance strategies. For example, some patients may need support in increasing the active time spent on light activities and reducing sedentary behaviour, while others may need a structured exercise plan to participate in a half-marathon. With each patient an individual goal and action plan is developed in a shared decision process.

Group counselling interventions may vary in time (5-45 min) and can be designed differently, according to the needs and interests of the group. Examples are, (a) theoretical and practical training on heart rate self-monitoring during aerobic exercise, and (b) group discussion on how to cope with barriers.

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d. *Fitness assessments*

During a regular exercise group session, a team of one senior (researcher) and several junior assessors (PT students) performs the fitness assessments with each participant, described as tertiary outcomes in Table 2 and Additional file 2. After the physical assessments, each patient is instructed to fill out six questionnaires at home. Furthermore, an exercise diary is explained and highly recommended, enabling feedback and reporting. Within 1 week, the individual assessment results are sent to the supervising PT for exercise counselling.

e. *Individual, unsupervised exercise training*

To fulfil the recommended amount of PA, one supervised exercise group a week is insufficient. The elements mentioned above should enable group members to engage in additional, unsupervised exercise. Based on the fitness assessments and personal preferences, the patient and PT agree on a training goal in one, or several, of the exercise dimensions and create an action plan. During the following counselling session, progress is evaluated and the goal reviewed.

Table 1. Elements of implementation strategy and implementation intervention activities according to Proctor (23)

Physiotherapists								
Element(s) of EG concept	Activity	Actors	Actions	Targets of change	Temporality (frequency)	Dose	Implementation outcomes affects; assessment	Justification
a)	Information	Study staff, self-study	Learn/recall characteristics of effectively dosed PA and exercise, purpose and methods of PA and exercise in line with actual guidelines/EULAR recommendations.	Knowledge and awareness	Workshop before implementation in EGs	2h	Knowledge, feeling of confidence in dealing with topic and promoting exercises; interview	Consciousness raising, Self-Reevaluation (both Transrational model)
a)	Education	PRISM expert	Aim, methodology and practical application of PRISM [27] in 1:1 counselling situation; communication skills to motivate and support groups, manage difficult situations, and encourage participants to perform (more) exercise.	Skills	Workshop before implementation in EGs	8h	Use of and adherence to the counselling elements (PRISM, MI); diary	Guided practice (Social Cognitive Theory)
a)	Education	Study staff, self-study	Learned/recalled how to elaborate a progressive exercise plan	Skills	Workshop before implementation in EGs	1h	Knowledge and development of exercise plans; diary	Guided practice (Social Cognitive Theory)
a)	Support	PT peer	PTs know each other and ask each other for support, exchange experiences	Peer-factor	n.d.	n.d.	Feeling supported; interview	Enhance network linkages (Theory of social networks)
c)	Supervision	Study staff	A «help desk» is provided by a study staff member to support in current issues. Regular refresher/supervision events with a PRISM expert are provided.	Motivation to ensure quality of intervention	As needed	As needed	Being motivated; interview	Feedback (Goal-Setting Theory, Social Cognitive Theory)

Table 1. Continued

Patients with axSpA								
Element(s) of EG concept	Strategy	Actors	Actions	Targets of change	Temporality (frequency)	Dose	Implementation outcomes affects; assessment	Justification
b) ; e)	Information	PTs, SVMB	PTs distribute handouts to patients and explain the four exercise dimensions and how to exercise appropriately. Questions are discussed in the EGs. SVMB supports the knowledge transfer by providing information on website and SVMB journals.	Knowledge and awareness of PAR	Weekly (PT) As needed (website) 4x/year (SVMB journal)	Ca. 5min as needed Ca.30min reading time	Awareness of how to perform effective exercises for each exercise dimension; exercise diary ¹	Consciousness -raising, Self-Reevaluation (both Transtheo-retical model)
b); e)	Support	Peer patients	Suitable peers, who successfully perform regular exercise, act as role models to support peers from their EG	Empower peer-factor	n.d.	n.d.	Feeling supported;	Modelling (social cognitive theory)
c); d)	Individualisation	PTs	Assessments help to identify active and non-active participants and which of the exercise dimensions have the potential for improvement. An individual goal and action plan is developed during the 1:1 sessions in a shared decision manner.	Setting goals, action planning, evaluation goal attainment	Bi-annual Assessments Quarterly counselling sessions	45min. 30min.	Performance in assessments and (frequency and dose) training in each exercise dimension; exercise diary ¹	Individualisation (Transtheo-retical model) Tailoring (Transtheo-retical model) Planning coping responses (Relapse Prevention Theory) Goal Setting (Goal Setting Theory) Set graded tasks (Social Cognitive Theory)

Table 1. Continued

Element(s) of EG concept	Strategy	Actors	Actions	Targets of change	Temporality (frequency)	Dose	Implementation outcomes affects; assessment	Justification
c)	Individual exercise counselling	PTs	PTs and each patient have five 1:1 exercise counselling sessions, to define exercise goals, identify and deal with barriers and utilisation of facilitators, supporting self-efficacy, relapse prevention. Furthermore, regular counselling sessions within the whole group are performed.	Motivation and coping, self-efficacy	5 sessions within 18months (3 sessions within first six months/ pilot phase, 2 booster sessions)	30min.	Goal and action plan; exercise diary, activity tracker Changes according to PRISM in the patients perceived burden of disease and importance of PA; PRISM	Feedback (Goal-Setting Theory, Social Cognitive Theory) Reinforcement (Social Cognitive Theory) Goal Setting (Goal Setting Theory) Set graded tasks (Social Cognitive Theory)
e)	Self-monitoring	Patients	Patients keep a diary about their exercise-activities, polar watches are provided for self-monitoring of the heart rate (not for data analysis)	Organisation in daily life / Routine	Daily reporting	Ca. 2-5 mins.	Exercise is part of the daily routine; exercise diary, activity tracker	Implementation interventions (Theories of Goal Directed behaviour) Feedback (Goal-Setting Theory, Social Cognitive Theory) Reinforcement (Social Cognitive Theory)

Table 1. Continued

Organisation	Actors	Actions	Targets of change	Temporality (frequency)	Dose	Implementation outcomes affects; assessment	Justification
Strategy Regular information exchange and discussion	Study staff	Study staff explains elements of the EG concept, which are discussed with SVMB management.	Awareness, decision to change routine care	Every three months	30min	Accept and implement new EG concept as usual care; vote of SVMB management	Sense-making (Organizational Development Theory)
Acquisition of third-party funds Support negotiations with insurers	CEO, SVMB project leader	Responsible members of SVMB management establish personal and financial resources to continue all elements of the EG concept after the pilot phase.	Embedding of new care in organization	n.d	n.d.	Establish finances and structures to maintain concept; staff positions, working hours/week	Technical Assistance (Organizational Development Theory)
Integration of SVMB-stakeholder in adaptation process	CEO, SVMB project leader	Study staff and SVMB management were in continuous exchange to ensure the feasibility of the new EG concept and satisfaction with its integration into routine care.	Acceptance EG concept	Every three months	30min	Feasibility and satisfaction; continuous contact	Increasing stakeholder influences (Stakeholder Theory)

n.d., not defined; SVMB, Ankylosing Spondylitis Association of Switzerland; PT, physiotherapist; EG= exercise group; PRISM, Pictorial Representation of Illness and Self Measure; ¹ paper or free app « Trainingstagebuch» by Johannes Tscholl

Targeting the SVMB

Regular meetings are held between SVMB management and study staff to ensure that the implementation activities align with the structures and processes of the SVMB. In addition, to increase the acceptance and feasibility of “moveSVMB”, a significant effort is put into establishing a long-term financial strategy and personnel resources.

Evaluations

Evaluation at T1

The primary outcome for the evaluation at the patient level was adherence to the recommended exercise behaviour, assessed by the number of reported training sessions per exercise dimension in the electronic exercise diary for over 6 months. The secondary outcomes at T1 were feasibility and satisfaction with the new exercise group concept, rated on a 0-10 numeric rating scale (0 = not satisfied, 10 = very satisfied; if > 50% of patients rate > 5, the concept was evaluated as “satisfying”) and changes in the perceived burden of disease or importance of PA, measured with PRISM. The tertiary outcome to evaluate the effectiveness of the individualised PA recommendations was the measured changes in the fitness levels of patients (T0 - T1), assessed by fitness parameters (Table 2).

The primary outcome for the evaluation at PT level was fidelity to the program design concept, assessed using a diary. Fidelity was rated as sufficient when 75% of PTs fulfilled the program. The secondary outcomes were treatment quality, feasibility and satisfaction, evaluated through semi-structured interviews.

The evaluation at the SVMB level focused on acceptance of the new exercise group concept and its establishment within organisational structures. In addition, regular progress meetings between study staff researchers and SVMB management were used to appraise the feasibility and effectiveness of the implementation interventions.

Evaluation at T2

Maintenance was monitored at T2 (1 year after T1) by assessing the number of patients and supervising PTs still adhering to the new group concept.

Adaptations of “moveSVMB”

After 6 months, the findings of evaluations on all three levels were considered while deciding on adaptations of the program concept of “moveSVMB”. Both SVMB management and study staff agreed on findings that negatively impacted the feasibility. Accordingly, they developed adaptations needed for a successful nationwide implementation of the new exercise group concept.

Study procedures

The four pilot exercise groups, comprising the supervising PTs and 5-12 patients with axSpA, from the German-speaking region of Switzerland were asked by the SVMB management

to volunteer. Criteria were a location close to the study center and the motivation and availability of PTs and group members. The participant PTs and patients were informed face-to-face about the new group concept “moveSVMB” well in advance. Group members declining to be measured or not providing written informed consent were offered the usual exercise group intervention.

Eligibility criteria for patients with axSpA were ≥ 18 years old, a member of a SVMB exercise group, and provision of written informed consent. All patients were screened for cardiovascular risk (29). Patients identified as at increased risk required confirmation from a PT or medical doctor that a higher level of exercise was not contraindicated. Criteria for exclusion were medically relevant contradictions to exercise (8). Eligibility criteria for PTs were being a supervisor PT of an existing SVMB group, willingness to follow the implementation protocol of the new exercise group concept (including a 2-day educational workshop), and provision of written informed consent.

At the beginning of the pilot study, some organisational requirements were defined. A cooperation with the BSc in physiotherapy programme at the ZHAW was established to recruit second year PT students to perform the fitness assessments in exercise groups under the supervision of a senior researcher. Additionally, third-party funding was secured prior to the start of negotiations with insurers concerning reimbursement. Throughout the pilot phase, the SVMB provided personnel (project manager, c.a. 17 h/week (40%), additional IT support), and was prepared to increase resources after evaluation of the pilot phase.

Statistics

Demographic, disease-specific, self-reported (diary or patient-reported outcome measures PROMS) and assessment data were presented as mean and standard deviations, or median and associated range for continuous data or as frequencies (percentages) for categorical variables. During the fitness tests, the maximal time of one leg stance was limited to 60 s, this being the length of time indicating that the individual has no balance problem. For each exercise dimension, a linear mixed model with random intercept was fitted to the data with the within-subject variables of time and measurement condition and the between-subject variables of age, disease duration, disease activity (Bath Ankylosing Spondylitis Mobility Index BASMI), and PA level (metabolic equivalent of tasks METs) as explanatory variables. PRISM data (in cm) were correlated with the Bath Ankylosing Spondylitis Disease Activity Index (BASDAI) and weekly METs using spearman rank correlation. Paired t-tests and Wilcoxon tests, with corresponding parametric and nonparametric effect sizes (ES), were computed to analyse within-group changes. All statistical analyses were performed using the R statistical software, R version 3.5.2 (R Foundation for Statistical Computing, Vienna, Austria).

Table 2. Evaluation of the implementation strategy and the effectiveness of the recommended PA behaviour at the level of patients with axSpA.

Evaluation of..	Patients with axSpA		Physiotherapists		Organisation	
	Outcome	Assessment (time of measure)	Outcome	Assessment (time of measure)	Outcome	Assessment (time of measure)
Implementation strategy	Primary: Adherence to recommended exercise behaviour	Exercise diary (continuous reporting)	Fidelity to new EG concept	Diary (continuous reporting)	Integration within organisation	Quality concept (T1)
	Secondary: feasibility & satisfaction	Survey (T1)	Feasibility	Interview (T1)	Finances	Funding, status of negotiations (T1, T2)
Effectiveness of interventions	Tertiary: effectiveness of recommended PA behaviour	PRISM (every counselling-session)	Satisfaction (feeling supported)	Survey (T1)	Personal resources	Working hours/week (T1, T2)
		Survey (T1)	Physical fitness in all exercise dimensions	Chester Step Test [61, 62] Swiss Olympic Core Test Battery [63] adapted for patients with axSpA [64] Single leg stance [65] Bath Ankylosing Spondylitis Mobility Index/BASMI [66]	Satisfaction	Interview (T1)
Effectiveness of interventions	General physical activity	International Physical Activity Questionnaire/IPAQ [67]	General physical activity	International Physical Activity Questionnaire/IPAQ [67]		
	Disease activity	Bath Ankylosing Spondylitis Disease Activity Index/BASDAI [66]	Disease activity	Bath Ankylosing Spondylitis Disease Activity Index/BASDAI [66]		
	Health status	Assessment of SpondyloArthritis international Society/ASAS-HI [69]	Health status	Bath Ankylosing Spondylitis Global Score/BAS-G [68]		
	Disease related quality of life	Euro-QoL Questionnaire [70]	Disease related quality of life	Assessment of SpondyloArthritis international Society/ASAS-HI [69]		

Time of effectiveness measures was T0 (baseline), T1 (after six months), T2 (after 12 months)
 The tertiary outcomes are the regular fitness assessments in the exercise groups, which were used to evaluate the effectiveness of interventions. Assessments are described in Supplement A.
 PRISM, Pictorial Representation of Illness and Self Measure; PA, physical activity; CEO, chief executive officer.

Results

Demographic and clinical data of exercise group members

Of the 43 patient members of the four pilot groups, 30 (70%) signed informed consent and participated in the baseline assessments. Reasons for non-participation were reported by ten members of the groups: timing of assessments due to holidays (3), lack of time (2), age or disease activity (2), no interest (2), no axSpA (1). The characteristics of the four pilot groups are described in *Table 3*.

During the 6-month pilot phase, two patients dropped out due to specified reasons: “I do not need exercise counselling”, and “it is too much pressure for me”. In addition, two patients did not participate in the assessments after 6 months due to an influenza.

Results at the level of patients with axSpA

Adherence to recommended exercise behaviour

Thirteen patients (43%) submitted an exercise diary each week to assess adherence to PA recommendations. None of these thirteen people fulfilled the PA recommendations in all four exercise dimensions. Four patients fulfilled the recommended dose of weekly cardiovascular exercises, one the recommendation of one additional exercise dimension, and two patients the recommendations of two additional exercise dimensions.

Feasibility and satisfaction

The survey's response rate was 90% (27/30). Since two were returned empty, 25 were used for analysis. Of these, 15 (62%) patients were satisfied with the concept “moveSVMB” (mean satisfaction 6.7 ± 2.2) and 20 (80%) with the exercise counselling (mean satisfaction 7.7 ± 2.9). Patients rated and commented the use of PRISM contrary (11 “not useful” vs 12 “useful”); appreciating (“I understand the relation between axSpA and my life” (*ID15*)) or criticising (“this is coffee cup reading to me” (*ID05*)). Twenty-two (88%) patients defined a training goal, 17 (68%) developed an action plan and 15 (60%) achieved their training goal. Sixteen (64%) patients used the exercise diary, five used app-based reporting. Reasons for non-reporting were: the daily effort, technical problems with the app, and problems with allocating activities to exercise dimensions correctly (e.g. is the SVMB exercise group strength or neuromotor exercising?). Personal adaptations were made to individual exercise goals (e.g. in terms of frequency or intensity of training) and to individual exercise diaries (e.g. notes in the personal agenda instead of the proposed sheets). A minority ($n = 7$, 28%) reported using a technical device (such as a heart rate tracker) for cardiovascular exercise. Seventeen (68%) were satisfied with the fitness assessment (mean 7.5 ± 1.8). Patients did not use the project name “moveSVMB” but suggested names such as “Bechterew-Fit” or “Bechterew-Gymnastics”.

Table 3. Characteristics of axSpA patients and supervising PTs at baseline

Characteristics	Total	Group 1	Group 2	Group 3	Group 4
Patients with axSpA					
Total number per group (n)	43	8	11	8	16
Number participating in "moveSvMB" (n)	30	3	6	7	14
Gender, women, n (%)	10 (33.3)	1 (33.3)	2 (33.3)	2 (28.5)	5 (35.7)
Years of age (median, range)	57.5 (37-75)	68 (37-72)	58 (51-71)	57 (45-68)	56.5 (49-75)
Disease duration, years (median, range)	30 (12-60)	49 (23-51)	33 (20-46)	30 (18-35)	30 (12-60)
ASAS-HI (median, range)	2.1 (0-11)	1 (0-3)	2.1 (0-6)	2 (0-8)	3 (0-11)
Physical activity level (IPAQ), total MET per week (median, range)	3919 (1520-14958)	3916 (2526-6933)	5820 (2298-10260)	2697 (1600-10638)	2853 (1520-14958)
Supervising PTs (n=4)					
PT group leader, gender (female/male)	-	f	f	f	m
PT group leader, age, years (median, range)	48.2 (34-54)	52	45	34	54
PT group leader since, years (median, range)	12 (2-23)	23	8	2	16

n, number; ASAS-HI, Assessment of SpondyloArthritis International Society Health Index; PT, Physiotherapists; IPAQ, International Physical Activity Questionnaire.

Changes according to PRISM

Neither the perceived burden of disease (distance to self at T0: 13.7 ± 7.2cm; at T1: 12.1 ± 6.2cm; t=0.386, p=0.703) nor the importance of PA (distance to self at, T0: 7.3 ± 5.3cm; at T1: 7.0 ± 4.5cm); t=0.246, p=0.808) changed over six months. The perceived importance of PA correlated with the International Physical Activity Questionnaire (IPAQ) measured METs at T1 (r=0.572, p=0.00), no correlation between perceived burden of disease and METs was found.

Effectiveness of individualised PA recommendations: Fitness status

Table 4 reports the results of the fitness assessments at baseline (T0) and after 6 months (T1). Patients' cardiorespiratory fitness (ES 1.22 (95%CI 0.59,1.90), large ES and significant) and core strength ventral muscle chain (ES 0.62 (95%CI 0.19, 1.06), medium ES and significant) improved over the six months. Core strength lateral and dorsal muscle chain, balance and flexibility did not change significantly over six months.

The linear mixed model analysis showed that disease activity was negatively (slope=-1.49, p=0.01) associated with cardiorespiratory fitness and the PA level (MET) positively (slope=3.28, p=0.01). The PA level was also positively associated with core muscle strength (slope= 8.62, p=0.05). Age was positively associated with flexibility (slope=0.10, p=0.04), but negatively associated with balance time (slope = -0.84 (p=0.00).

Table 4. Results of fitness assessments of the whole patient sample at T0 (baseline) and T1 (after six months).

Fitness assessment n missing values mean (SD) median (IQR 25/75)	T0 (n=30)	T1 (n=30)	Change (n=30)	ES (95% confidence interval)
Cardiorespiratory fitness, VO2max				*1.22 (0.59, 1.90)
n missing values	4	11	13	
mean (SD)	35.2 (6.5)	41.6 (6.5)	7.9 (6.5)	
median (IQR 25/75)	34.5 (32.6/39.7)	39.9 (38.2-46.0)		
Core strength, ventral, sec				*0.62 (0.19, 1.06)
n missing values	1	5	5	
mean (SD)	78.8 (51.9)	107.5 (65.4)	23.8 (38.6)	
median (IQR 25/75)	69.0 (40.0-100.0)	90.0 (64.0-149.0)		
Core strength, lateral, sec				0.17 (0.01, 0.55)
n missing values	1	5	5	
mean (SD)	49.0 (31.5)	57.9 (31.1)	7.6 (30.2)	
median (IQR 25/75)	39.0 (29.0-66.0)	51.0 (38.0-82.0)		
Core strength, dorsal, sec				0.30 (0.02, 0.65)
n missing values	1	7	7	
mean (SD)	58.5 (50.1)	71.7 (56.6)	9.7 (35.5)	
median (IQR 25/75)	35.0 (24.0-80.0)	59.0 (32.5-85.5)		
One leg stance, open eyes, mean of 3 reps, sec				0.10 (0.00, 0.48)
n missing values	0	4	4	
mean (SD)	43.1(21.1)	46.6 (19.6)	3.7 (14.0)	
median (IQR 25/75)	60.0 (24.5-60.0)	60.0 (34.0-60.0)		

Table 4. Continued

Fitness assessment n missing values mean (SD) median (IQR 25/75)	T0 (n=30)	T1 (n=30)	Change (n=30)	ES (95% confidence interval)
One leg stance, closed eyes, mean of 3 reps, sec	0	4	4	0.30 (0.02, 0.63)
n missing values	7.7 (5.8)	9.5 (7.8)	1.7 (5.5)	
mean (SD)	5.5 (5.0-15.5)	7.9 (3.0-14.9)		
median (IQR 25/75)				
BASMI, Score	0	4	4	*-0.28 (-0.68,0.12)
n missing values	3.1 (2.3)	2.9 (2.0)	-0.2 (0.9)	
mean (SD)	2.4 (1.2-4.5)	2.3 (1.2-4.7)		
median (IQR 25/75)				
IPAQ, MET per week				0.15 (0.00, 0.58)
n missing values	1	9	10	
mean (SD)	5013 (3479)	4101 (4262)	-199.8 (2712.2)	
median (IQR 25/75)	3916 (1520-14958)	3150 (1470-4502)		
BASDAI				*0.06 (-0.39, 0.51)
n missing values	1	9	10	
mean (SD)	3.0 (1.7)	3.0 (2.2)	0.0 (1.1)	
median (IQR 25/75)	3.0 (1.8-4.1)	2.2 (1.3-4.4)		
BAS-G				0.02 (0.00, 0.49)
n missing values	1	9	10	
mean (SD)	2.9 (1.8)	2.6 (1.8)	-0.2 (1.6)	
median (IQR 25/75)	2.4 (1.4-4.5)	2.2 (1.1-3.7)		
ASAS-HI				0.12 (0.00, 0.54)
n missing values	1	9	10	
mean (SD)	3.0 (2.6)	2.5 (0.7)	-0.8 (3.3)	
median (IQR 25/75)	2.1 (1.0-4.0)	3.0 (2.0-3.0)		

Effect sizes (ES) were computed from Wilcoxon tests and paired t-tests, using r for non-parametric and Cohen's d for parametric* analysis, respectively. Interpretation of ES: r: 0.1-0.3 (small), 0.3-0.5 (moderate) and > 0.5 (large). Cohen's d: 0.2 (small), 0.5 (medium), 0.8 (large).

IQR, interquartile range; sec, seconds; SD, standard deviation; BASMI, Bath Ankylosing Spondylitis Mobility Index; reps, repetitions; IPAQ, International Physical Activity Questionnaire; BASDAI, Bath Ankylosing Spondylitis Disease Activity Index; BAS-G, Bath Ankylosing Spondylitis patient global score; ASAS-HI, Assessment of SpondyloArthritis international Society Health Index.

Results at the PT level

Fidelity to the new exercise group concept

Three of the four PTs (75%) performed and reported on three group counselling sessions within the 6 months, with a mean duration of 18 (\pm 13) minutes. Due to a misunderstanding, one PT did no group counselling sessions. The counselling sessions consisted of knowledge transfer (e.g. reading and discussing PA recommendations) and skills training (e.g. training with a heart rate monitor). The number of patients participating in the group counselling interventions varied between four and twelve per session and group.

All four PTs performed and reported three individual exercise counselling sessions with 27 of 30 patients (90%). Two patients dropped out after the first session and one patient participated in only two sessions before leaving the group for personal reasons. Of the 27 patients receiving the three counselling sessions, 11 (40%) received the three counselling sessions within 6 months, as required by the concept; 10 (37%) within 9 months, and six (22%) within 12 months. The delay was due to organisational factors in all cases.

The mean duration of an individual counselling session was 35 (± 7) minutes. During the first session, the PTs used the PRISM to take the patient's history, explain the results of the fitness assessment and, through shared decision-making, to define one, or more, training goals. Subsequently, based on the patient's preferences, an action plan was developed. During the second and third sessions, PTs used PRISM to evaluate, together with the patient, whether the goal(s) had been reached, or whether adaptations to the goals or planned actions were needed due to changes in fitness status or PA-behaviour.

The mean duration of PRISM usage was 9 (± 3) minutes during the first session, 10 (± 4) minutes during the second, and 7 (± 3) minutes during the third.

Using PRISM, PTs measured and reported on the burden of disease and importance of PA for 25 participants.

Feasibility and satisfaction

PTs perceived the PRISM communication and exercise counselling as very useful, since they previously had little knowledge of the history and exercise goals of their patients. Exercise counselling supported the possibility of personalized exercise. They emphasised that the frequency of the sessions must be flexibly planned, based on the patient's individual training goal and motivation. The PRISM was perceived as a useful door opener, triggering emotions and information, if the patient's attitude was open to the new communication tool. PTs reported that they initially felt unconfident when applying PRISM; this feeling was diminished during the pilot phase through supervision and practice. The PTs perceived varying reactions from patients regarding the fitness assessments, some found that they increased motivation to exercise and others found them demotivating. During exercise counselling, PTs indicated that they found the fitness assessment data difficult to interpret because of the lack of background information (e.g. norm data) and that they rarely relied on them. The PTs felt, that the frequency of fitness assessments could be reduced from bi-annually to annually.

Results at the organisational level

Satisfaction and commitment of the SVMB management was found to be high after the pilot phase. Consequently, the SVMB management decided to integrate the new exercise group concept into the organisation and implement it as the new usual care in all its SVMB exercise groups.

Maintenance

After 1 year (T2), the same supervising PTs were responsible for their exercise groups and were actively involved in the nationwide implementation process. The four pilot exercise groups lost one member due to personal reasons, but gained two new members. Therefore, 29 patients actively participated in the programme, of whom 21 (72%) participated in the fitness assessments at T2.

Adaptations to the implementation strategy

Some implementation activities were found to be not fully feasible in our setting. Minor adaptations were made to improve adherence to the recommended exercise behaviour (patients), concept fidelity (PTs), and feasibility of nationwide implementation (SVMB). The barriers and adaptations are described in Table 5.

Table 5. Adaptations of Implementation Strategy to increase feasibility for nationwide implementation

Physiotherapists			
Strategy	Target of change	Barriers	Adaptation
Education	Skills	Two-days workshop was too expensive and too time-consuming. Future supervising PTs do not need information on study procedures.	Reduction to one-day workshop + supervision
Patients with axSpA			
Individualisation, Exercise counselling	Motivation and coping, self-efficacy	Due to organisational reasons, PTs had three exercise counselling sessions with only 40% of group members within 6 months. Group setting was not asked for, but 1:1 setting was appreciated.	Number of exercise counselling sessions reduced to 1-2 per year. No fixed, mandatory group discussions.
Individualisation, Exercise counselling	Setting goals, action planning, evaluation goal attainment	PTs did not use the assessments to define exercise goals, as there were no norm data or previous data available. The exercise diary was approved as a useful tool. Paper version needs adaptations. Electronic version ("Trainingstagebuch" by Johannes Tscholl) prone to error.	New project on norm data will be launched. The more measurements are carried out, the more comparisons exist and enable a better interpretation. Paper version adapted (better explanations, examples). Development of electronic version is currently considered by SVMB IT.
Organisation			
Integration of stakeholders	Acceptance of EG concept	62% satisfied with EG concept, 80% satisfied with exercise counselling, 68% satisfied with fitness assessments. « MOVE SVMB » was not used by participants.	« MOVE SVMB » changed to «BeFit» and a new logo was released

PA, physical activity; SVMB, The Ankylosing Spondylitis Association of Switzerland; PT= physiotherapist, EG= exercise group, PRISM = Pictorial Representation of Illness and Self Measure

Exercise counselling and the fitness assessments were generally appreciated by the patients, but the frequencies of both was perceived as being too high. Accordingly, the fitness assessments were reduced from bi-annually to annually, and the individual exercise counselling sessions reduced from three to two sessions in the first 6 months. The first session was compulsory for all participants and the second dependent on individual needs and training goals. The group counselling sessions were perceived to be useful, but the definition of frequency and structure was removed. There is a great need for a simple exercise diary, covering all the exercise dimensions. An improvement was made to the paper diary through providing better explanations. This version will be used until a digital

exercise diary becomes available.

The 2-day educational workshop for PTs was thought to be too time-consuming for clinicians. Furthermore, the information strategy of the SVMB had already increased awareness and knowledge of the new concept amongst the PT community. The training will therefore be reduced to 1 day and the workshop will focus on exercise counselling (including behavioural change techniques and PRISM).

Based on suggestions from patients, the name “moveSVMB” was changed by the SVMB to “BeFit” (“Bechterew Fitness”) and a new logo was developed. Following the pilot phase, information about BeFit was released by the SVMB, with no involvement of the study staff. In addition, the financial and personnel resources were established to ensure a continuation of the implementation.

Discussion

To our knowledge, this is the first study to translate and implement PA recommendations within a specific patient organisation into an exercise group concept for patients with axSpA and their supervising PTs. Findings will inform the nationwide implementation in Switzerland and similar projects in the Netherlands.

The findings of the pilot phase found the implementation strategy was acceptable and satisfactory to patients, PTs, and the SVMB. This resulted in SVMB management adopting the exercise group concept as its new usual care and implementing it in all its exercise groups. Successful implementation can only happen if the SVMB takes responsibility and initiates crucial changes at organisational level. Findings generally confirm the value of evidence-based exercise groups provided by a patient organisation to support active PA behaviour.

The patients' adherence to recommended exercise behaviour was assessed as insufficient. Reasons for non-adherence of patients may be two-fold: (1) The assessment of adherence to recommended exercise behaviour in patients with axSpA was difficult due to technical problems with the app and possible reporting bias; (2) the adherence was low in terms of performing insufficient amount of exercise according to recommended frequency and dose, as well as reporting exercise sessions. According to the reporting, only four patients fulfilled the recommended amount of aerobic exercise, three of them fulfilled one or two additional exercise dimensions. Factors like limited personal motivation may moderate the level of adherence to change current exercise behaviour or difficulty to achieve the agreed goals. However, it would have been useful to have learned more about the attitude of the patients towards changing their PA behaviour through asking them, prior to the first counselling session, about their satisfaction with their current PA level and whether they were motivated to increase their exercise behaviour. To show improved fitness in exercise dimensions, specific and adequately dosed training is needed. The implementation fidelity in PTs was found to be good, with their adherence to performance and the reporting of exercise counselling being sufficient. The level of adherence was affected by factors such as patient' responsiveness, quality of counselling, and organisational aspects (e.g. time constraints). However, only small organisational adaptations needed to be made by the PTs, according to the individual local group setting, such as to the scheduling and the setting of counselling sessions. The reduced number and more flexible planning of counselling sessions should enhance feasibility in the future and result in improved performance (during pilot study only 40% of patients had the counselling sessions within six months).

The four pilot PTs could be viewed as a special group since they were presumably "innovators", an active group keen on new ideas and innovations (30, 31). The pilot PTs were immediately willing to adapt their usual care and confirmed the value of change. GroI and Wensing describe five phases in the process of change for health professionals:

orientation, insight, acceptance, change, maintenance (19). Other supervising PTs might be harder to persuade of the benefits of the new concepts, since old routines need to be first de-implemented to move from acceptance to change and maintenance. Therefore, clear leadership by the SVMB management and the pilot PTs, as role models, are essential for the further implementation among supervising PTs.

Patients reporting could be improved in future through technical applications, which might be more appropriate to the collection of objective data than a paper diary (32). These could also be used as a promotion strategy (e.g. feedback, reinforcement) (33, 34). However, the assessment of PA and reporting on all fitness dimensions simultaneously in the same tool is a big challenge, and a perfect tool is not yet available (35, 36). The adapted paper version of the diary must serve as a placeholder until an electronic solution is developed.

PT needs two critical competencies to work with an exercise group: detailed knowledge of the PA recommendations and communication skills. Even though PA promotion is a key concept of physical therapy (37), and both patients and PTs agree that advice and support of active PA behaviour is part of the therapist's role (38, 39), there seems to be a PT educational gap. Data from the UK and Canada indicate that the majority of PTs neither have detailed knowledge of PA recommendations, nor meet the recommended PA level themselves (40, 41).

A preliminary analysis of counselling sessions has revealed that during the first counselling session one of the techniques most used by PTs to change behaviour (42) was 'general intention building'. No specific goal setting technique was applied (unpublished data). PTs generally use only a few behavioural change techniques (43). This finding underpins the need for continuous training of PTs in communication and behaviour change techniques. Hilberdink and colleagues (44) have mapped a toolkit to optimise exercise behaviour of people with axSpA: (1) Patients should be offered behavioural change guidance, including education, motivational interviewing, goal setting, action planning, monitoring and feedback. Patients need to be encouraged to exercise in a group setting. (2) PTs need to be educated to tailor and instruct an exercise programme and apply behaviour change techniques. Some first effort is made to downscale the lack of evidence-based education and training for health professionals working with rheumatic conditions (45). Others (9, 44, 46) emphasise that interventions are needed for patients with axSpA including behaviour change techniques, that aim to deliver intrinsic motivation to overcome barriers to exercise (47-49) and to sustain an active lifestyle.

In this project, it took several years to determine the appropriate implementation process, following the cyclical approach of Grol and Wensing's implementation of change model (19). During this development period Koorts and colleagues (47) published the PRACTIS guide, which supports the planning and scaling-up of physical activity implementation projects. PRACTIS focuses more specifically on PA promotion research translation and gives

detailed “how to” support. Both approaches have a common ground and are appropriate theoretical approaches to describe an implementation process and to explain what influences implementation outcomes and the implementation success. One strength of this pilot project is that an implementation scientist was involved from the start, following the “innovative collaborative model” (48). Further strengths are the in-depth contextual analysis that has been undertaken (20, 21) and the stakeholder involvement from the beginning. The group setting for exercise therapy is considered equally effective as individual therapy, but with lower healthcare cost (49). Furthermore, group therapy is attributed a potentially motivating factor for physical activity behaviour change (50). Despite this knowledge, however, the social rules or “group dynamics” (51) within the pilot groups and their impact on individual motivation or PA adherence was not investigated in this study. Social learning (52) within group activities (counselling, and assessment) appears to be an important subject and should be investigated further in future studies.

The sample size of the four pilot groups with 30 patients was small. However, since effectiveness aspects were not the main focus, no prior sample size calculation or bias-prevention, such as blinding, were necessary. According to literature, men and women are equally affected by axSpA (53). However, in the pilot groups there were more men than women participated (2:1 ratio). A further limiting factor is the use of self-reported outcomes and not of validated assessments to measure the implementation success. However, this approach was pragmatic and feasible. Future research projects should try to overcome these limitations. The exercise group concept could be a valuable strategy in enhancing patients’ daily exercise routines. However, fulfilling the PA recommendations in all exercise dimensions is a very high goal. Continuous monitoring of the exercise group concept is needed to follow-up on patients’ exercise behaviour and further improve the strategies of how to fulfil the PA recommendations.

Many patients prefer individual therapy. For example, 32% of the Swiss axSpA patients prefer individual, mainly inactive therapy (20). Dutch patients participating in axSpA exercise groups, however, were positive about subsequently established additional home exercises, annual assessments and training using heart-rate monitors (54). To reach patients who prefer an individual setting, or the inactive therapy approach, a patient education and PA promotion concept supporting the understanding of exercise as medicine needs to be developed.

Further research is also needed to investigate the effects on patients with axSpA of strength or neuromotor exercises alone, not in combination with cardio-respiratory exercises, since no such studies have been conducted as yet (11). It has also previously been stated that flexibility exercises are beneficial to spinal flexibility (2). However, no studies on flexibility exercises alone were found although exercises combined with muscle strength or aerobic exercise did not affect flexibility (11). Recent studies have confirmed that intensive cardio-respiratory exercise is effective, safe and feasible in patients with axSpA (55). No detrimental

effects were shown, rather a beneficial impact on disease activity and risk of cardiovascular diseases was approved (9, 56, 57). Similar strong evidence is lacking for the other fitness dimensions. A recently published review confirmed that exercise intervention studies in people with inflammatory arthritis are not adequately reported, neither was the exercise dose underpinned with evidence (58). Furthermore, better knowledge of adherence patterns, e.g. coping mechanism related to PA, or patient profiles matching group versus individual exercise modes, is needed (59).

During a national implementation, continuous monitoring will be needed to avoid ineffective elements of the exercise group concept (60). The balance between fidelity (degree of adherence) to and adaptation of the implementation strategy and interventions (the degree to which users modify the strategy and interventions to suit local needs) should be monitored and evaluated. A threshold for patient adherence should be defined for better evaluation of an implementation success. Furthermore, economic analysis on the levels of patient, provider, organisation and system should be performed to evaluate the concept's efficacy from an economical point of view.

Conclusions

This manuscript describes an implementation strategy to translate PA recommendations for patients with axSpA into a new exercise group concept for clinical practice and to embed then into the routine process (usual care) of a patient organisation. The implementation strategy was successfully evaluated in a pilot study including key stakeholders: patients, PTs, and patient organisation. The implementation project addressed a need at organisational level through delivering evidence-based therapy to patients and enhancing the competencies of the supervising PTs. Based on the results of the pilot study, technical problems, which hampered a reliable evaluation of the adherence rate of patients, and some other adaptations were necessary to increase the feasibility for a nationwide implementation. Further work is required in order to improve the quality of the assessments, the exercise counselling, and the individual exercising. The successful pilot strategy and necessary adaptations are explained in detail to make the knowledge available to future translational research projects in the field of RMDs. The upcoming nationwide implementation process needs to be monitored so that implementation problems or changes in the needs of patients with axSpA, PTs, or SVMB can be addressed early.

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Authors' contributions

AKRO drafted the manuscript, all authors reviewed it for important intellectual content, all authors approved the final version to be published. Study initialisation and execution: AKRO, KN. Study conception and design: AKRO, KN, TVW, LVB, SB, AC. Acquisition of data: AKRO, KN, BT, IN. Analysis and interpretation of data: AKRO, KN, IN, AM, TVW, LVB. All authors read and approved the final manuscript.

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Competing interests

The authors declare no conflict of interest.

Additional Files:

- Additional file 1. Standards for Reporting Implementation Studies: the StaRI checklist for completion.
- Additional file 2. Description of assessments (PRISM, fitness assessments, interview with PTs).

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8

General discussion

Physical Activity (PA) is one of the most important lifestyle factors influencing human health. The general and disease-specific health benefits of PA are well known to the general population and to those people living with rheumatic musculoskeletal diseases (RMDs) (1-4). The importance of PA as an intervention for the management of RMDs has been endorsed by various stakeholders, e.g. the World Health Organisation/WHO (5), the European Commission (6), and the European Alliance of Associations for Rheumatology/EULAR (7). The early translation of research evidence into clinical care benefits patients with RMDs greatly.

Axial spondyloarthritis (axSpA) is a chronic inflammatory RMD that predominately affects the axial skeleton, sacroiliac joints, and spine. It causes structural and functional impairments that have a significant impact on the individual's quality of life and ability to work (8, 9).

This thesis is focused on the effects and promotion of PA and exercise on people with RMDs, and particularly those with axSpA.

The overall aim of this thesis was to document the journey from the development of the EULAR PA recommendations for people with RMDs (including axSpA) to the practical implementation of a concept for group exercise therapy for people with axSpA that conforms to these recommendations. Chapter 1 outlines the background of this thesis. Chapter 2 describes the development and definition, based on expert opinion and current evidence, of the EULAR PA recommendations for people with RMDs. Chapter 3 addresses the effectiveness of PA interventions (based on the four exercise dimensions of cardiorespiratory, muscle strength, flexibility and neuromotor) and the promotion of PA to meet public health recommendations for people with RMDs. The following chapters, 4 to 7, outline the process of translating the EULAR PA recommendations into the "BeFit" group exercise therapy concept. This concept was subsequently pilot-tested in group exercise therapy for people living with axSpA in Switzerland.

General conclusions

In Chapter 2, one of the EULAR recommendations on PA developed by an international, multistakeholder task force, states that the public health recommendations are also applicable to people with RMDs. Chapter 3 corroborates the evidence that exercising according to public health PA recommendations is effective, safe and feasible for people with RMDs, and that exercises should cover the four exercise dimensions of cardiorespiratory, muscle strength, flexibility and neuromotor exercise. The promotion of PA consistent with these recommendations should be an integral part of routine care throughout the course of RMDs (Chapter 2). It is noted, however, that people with RMDs may have disease-related barriers to PA and additional requirements might need to be considered. Therefore, the EULAR PA recommendations emphasise other important aspects relating to the planning and delivery

of PA interventions, such as shared decision-making, the consideration of behavioural change techniques, and the addressing of contraindications and related comorbidities (Chapter 2). The EULAR PA recommendations for people with RMDs strengthen the non-pharmacological treatment of their diseases.

Specifically in axSpA, exercise recommendations have been made for decades, however, new insights warranted an update of research on this topic. These insights concerned firstly the realisation that people with axSpA have an increased risk of cardiovascular diseases and, secondly, the questionable therapeutic validity of conventional exercises programmes compared with exercising according to general PA recommendations for people with axSpA. Through the publication of the EULAR PA recommendations (Chapter 2), appropriate exercise principles and standards of support were determined for people with axSpA. However, new scientific insights do not automatically get implemented into daily practice and tailored strategies were needed to embed the EULAR PA recommendations into routine clinical care. This thesis presents the process of translating the state-of-the-art knowledge on exercising according to the EULAR PA recommendations into the group exercise concept BeFit and, thus, to complement the care of people with axSpA living in Switzerland (Chapter 7). The BeFit concept aims to support people with axSpA in performing exercise training according to the EULAR PA recommendations by means of several implementation activities. The development of these tailored implementation strategies required several steps:

- The evaluation of the current usage, experiences, and preferences regarding the delivery of individual and group exercise physiotherapy in Switzerland and the Netherlands (Chapter 4). This study showed that: more than 80% of participants had received physiotherapy; the interventions in an individual setting were mainly of a passive nature; and that the majority of participants were unaware of the increased cardiovascular risk and the subsequent importance of aerobic exercises.

These findings led to:

- A qualitative study exploring patients' behavioural, normative and control beliefs regarding PA (Chapter 5). This study confirmed that some people with axSpA were unaware of the conceptual difference between general PA and specific aerobic exercises. However, the findings also revealed that people with axSpA had a positive attitude towards exercise and that they considered exercising to be an effective self-management strategy.
- A cross-sectional study (Chapter 6) focusing on finding a suitable assessment to measure core strength. This is essential when developing an exercise programme tailored to individual capabilities. Previously, an appropriate assessment for people with axSpA in a group setting had not been available. The intra-tester reliability was found to be moderate to substantial. Additionally, no correlations with disease-specific factors, such as functional status, pain, or perceived strength, were identified. The adapted test battery chosen in the study to assess core strength was therefore used in the BeFit exercise concept.
- A final description of the implementation strategies for BeFit and pilot-testing

of the programme (Chapter 7). Overall, the acceptance and satisfaction with the new concept were found to be 'sufficient' at all levels, i.e., that of patients, physiotherapists, and the organisation. However, some adaptations were deemed necessary prior to its nationwide implementation, e.g., a reduction in the frequency of assessments and exercise counselling, the need of developing an electronic exercise diary (Chapter 7).

This thesis adds value by describing the entire development process in Switzerland, from the development of the EULAR PA recommendations for people with RMDs to their clinical implementation for people with axSpA. The relevant stakeholders were involved at all stages.

Methodological considerations

According to the principles of good clinical research practice, scientific quality standards for design, execution and reporting, as well as ethical considerations, should be taken into consideration (10). The studies described in this thesis included a systematic review with meta-analyses, guideline development, qualitative and quantitative observations, and a pilot implementation study with a hybrid design. All such studies have inherent strengths and limitations.

Chapters 2 and 3: Development of the EULAR PA recommendations

The methodology of the development of the EULAR recommendations is clearly defined and the related scientific publications were all multi-stage peer-reviewed and EULAR-approved (11). The EULAR standardised operating procedures (SOPs) (11) align with the AGREE (Appraisal of Guidelines for Research and Evaluation) instrument for developing and reporting guidelines (12).

Some strengths and limitations of this approach should be discussed. Firstly, to increase their generalisability and applicability, the recommendations focused on three relatively prevalent RMDs, i.e., rheumatoid arthritis, spondyloarthritis, and hip/knee osteoarthritis. However, due to the large heterogeneity of these conditions, this may have limited the precision of the recommendations. On the other hand, it can also be debated whether this selection of RMDs may limit the generalizability to other RMDs. In that respect, the further development of additional, disease-specific recommendations could be of use. Moreover, there were some challenges regarding the informing SR and MA described in Chapter 3. The data extraction and interpretation of the included studies were hampered by the overall incomplete reporting of interventions. The investigated exercise intervention modalities or dosage were often not transparent (FITT-VP principles: **f**requency, **i**ntensity, **t**ype, **t**ime, **v**olume, **p**rogression). Therefore, it was often difficult to determine whether a study fulfilled the inclusion criteria. Consistent reporting, according to the template for intervention **d**escription and **r**eplication checklist (TIDieR) (13) or FITT-VP principles

(14), would have eased understanding and interpretation of the studies. A vast array of outcomes and assessments exists in the field of PA, including in the exercise dimensions of cardiorespiratory, strength, flexibility and neuromotor exercise, that limits the conduct and generalisability of MAs. Indeed, the observed variation in reporting outcomes was large, elucidating the fact that a consensus on PA outcomes and their assessment could facilitate research using comparative outcomes and findings. For example, the use of verified objective measures and similar definitions of low, moderate, and high intensity PA, could positively influence the internal and external validity of findings. The task force members, however, were aware of the limitations regarding cross-study comparison and the MA formed a useful basis for their work. The need for more studies investigating long-term interventions with a larger number of participants and harmonised assessments nevertheless remains. A further limitation was that no, or minimal, information was found on the effects of the following interventions: flexibility exercise alone on flexibility/joint range of motion; of neuromotor exercise on neuromotor performance; or of interventions that targeted all four exercise dimensions. Lastly, the searches were performed over the period up to 7/2017 and do not, therefore, include more recent evidence. The research field of exercise interventions and the promotion of PA is a highly active one. In addition, the current WHO PA recommendations differ slightly from the recommendations that were authoritative during the development process of the EULAR PA recommendations, e.g., with respect to the minimum amount of activity to be counted as aerobic activity. From today's perspective, it can be assumed that important literature, e.g. on high intensity aerobic exercise, dose-response-relationship, or on the value of wearable-based PA promotion, could be added to fully reflect the fast-developing state of knowledge (4, 15-25). According to the update policy embedded in the EULAR SOPs (11), new insights should be monitored and considered by the convenor and members of the original task force, or experts in the field who can also apply for an update grant to EULAR. This process might be initiated in the near future.

Chapters 4 to 7: Implementation of the EULAR PA recommendations

The average time between an innovation and the application of the evidence into health care is 17 years (26). Even more important is the prompt real-world implementation of evidence-based interventions to improve health care. Therefore, specific implementation studies are needed to evaluate the effectiveness of a PA intervention in the real-world setting and the reasons for the success or failure of PA interventions in a specific context (27).

Study designs in implementation research

The benefit of a hybrid study design is that it takes a dual focus a priori on the assessments of clinical effectiveness and implementation (28). This enables a more rapid transfer of evidence into clinical care. There are three types of hybrid study designs that vary depending on the level of their focus on effectiveness and implementation: hybrid type 1 is primarily used to investigate the effectiveness of a clinical intervention, while simultaneously gathering information on its implementation in a real-world setting (28); hybrid type 2 has a dual focus on the effectiveness of the intervention and implementation related factors (29). It

was decided to use the hybrid type 3 design for the study on the implementation of a novel approach for group exercise therapy in axSpA (Chapter 7). A hybrid type 3 is focused largely on the implementation of the intervention once the effectiveness of the intervention has been established (28). This design is characterised by an explicitly described plausible implementation strategy in the real-world setting, together with clearly defined outcomes for implementation (primary) and intervention (secondary) components (29). This design is used for pilot-implementation studies evaluating feasibility and risks compromising the implementation or intervention. The study described in Chapter 7 indeed struggled with unclear cut-offs for sufficient implementation outcomes, such as patient adherence. However, lessons learned from this pilot study will feed into the national implementation study, which is likely also designed as a hybrid type 3 study.

Implementation approaches and frameworks

The task force responsible for the EULAR PA recommendations (Chapter 2) stated that specific strategies are needed to implement the recommendations in the different health systems and cultures across Europe. To ensure tailoring to the individual target groups, all stakeholders need to be involved from the start of the process. Accordingly, in Switzerland, the EULAR PA recommendations were translated into the BeFit concept for group exercise therapy, to be offered by the Ankylosing Spondylitis Association of Switzerland (SVMB) for people with axSpA (Chapter 7). Some of the concept development steps are described in Chapters 4-6, whereas other important steps have been published (or submitted) independently of this thesis. These steps included the: evaluation of the barriers and facilitators for vigorous exercise from the perspectives of the patients, physiotherapists, and rheumatologists (24); translation and validation of the German exercise self-efficacy scale (30); evaluation of the communication skills of physiotherapists (31); and the evaluation of the feasibility of assessments in a group exercise setting (32).

The implementation steps established in this thesis were the development of an implementation strategy, nested implementation activities, and evaluation procedures for each relevant target group, e.g., people with axSpA, physiotherapists and SVMB management.

Several systematic approaches are available to guide the process of translating research into practice (33). The implementation of change model by Grol&Wensing was applied in this thesis (34). It is comprised of seven iterative steps: (1) the development of a proposal for change; (2) analysis of the current situation; (3) understanding of the target groups and setting; (4) development of strategies and measures of change; (5) pilot testing; (6) adaptation; (7) continuous evaluation. This is one of the most established approaches from a vast number of models/frameworks/theories underlying implementation sciences (35) and has been applied across a wide range of health-care settings and clinical behaviours (36-38).

When the conceptualisation of this thesis was already well advanced, Koorts and colleagues

(39) published a similar, but more specific, guide on the planning and scaling-up of PA implementation projects, called PRACTIS (**P**RACTICAL planning for **I**mplementation and **S**cale-up). PRACTIS follows four steps that guide, with detailed 'how to' support, through: 1) exploration of the implementation setting; 2) identification and engagement of the key stakeholder; 3) identification of barriers and facilitators; and 4) addressing the potential barriers and facilitators to implementation. An increasing number of studies implementing PA interventions are using this approach (40-42).

Both approaches have common ground and are theoretical approaches appropriate to describing an implementation process and explaining the influences on the implementation outcomes and success. However, Grol&Wensing's model covers the whole implementation process, emphasising the importance of continuous evaluation and adaptation of strategies and measures. PRACTIS focuses on the initiation of contextually relevant processes to translate research into practice. It implies a participatory approach, putting emphasis on the early identification and systematic collaboration of key stakeholders at multiple levels, whether part of the study staff or advisory board. Following the model of Grol&Wensing, the important stakeholders, such as patients, physiotherapists, rheumatologists, and SVMB management were indeed involved, but not in the systematic and collaborative way as proposed by PRACTIS. In this study, people with axSpA, the patient organisation SVMB, and experts representing several relevant professions were included at some stage during the development of the implementation strategy, through participation in focus groups, interviews and surveys. Engaging people with axSpA and physiotherapists more intensively from the very start, e.g., by means of regular consultation at a stakeholder advisory board, could have had a more positive impact on the acceptance of the implementation activities of the new group exercise concept. Although acceptance was found to be sufficient during the pilot phase, a great deal of effort was needed by the staff members, patients and physiotherapists. Both, patients and physiotherapists had to be persuaded to participate. Patients and physiotherapists had to be educated on the new insights regarding exercise, especially the importance of cardiorespiratory exercise. They had to be convinced of the value of the new group exercise concept. The patients, particularly, approved of the evidence-based adaptations to the concept. They wanted individual training support and to be sure that the health insurances would continue to pay for the group exercises. However, only 70% of the pilot group members agreed to participate in the new group exercise concept and give informed consent for data collection. The physiotherapists supervising the pilot groups were very motivated, enthusiastic about the application of the new ideas and did not expect to be fully compensated for their effort. Although the SVMB paid for the group exercise therapy and counselling sessions, the introduction of new ideas always takes the physiotherapist additional time, such as for organising appointments or explaining procedures. The physiotherapists were willing to adapt their usual care and facilitated a positive attitude towards BeFit within the groups. This positive view may consequently support the long-term maintenance of the therapy for both physiotherapists and the group members with axSpA. According to Grol&Wensing (34), health professionals go through

five phases of change behaviour: orientation, insight, acceptance, change, maintenance. Physiotherapists generally (other than those supervising the pilot groups) may initially not be so enthusiastic about the change to the group exercise concept and could resist its implementation. Clear leadership by SVMB management and the pilot physiotherapists, as role models, is essential for national implementation.

Research into insights in current care delivery and patients' beliefs regarding PA and exercise

Chapter 4 presented a cross-sectional survey conducted on the use of physiotherapy in the western region of the Netherlands and the German-speaking part of Switzerland. This study was performed to learn more about the current situation in both countries and to provide information for upcoming implementation projects in Switzerland (project lead K. Niedermann and A. Rausch) and in the Netherlands (project lead T. Vliet Vlieland, S. van Weely, and B. Hilberdink). A number of limitations are associated with this survey. The recruitment and selection of respondents varied in the two countries, being drawn from the members of a patient organisation in Switzerland and from outpatient rheumatology clinics of three hospitals in the Netherlands. The survey was self-developed and could have been more specific about the therapy modalities (e.g., intensity, content of group therapy), especially in the group exercise setting. No pilot testing was performed to evaluate face or construct validity. Finally, the translation from the Dutch language into German and its cultural adaption was not guided by an appropriate approach, such as TRAPD (Translation, Review, Adjudication, Pretest, Documentation) (43) or back-translation (44). An additional survey conducted with the patients' physiotherapists could have delivered interesting information from their perspective. It is conceivable that physiotherapists would have described the content of the therapy differently to their patients, which would be relevant for the validity of findings. Although only an indication, research into other rheumatic conditions in which both the patient and physiotherapist perspectives were examined, showed their perceptions to be quite similar (45-48). Despite these limitations, the survey was a good starting point to explore the current use of physiotherapy by people with axSpA in the individual and group settings.

The focus group study on the beliefs related to PA (Chapter 5) should be interpreted with caution in terms of generalisability. As is common in focus groups, participants have a vested interest in the topic under study (49). Therefore, findings might not be representative of those individuals disinterested in PA and the study may thus suffer from selection bias (50). However, purposive and convenience sampling was also used to gain a broad insight into the topic (51). Generating a broad, but theory-driven, outline of views and ideas regarding PA was also the reason for the decision to use focus groups instead of individual interviews, despite the fact that individual interviews are in general considered to be more efficient in terms of time and the quality of in-depth answers (52). The focus group technique may have a further specific value since it depends less on the questions of the moderator. The moderator rather has the role of a facilitator with an investigative focus, asking questions, controlling the dynamics of group discussions, and sometimes engaging in dialogue with specific participants (53).

The findings of the study revealed the often neglected difference between the concepts of cardiorespiratory exercise and general PA, and the possible consequential impact on health. Furthermore, the study results support the importance of general PA and exercise as a self-management strategy for people with axSpA. This is reflected in the phenomenon that facilitators, such as internal motivation, may outweigh strong disease-related barriers, such as pain or fatigue. Physiotherapists need to learn how to use this knowledge wisely and integrate it into long-term interventions to promote successful active PA behaviour. With respect to cardiorespiratory training, the studies by Sveaas and colleagues (16, 18) show that even high intensity training is feasible and accepted by people with axSpA and that it has a positive effect on disease activity and quality of life.

Assessment of core strength in people with axSpA

According to the EULAR PA recommendations, regular fitness assessments in all the exercise dimensions are crucial in identifying those areas that have potential for improvement. However, a suitable assessment to measure core strength in people with axSpA was unavailable. This is a deficiency, since core strength exercising was part of previous exercise programmes for people with axSpA (54). As yet, no randomized controlled trials have been conducted to investigate the effect of core muscle strength exercises alone on muscle strength performance and disease-related outcomes in people with axSpA (Chapter 3). To provide an easy-to-perform assessment and to prepare for possible studies focusing on this under-researched topic, the adaption and testing of a core strength assessment battery (55) formed an important part of this thesis (Chapter 6). One limitation was that the reliability of the core strength assessment battery was tested by the physiotherapists normally leading the group exercise therapy, rather than an independent assessor in a laboratory setting. However, the pragmatic approach yielded clinically relevant information, showing that the physiotherapists were challenged in terms of timing and the accuracy of assessments. The physiotherapists performed the assessments during the usual exercise session and reported that it was difficult to measure all the participants within the planned schedule. This may have influenced their adherence to protocol. To improve reliability, the test conditions were adapted for the BeFit concept, with an external assessment team of physiotherapy students performing the regular assessments.

The implementation of the EULAR PA recommendations for RMDs: current status and lessons learned

Since the EULAR PA recommendations (Chapter 2) were published, some initiatives have been launched to (linguistically) translate (56, 57) or to implement them into clinical care for people with axSpA (58-60). The working groups, led by Nikiphorou (60) and Metsios (58), followed an educational approach by developing EULAR recommendations on self-management intervention and learning-courses for health professionals in rheumatology respectively, both referring to the EULAR PA recommendations. Dutch researchers have also

carried-out research on the implementation of the EULAR PA recommendations specifically for people with axSpA. Firstly, Hilberdink et al. used the Intervention Mapping Protocol to develop components of an ideal intervention for people with axSpA living in the Netherlands and optimise exercise behaviour through: 1) behaviour change guidance; 2) training for physiotherapists on how to provide behaviour change guidance and how to tailor exercises; and 3) encouraging exercise in a group setting (61). Secondly, based on surveys, it was concluded that PA promotion intervention for the Dutch setting should focus on aerobic PA, vigorous-intensity PA, and education of the physiotherapists supervising the group exercises (62, 63). Thirdly, a hybrid effectiveness-implementation study was performed to evaluate the implementation success and effectiveness of an adaptation of the supervised exercise groups in four regions of the Netherlands (59). Patient satisfaction was found to be high. However, criticism arose concerning the lack of a patient-education intervention and tailored exercise instructions (additional to the group exercise sessions) (64). Furthermore, the moderate physiotherapists' fidelity to the implementation activities, partly caused by limited resources, e.g., uncompensated level of high effort required for assessments, was challenging. The patients did not increase their individual exercise behaviour outside the group exercise sessions, which are usually quite long. Participants could have suffered from exhaustion since fatigue is a major barrier. Hilberdink and colleagues concluded that the implementation activities need to be adapted to increase feasibility and that the implementation strategy should be extended to all stakeholders, including patients.

The implementation projects in Switzerland (65) and the Netherlands (59) have pursued the same goal, but with different strategies. Interestingly, some of the lessons learned are very similar: the quite low adherence to individual (not-supervised) exercise by patients (according to the EULAR PA recommendations) and the relatively moderate fidelity of physiotherapists to the implementation activities remain challenging (Chapter 7, (59)). Even if the major stakeholders (patients, physiotherapists, patient organisations, rheumatologists) are aware of the importance of PA and are, theoretically, willing to change their behaviour or procedures, the road to real short- and long-term change is very long and difficult. Motivation is the key! This is, of course, not a new insight. Behavioural psychology has shown this to be the case (34, 66). All stakeholders need to improve their conceptual understanding of PA versus exercise and the skills to perform or instruct them, according to the EULAR PA recommendations (Chapter 4, (24, 67, 68)). External factors, such as time management or limited resources, were found to be restricting for physiotherapists (59). In addition, SVMB management reflects that physiotherapists might believe that these changes are unwanted by the group participants. This stands in contrast to the patients' needs for tailored exercise programmes and continuous individual support (Chapter 5, (69)). Patients want physiotherapists to take on the role of counsellor, supporting self-management collaboratively and with a positive patient-therapist relationship (70). Clear incentives and successful framing of the most important message "Be physically active" are crucial. Some public health initiatives follow the approach of financial incentives, such as a reduction in health insurance premiums if proof of regular training can be provided, but non-financial

incentives, such as gamification and social incentives, are also considered motivating (71, 72).

Implications for future research

The EULAR PA recommendations have been cited in 215 publications (6th March 2022, Web of Science Cited Reference function), of which 62 were reviews and 6 guidelines. Only two of these had the aim of implementing the EULAR PA recommendations into routine clinical practice (Chapter 7, (59)). This relatively low number highlights the need for a compulsory and standardised implementation agenda following research projects, which would be a catalyst for the clinical implementation of evidence. It should be noted, however, that not all implementation activities are accompanied by (published) research.

Since the implementation of the BeFit group exercise concept is an iterative process that has been considerably delayed due to the Covid-19 pandemic, some accompanying projects are currently ongoing, e.g., the development and usability study of an electronic exercise diary. This diary will be useful to better evaluate the patients' adherence to exercise. The pandemic has had a significant impact on group exercise therapy and a large effort will be required to reflate and keep BeFit alive. An unpublished statistic by the SVMB indicates that, due to the special conditions of the Covid-19 pandemic, only some 12% of its members regularly participated in group exercise therapy in 2021.

There is data to underpin the social importance of group exercise (Chapter 4, (24, 61)). Some people, however, prefer to exercise in groups not specifically designed for people with axSpA (Chapter 4), or to perform individual exercise, or to not exercise at all. In times of Covid regulations, remote care options must be considered. Therefore, the SVMB will need to apply different PA promotional concepts that target the majority of its members who are not participating in group exercise therapy. These can probably be divided into several subgroups, characterised by diverse needs with respect to exercise behaviour. Further research is needed to develop specific strategies for self-management and PA promotion interventions to target these subgroups of SVMB members, to attract the young, and keep the older people on board. In this process, the promising approach of technology-based counselling must be considered, which enables regular remote contact when a weekly group setting is inappropriate (22, 73). Although there is currently no available gold standard for the objective assessment of PA (21, 74), studies have provided evidence on the efficacy of electronic or mobile health (e/mHealth) approaches in PA promotion (75-77). Passalent and colleagues (78) support the idea that targeted e-health interventions, with the aims of integrating the patient perspective, addressing barriers, using existing knowledge and filling knowledge gaps, may promote PA uptake in people living with axSpA. In line with this, and in the face of the Covid-19 pandemic, the SVMB has launched an online portal (www.rheumafit.ch). Currently, there are different video-based exercise instructions available.

Further development activities are needed to realise a concept supporting individual PA promotion interventions. Additionally, PTs' fidelity to BeFit need to be further supported by addressing individual (e.g. increasing knowledge and skills) and organisational (touching upon perceived lack of time or organisational support) factors (79).

During the further national implementation of BeFit, a continuous evaluation of its implementation success will be mandatory to support adoption and avoid ineffective interventions. Furthermore, an economic analysis of BeFit should be performed to evaluate its cost-effectiveness. Findings of positive economic benefits could support negotiations with the health insurance authorities. The fact that the SVMB group exercise therapy is covered by health insurance annually is unique. In the Swiss health system, it is more common that only a proportion of group exercise costs are recompensed, or for a limited period. If this special status were to change, the BeFit concept would have to be adapted.

Conclusion

This thesis adds value to the wealth of research on PA by presenting the complete journey from the development of the EULAR PA recommendations for people with RMDs (including axSpA), which state that exercise according to public health recommendations is effective, safe, and feasible, to the practical implementation of a concept for group exercise therapy for people with axSpA that conforms to these recommendations. The studies in this thesis were supported by international experts from the fields of rheumatology, health behaviour, and implementation science, as well as national stakeholders, such as the Swiss patient organisation, SVMB. The EULAR PA recommendations provide a solid foundation for further, urgently needed research in the field of PA for people with RMDs. This thesis shows that the current state of the non-pharmacological treatment of axSpA has potential for improvement. In addition, it gives valuable insights into some of the challenges associated with the initialisation and maintenance of change in the provision of exercise therapy for people with axSpA.

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9

Summary

Exercise that is correctly dosed and wisely chosen is medicine for people with rheumatic and musculoskeletal diseases (RMDs), such as inflammatory arthritis and osteoarthritis. Even though the available guidelines and recommendations on disease management of RMDs in general stressed the importance of exercise, they were not sufficiently precise for clinical use and did not consider the public health recommendations for health-enhancing physical activity (PA). The current general PA recommendations for adults to gain health benefits and to reduce the risk of cardiovascular diseases include at least 150-300 minutes of moderate-intensity or 75-150 minutes of vigorous-intensity cardiorespiratory training per week. According to general PA recommendations, there are four domains of activities: cardiorespiratory/aerobic, strength, flexibility and neuromotor performance. Exercise is a subcategory of PA that is planned, structured, repetitive and has the objective to maintain or improve physical fitness.

PA behaviour is complex and even more so in people with RMDs. In addition to the challenges confronting the general population in living an active PA behaviour, people with RMDs, such as axial Spondyloarthritis (axSpA), face disease-specific barriers. In addition, they may have an increased risk of cardiovascular diseases.

This thesis reports on the development of PA recommendations for people with RMDs (including axSpA), as well as their implementation into a group exercise therapy concept specifically for people with axSpA in Switzerland.

Chapter 1 provides a general introduction into the content and context of this thesis. Firstly, it presents an overview of the definition, epidemiology, and management of axSpA and the definition of and recommendations for PA and exercise in people with RMDs. Secondly, the literature on the importance and challenges of PA promotion in people with axSpA is summarised. Thirdly, the Swiss Health System and the Swiss patient organisation ‘Ankylosing Spondylitis Association Switzerland’ (Schweizerische Vereinigung Morbus Bechterew, SVMB), which offers group exercise therapy for people with axSpA, were introduced. Based on the conclusions from this overview, the two goals of this thesis were formulated. These were to:

- 1) Describe the development, definition, and evidence base of the 2018 EULAR recommendations for PA in people with inflammatory arthritis and osteoarthritis.
- 2) Detail the pilot implementation of exercise groups for people with axSpA in Switzerland, based on the EULAR PA recommendations. This includes an analysis of the situation, exploration of the determinants of PA behaviour, and the evaluation of a strength assessment.

Main Findings of this thesis

In Chapter 2, the development of the EULAR (European Alliance of Associations for Rheumatology) recommendations for PA in people with RMDs (including axSpA) is described. Chapter 3 elaborates on the evidence base for these PA recommendations by means of a systematic review and meta-analysis.

Chapter 2 outlines the process of developing and defining PA recommendations for people with inflammatory arthritis and osteoarthritis, according to predefined EULAR standardised operating procedures. A task force comprised of members from 16 countries (including rheumatologists, other medical specialists and physicians, health professionals, patient-representatives, and methodologists) met twice. At the first meeting, 13 research questions were identified and defined. Following the meeting, a systematic literature review was performed to answer the 13 research questions. The evidence was presented and discussed at the second meeting. The evidence and expert opinion informed the definition of four overarching principles and ten recommendations. Given the evidence for its effectiveness, feasibility and safety, PA, guided by public health recommendations, was advocated as an integral part of standard care throughout the course of inflammatory arthritis and osteoarthritis. Nevertheless, it was found that general and disease-specific contraindications and barriers, as well as individual adaptations based on assessments of physical, social, and psychological factors need to be considered. Additional recommendations were defined, e.g., that individual exercise goals should be defined by shared decision and that the health care professionals providing PA interventions should apply behaviour change techniques (BCTs). The mean level of agreement on the overarching principles and recommendations (scale 0-10) ranged from 8.8 - 9.8 among the task force members.

Finally, the task force agreed on a related and comprehensive research and education agenda. It also formulated the ambition to implement the EULAR PA recommendations into clinical routine, using implementation strategies targeted at specific groups and taking into account the differences between health systems across Europe.

Chapter 3 addresses the effectiveness of PA interventions meeting the requirements of the public health recommendations for PA in people with inflammatory arthritis (rheumatoid arthritis /RA and spondyloarthritis /SpA) and osteoarthritis (hip and knee /HOA and KOA). The systematic review included 63 randomized controlled trials (RCTs) in adults with RA, SpA, or H/KOA, investigating the effect of either: a) aerobic exercises on cardiorespiratory fitness; b) muscle strength exercise on lower limb muscle strength; c) flexibility exercise on flexibility; d) neuromotor exercise on neuromotor performance; or e) PA promotion (based on behaviour change techniques/BCTs) on the amount of daily PA. Studies were only included when the content and dosage of intervention was in accordance with the public health recommendations for PA, in particular the exercise principles advocated by the American College of Sports Medicine (ACSM). Data from 49 RCTs were pooled in a meta-

analysis, using a random-effect model, and presented as standardised mean difference (SMD). Moderate effects were found for aerobic exercises on cardiorespiratory fitness (SMD 0.56 (95% CI 0.38 to 0.75)) and for resistance training on muscle strength (SMD 0.54 (95% CI 0.35 to 0.72)). However, no effects of combined strength/aerobic/flexibility exercises on flexibility (SMD 0.12 (95% CI -0.16 to 0.41)) were seen. PA promotion interventions led to a small increase in PA behaviour (SMD 0.21 (95% CI 0.03 to 0.38)). The conclusions were that a) exercising according to ACSM principles has a moderate effectiveness on cardiorespiratory fitness and muscle strength, and b) PA promotion based on behaviour change techniques had a small effect on PA behaviour in people with RA, SpA, or H/KOA. No evidence was found for the effects of flexibility exercises and very little literature was available that evaluated neuromotor exercises.

Many studies had to be excluded due to poor reporting of the interventions. It was suggested that future studies should apply appropriate reporting guidelines for intervention studies, which will enable clinicians and researchers to better understand, compare and replicate findings.

The EULAR PA recommendations provide guidance for the development, conduct and evaluation of interventions on PA, exercise, and promotion of an active lifestyle in people with inflammatory arthritis and osteoarthritis. Due to the differences in health systems across Europe, culturally specific implementation strategies for specific target groups involving all stakeholders are needed. Chapters 4 to 7 describe the preparation, development, and evaluation of an implementation strategy for exercising according to EULAR PA recommendations in the group exercise setting for people with axSpA in Switzerland.

In **Chapter 4** the findings of a cross-sectional survey, conducted among people with axSpA living in the western region of the Netherlands and the German-speaking part of Switzerland, are presented. The aim of the survey was to evaluate and compare the usage, experiences, and preferences regarding the delivery of individual and group exercise physiotherapy. In both countries, supervised exercise therapy was offered on an individual or group basis. The latter was usually water-based and/or land-based, offered once a week, supervised by a physiotherapist, and included an important social factor. In total, 713 (206 Dutch, 507 Swiss) individuals with axSpA participated (56% male, median age 55 years). Of these participants, 83% were using or had used physiotherapy in group and/or individual setting. Of these, individual therapy alone was used or had been used by 36%, a combination of individual plus land-based or water-based group therapy by 29%, and group therapy alone by only 5%. Less than half the participants attending individual therapy reported active therapy (such as aerobic, muscle strength and flexibility exercises). Although the majority (76%) was not aware of the increased cardiovascular risk, participants showed an interest in aerobic exercises, either in an individual or supervised setting. If supervised, the majority would prefer supervision by a specialised physiotherapist.

The findings of this survey suggested that there is a need to implement active exercises at an appropriate dose according to current exercise recommendations, particularly with a higher focus on aerobic exercises in an individual or group setting. Enabling people with axSpA to perform exercises independently (unsupervised) would most likely meet their needs and could enhance their daily PA.

Chapter 5 summarises a qualitative study in people with axSpA aiming at exploring behavioural, normative and control beliefs concerning general PA and cardiorespiratory training. Five semi-structured focus groups with 24 individuals living with axSpA were performed and data were analysed using structured thematic qualitative content analysis. Data were categorized into behavioural, normative and control beliefs. *Behavioural beliefs* revealed a positive attitude towards general PA, with participants mentioning numerous physical, psychological, and social benefits, but only few risks. However, the conceptual difference between general PA and cardiorespiratory training, and the relevance of cardiorespiratory training to reducing the increased risk of cardiovascular disease, was unclear to some participants. *Normative beliefs* were expressed as the beliefs of significant others that influenced their motivation to comply with such beliefs. Significant others can be spouses, other people living with axSpA, or rheumatologists. Regarding *control beliefs*, general PA and cardiorespiratory training were both mentioned as effective self-management strategies to control the disease. From experience, a high level of self-discipline, as well as the use of technology, were shown to be useful. Physiotherapists play a key role in PA promotion and could influence normative beliefs. This potential could be used to a greater extent in the future to promote active lifestyle competencies in people living with axSpA.

Chapter 6 focuses on the assessment that is needed to develop an exercise programme tailored to an individual axSpA patient's capabilities. Core muscles are particularly important for this group of patients, since inflammation and reduced mobility affect the dynamic stabilisation of the spine. A certain level of core stability is needed, in terms of strength and muscle fatigue resistance, for the activities of daily living and sport performance. However, the assessment of core strength is challenging and no appropriate assessment for people with axSpA in a group exercise therapy setting existed. The aim of this study was to adapt the isometric Core Strength Endurance test battery (aCSE), previously used for athletes, for use in people with axSpA and to evaluate the intra-tester reliability and its associations with the disease-specific factors of functional status, self-reported pain, and perceived strength performance. A cross-sectional study was conducted in exercise therapy groups, including 62 people with axSpA and 13 physiotherapist group leaders. The aCSE was repeated after 7-14 days to measure intra-tester reliability of the same rater (PT group leader). Reliability was calculated by means of computing the intraclass correlation coefficient (ICC), using a nested design. A moderate to substantial intra-rater reliability (ICCs (95%CI)) was found for the ventral (0.54 (0.35, 0.74)), lateral (0.52 (0.33, 0.70)) and dorsal (0.71 (0.58, 0.86)) core muscle chains. The associations between ventral, lateral and dorsal strength endurance and the disease-specific factors were calculated using Pearson correlation coefficients.

It was concluded that the aCSE was a feasible and reliable assessment instrument to measure core strength in people with axSpA. It can be combined with other appropriate assessments, covering the cardiorespiratory fitness, (spinal) mobility and neuromotor performance domains, to establish an inexpensive, practical, yet comprehensive, assessment battery for the assessment of individuals with axSpA in the group exercise setting. However, none of the aCSE measures correlated significantly with the disease-specific factors.

The aim of the SVMB was to revise their group exercise therapy concept according to state-of-the-art practices. Therefore, the previously described 2018 EULAR recommendations for PA in people with inflammatory arthritis and osteoarthritis were translated into a new group exercise therapy concept, called “BeFit”, by executing five key implementation activities: a) training for the supervising physiotherapists; b) correctly dosed exercises in all fitness dimensions; c) exercise counselling; d) bi-annual fitness assessments; and e) individual exercise training (in addition to group exercise). By applying this concept to group exercise therapy, the programme not only meets the requirements of disease-specific exercises, but also accords to public health PA recommendations.

Chapter 7 details the development of a tailored implementation strategy for BeFit and its pilot testing in four exercise groups, consisting of 30 people with axSpA and four physiotherapists. After six months of testing, the implementation success was evaluated at the levels of patient, physiotherapist, and the organisation. At the patient level, the primary outcome was adherence to the recommended exercise behaviour, assessed by the number of reported training sessions per exercise dimension in the electronic exercise diary over 6 months. The secondary outcomes were feasibility and satisfaction with the new exercise group concept, rated on a 0–10 numeric rating scale. The tertiary outcome, to evaluate the effectiveness of the individualised PA recommendations, was the measured change in the fitness levels of patients, assessed by fitness parameters. At the level of physiotherapist, the primary outcome was fidelity to the programme design concept, assessed using a diary. The secondary outcomes were treatment quality, feasibility, and satisfaction, evaluated with semi-structured interviews. Acceptance and the establishment of BeFit within the organisational structure were evaluated at the organisational level. The patients’ self-reported adherence to the PA recommendations was found to be insufficient (43%), possibly due to technical problems with the electronic diary. The physiotherapists’ fidelity to the new exercise group concept was reported as satisfactory. On all levels, the new concept was generally perceived as feasible and useful for supporting individual exercise. The suggested frequency of exercise counselling (quarterly) and the fitness assessments (bi-annually) were found to be too high and too rigid by both patients and physiotherapists. Overall, the pilot implementation of PA recommendations showed sufficient acceptance and satisfaction. Nevertheless, it appeared that some adaptations are needed to enhance its feasibility for nationwide implementation. These adaptations were described in detail to make the knowledge available for future implementation research projects. During the national implementation of BeFit, a continuous monitoring will be needed to avoid ineffective elements of the concept.

General Discussion

The 2018 EULAR recommendations for PA in people with inflammatory arthritis and osteoarthritis and the underlying literature review and meta-analysis, strengthen the evidence base for non-pharmacological care in RMDs. Based on strong evidence (Chapter 3), exercising according to the general PA recommendations covering the four exercise dimensions of aerobic, muscle strength, flexibility and neuromotor exercising, were acknowledged to be effective, safe and feasible for people with RMDs (Chapter 2). The EULAR PA recommendations highlight important considerations that should be followed in the context of PA interventions for people with RMDs. People with RMDs may face several disease-specific challenges, requiring adaptation according to individual needs, capabilities, and resources. Thus, it remains to be established whether further refinements are needed for their use in the clinical routine, in the form of additional disease-specific recommendations. Furthermore, there are still some relevant knowledge gaps, such as: the most effective intervention strategies for long term PA promotion; the feasibility of exercise interventions covering all four exercise dimensions; the most appropriate, valid and preferable objective PA assessment for clinical use. Fortunately, PA interventions and PA behaviour are highly researched fields and, by joining forces and good alignment, further steps can be made in the future.

The implementation of the EULAR PA recommendations into clinical routine demands a structured and theory-driven approach. This thesis described the translation of the EULAR PA recommendations into the group exercise therapy concept BeFit, together with its pilot implementation, based on Grol&Wensing's model of change and using a hybrid design type 3. Three studies (Chapters 4-6) were described that were designed to analyse the current situation and support the development process of the implementation activities. Strengths of this study were the inclusion of an implementation expert in the study staff and the in-depth contextual analysis. The relevant stakeholders, such as people with axSpA, physiotherapists, and the SVMB organisation were involved in this process. If we had used a different implementation approach to Grol&Wensing's model of change [1], e.g., the Practical planning for Implementation and Scale-up (PRACTIS) approach [2] that was designed specifically for the planning and scaling-up of PA interventions, the collaboration of stakeholders might have been even greater in the early phase. This could have had an additional positive impact on the acceptance of BeFit. Even though the physiotherapists and most participants in the pilot groups were interested in the new concept and willing to adapt their usual care, other exercise therapy groups may not be such "innovators" and not see the value of change. One important change for the physiotherapists was their new role as PA counsellor. Even though PA promotion is a key concept of physiotherapy [3], some physiotherapists might not yet have the necessary communication skills, behaviour change techniques, or detailed knowledge of PA recommendations to embed it successfully into their practice.

The focus group study (Chapter 5) on behavioural, normative and control beliefs concerning general PA and cardiorespiratory training in people with axSpA showed the relevance of PA as a self-management strategy. However, the conceptual difference between general PA and cardiorespiratory training was unclear to some participants. It was concluded that, because of the increased risk of cardiovascular diseases in people with axSpA of which most of the survey participants (Chapter 4) were unaware, patients and physiotherapists need to understand the difference between the concepts and also how to perform cardiorespiratory training. The survey (Chapter 4) showed that most people with axSpA use physiotherapy in an individual and/or a group setting. Therefore, physiotherapists are in a strong position to strengthen the individual's skills in using exercise as a self-management strategy. Exercise should be planned according to individual goals that should be re-evaluated regularly using (preferably objective) assessments. Chapter 6 showed a reliable, easy-to-perform method of how to assess core strength in people with axSpA. As such, it contributes to the desired, regularly performed comprehensive assessment of every individual with axSpA as part of an exercise programme. Only by means of an appropriate assessment can exercise and PA be tailored to the individual's health status and personal goals.

Conclusion

This thesis adds value to the wealth of research on PA by presenting the complete journey from the development of the EULAR PA recommendations for people with RMDs (including axSpA), which state that exercise according to public health recommendations is effective, safe, and feasible, to the practical implementation of a concept for group exercise therapy for people with axSpA that conforms to these recommendations. The EULAR PA recommendations provide a solid foundation for further research. Additionally, this thesis gives insights into some of the challenges associated with the initialisation and maintenance of change in the provision of exercise therapy for people with axSpA.

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10

Nederlandse samenvatting

Lichaamsbeweging, mits goed uitgevoerd en juist gedoseerd, werkt als een medicijn bij mensen met reumatische en musculoskeletale aandoeningen (Rheumatic and Musculoskeletal Diseases, RMDs). Hoewel de tot voor kort beschikbare richtlijnen en aanbevelingen voor de behandeling van mensen met RMDs wel het belang van bewegen in het algemeen benadrukten, waren ze niet erg specifiek met betrekking tot de praktische toepassing en namen ze de beweegerichtlijnen die voor de algemene bevolking gelden niet mee. Volgens de beweegerichtlijnen voor de algemene bevolking moeten volwassenen minimaal 150-300 minuten met matig intensieve, of 75-150 minuten met hoog intensieve intensiteit per week bewegen om hun gezondheid te verbeteren en de kans op cardiovasculaire aandoeningen te verkleinen. In deze beweegerichtlijnen worden naast bovengenoemde cardiorespiratoire/aerobe bewegvormen drie andere bewegvormen onderscheiden, te weten activiteiten om de spierkracht, flexibiliteit en neuromotorische ofwel functionele capaciteiten en/of balans te verbeteren.

Bij het spreken over lichaamsbeweging moet een onderscheid gemaakt tussen oefenen en bewegen. Bewegen is elke vorm van lichamelijke activiteit waarbij energie wordt verbrand. Oefenen of trainen is een subcategorie van bewegen, waarbij het gaat om geplande, gestructureerde, en herhaalde bewegingen die tot doel hebben de fysieke fitheid in stand te houden of te verbeteren.

Beweeggedrag is complex en dit is des te meer het geval bij mensen met RMDs. Voor gezonde mensen is het vaak al lastig om een actief leven te leiden, maar voor mensen met RMDs, zoals axiale spondyloarthritis (axSpA), is het ten gevolge van klachten die gepaard gaan met hun aandoening zoals pijn, stijfheid of vermoeidheid, vaak extra moeilijk. Toch is het voor hen uitermate belangrijk, niet alleen omdat ze door middel van lichamelijke activiteit hun klachten kunnen verminderen en algehele gezondheid kunnen verbeteren, maar ook omdat bij mensen met RMDs het risico op cardiovasculaire aandoeningen verhoogd is. Dit proefschrift beschrijft de ontwikkeling van een beweegerichtlijn specifiek voor mensen met RMDs (waaronder ook axSpA) en de integratie en implementatie van deze richtlijn in een concept voor groepsoefentherapie specifiek voor mensen met axSpA in Zwitserland.

Hoofdstuk 1 geeft een algemene inleiding op het onderwerp en schetst de context waarbinnen dit proefschrift tot stand is gekomen. Het hoofdstuk begint met de definitie van axSpA en een beschrijving van de epidemiologie van dit ziektebeeld, alsmede van de behandeling. Daarnaast worden de termen lichamelijke activiteit ofwel lichaamsbeweging en oefenen gedefinieerd en worden bestaande beweeg- en oefenrichtlijnen uiteengezet. Het hoofdstuk geeft vervolgens een overzicht van de literatuur over het belang van en de uitdagingen op het gebied van bevordering van lichamelijke activiteit van mensen met axSpA. Het hoofdstuk sluit af met de introductie van het Zwitserse gezondheidszorgstelsel en de Zwitserse patiëntenorganisatie voor axSpA, de Schweizerische Vereinigung Morbus Bechterew (SVMB), die een belangrijke rol speelt in verschillende studies beschreven in dit proefschrift. De SVMB verzorgt oefenprogramma's in groepsverband voor mensen met axSpA.

Hoofdstuk 1 wordt afgesloten met de volgende twee algemene doelen van dit proefschrift:

- 1) Het beschrijven van de empirische basis van de ontwikkeling en de formulering van een beweegrichtlijn specifiek voor mensen met inflammatoire artritis en artrose op initiatief van de “European Alliance of Associations for Rheumatology” (EULAR) in 2018.
- 2) Het toepassen en evalueren van de principes van deze beweegrichtlijn binnen de groepsoefentherapie voor mensen met axSpA in Zwitserland. Deze doelstelling omvatte naast een pilotstudie ook een analyse van de huidige zorgverlening, een exploratie van bevorderende en belemmerende factoren voor adequaat oefen- en bewegegedrag en een evaluatie van een methode om rompspierkracht te meten.

De belangrijkste bevindingen van het onderzoek in dit proefschrift

In Hoofdstuk 2 wordt de ontwikkeling van de EULAR aanbevelingen voor lichamelijke activiteit van mensen met RMDs (inclusief axSpA) beschreven. Hoofdstuk 3 gaat dieper in op de empirische basis van deze richtlijn aan de hand van een systematische review en een meta-analyse van de relevante literatuur.

In **Hoofdstuk 2** wordt beschreven hoe de aanbevelingen voor lichamelijke activiteit van mensen met inflammatoire artritis en artrose werden ontwikkeld en geformuleerd volgens de bestaande “standard operating procedures” van de EULAR. Een taskforce met leden uit 16 verschillende landen (onder wie reumatologen, andere medisch specialisten en artsen, health professionals, patiëntvertegenwoordigers en methodologen) kwam in het kader van de richtlijnontwikkeling twee keer bijeen. Tijdens de eerste bijeenkomst zijn 13 onderzoeksvragen geformuleerd. Vervolgens zijn deze vragen beantwoord door middel van systematisch literatuuronderzoek. Tijdens de tweede bijeenkomst werden de uitkomsten van het literatuuronderzoek gepresenteerd en besproken en deze vormden, aangevuld met de expertise van de taskforce, de basis voor de uiteindelijke formulering van vier overkoepelende principes en tien aanbevelingen.

Omdat er voldoende bewijs is dat lichamelijke activiteit volgens de beweegrichtlijnen voor de algemene bevolking voor mensen met RMDs effectief, haalbaar en veilig is, werd aanbevolen om lichamelijke activiteit integraal deel uit te laten maken van de reguliere zorg voor mensen met inflammatoire artritis en artrose. Belangrijk is wel dat daarbij rekening moet worden gehouden met ziektespecifieke en algemene contra-indicaties en belemmerende factoren. Daartoe moeten, op basis van een uitgebreide assessment van lichamelijke, sociale, en psychologische factoren zo nodig individuele aanpassingen aan het individuele bewegplan gemaakt worden.

Andere aanbevelingen hadden onder andere betrekking op de noodzaak van het vaststellen

van individuele doelen op het gebied van oefenen en bewegen, en de toepassing van gedragsveranderingstechnieken door zorgprofessionals die beweeginterventies aanbieden. De gemiddelde score van de taskforceleden over de mate waarin zij het eens waren met de overkoepelende principes en aanbevelingen varieerde tussen de 8,8 en 9,8 op een schaal van 0 tot 10.

Tot slot stelde de taskforce agenda's op voor toekomstig onderzoek en onderwijs. De taskforce heeft ook de ambitie uitgesproken om de richtlijn te implementeren in de klinische praktijk met behulp van strategieën gericht op specifieke doelgroepen, rekening houdend met de verschillen tussen de gezondheidszorgstelsels binnen Europa.

In **Hoofdstuk 3** wordt een literatuuronderzoek beschreven naar de effectiviteit van beweeginterventies die voldoen aan de beweegrichtlijnen voor de algemene bevolking, bij mensen met inflammatoire artritis (reumatoïde artritis /RA en spondyloartritis /SpA) en artrose (heup en knie artrose /HKOA). In het literatuuronderzoek werden 63 gerandomiseerde, gecontroleerde onderzoeken (RCT's) bij volwassenen met RA, SpA, of HKOA betrokken, waarbij werd gekeken naar het effect van: a) cardiorespiratoire/aerobe oefeningen; b) spierkrachtoefeningen; c) flexibiliteitsoefeningen; d) neuromotore oefeningen ofwel functionele- of balansoefeningen; en e) bevordering van algehele lichamelijke activiteit door middel van gedragsveranderingstechnieken. Onderzoeken werden alleen meegenomen in de review als de inhoud en dosering van de interventie in overeenstemming waren met de beweegrichtlijnen voor de algemene bevolking, met name met de trainingsprincipes van de American College of Sports Medicine (ACSM).

De gegevens van 49 RCT's werden meegenomen in een meta-analyse en geanalyseerd met een random-effects model, waarbij de uitkomsten werden uitgedrukt als gestandaardiseerd gemiddeld verschil (Standardized Mean Difference, SMD). De uitkomsten van de meta-analyse lieten een matig groot effect zien van aerobe oefeningen op de cardiorespiratoire fitness (SMD 0,56 (95% Betrouwbaarheidsinterval (BI) 0,38-0,75)) en van (spier)krachttraining op spierkracht (SMD 0,54 (95% BI 0,35-0,72)), maar geen effect van gecombineerde kracht-/aerobe-/flexibiliteitsoefeningen op flexibiliteit (SMD 0,12 (95% BI -0,16-0,41)). Interventies ter bevordering van algehele lichamelijke activiteit leidden tot een kleine toename van lichamelijke activiteit (SMD 0,21 (95% BI 0,03-0,38)).

Opbasisvan de meta-analyse werden de volgende conclusies getrokken: a) oefeningen volgens ACSM-principes hebben een matig groot effect op cardiorespiratoire fitness en spierkracht; en b) het bevorderen van bewegen met behulp van gedragsveranderingstechnieken geeft een kleine verbetering van beweeggedrag bij mensen met RA, SpA, en K/HOA. Er werd geen bewijs gevonden voor de effectiviteit van flexibiliteitsoefeningen en er was te weinig literatuur beschikbaar over de effectiviteit van neuromotore oefeningen om daarover een conclusie te kunnen trekken.

Veel onderzoeken konden niet worden meegenomen in de meta-analyse omdat de interventies niet duidelijk genoeg waren beschreven. Om hier verbetering in te brengen werd geadviseerd om bij toekomstig onderzoek de richtlijnen voor de beschrijving van interventieonderzoeken vaker en beter toe te passen, zodat de bevindingen van onderzoeken beter kunnen worden geïnterpreteerd, vergeleken en gereproduceerd.

De EULAR aanbevelingen voor lichamelijke activiteit van mensen met RMDs zijn van toepassing op de ontwikkeling, het aanbod en de evaluatie van interventies gericht op bewegen, oefenen, en bevordering van een actieve leefstijl bij mensen met inflammatoire artritis en artrose. Vanwege de verschillen tussen de Europese gezondheidszorgstelsels moeten implementatiestrategieën op nationaal niveau worden ontwikkeld. Daarbij is het belangrijk dat steeds alle stakeholders worden betrokken. In de hoofdstukken 4 t/m 7 wordt de ontwikkeling en evaluatie van een planmatige implementatiestrategie voor de concepten van de EULAR aanbevelingen voor lichamelijke activiteit binnen de groepsoefentherapie voor mensen met axSpA in Zwitserland beschreven.

In **Hoofdstuk 4** worden de bevindingen van een cross-sectioneel vragenlijstonderzoek gepresenteerd. Het onderzoek werd uitgevoerd bij mensen met axSpA in het westen van Nederland en in het Duitssprekende deel van Zwitserland. Het doel van dit onderzoek was het evalueren en vergelijken van het gebruik, de ervaringen en de voorkeuren ten aanzien van fysio/oefentherapie. In beide landen wordt zowel gesuperviseerde individuele fysio/oefentherapie als groepsoefentherapie aangeboden. Groepsoefentherapie vindt in beide landen meestal één keer per week plaats, in het water en/of op het droge, onder toezicht van een fysio- of oefentherapeut, en bevat ook een belangrijke sociale component.

In totaal namen 713 individuen met axSpA (206 Nederlanders en 507 Zwitsers; 56% man; mediane leeftijd 55 jaar) deel aan dit onderzoek. Van deze groep maakte 83% op dat moment of eerder gebruik van fysiotherapie in groeps- en/of individuele setting; Hiervan 36% kreeg individuele therapie of had dit eerder gekregen; 29% kreeg een combinatie van individuele en groepsoefentherapie op het land of op het droge; slechts 5% volgde uitsluitend groepsoefentherapie. Minder dan de helft van de deelnemers aan individuele therapie meldde dat de therapie bestond uit het doen van actieve oefeningen (zoals aerobe oefeningen, spierkracht- en flexibiliteitsoefeningen).

Hoewel de meerderheid (76%) zich niet bewust was van het verhoogde risico op cardiovasculaire aandoeningen bij axSpA, toonden de deelnemers belangstelling voor adequaat gedoseerde cardiorespiratoire training, zelfstandig of gesuperviseerd. Bij gesuperviseerde oefentherapie werd door de meerderheid van de respondenten de voorkeur gegeven aan een fysiotherapeut met specifieke deskundigheid op het gebied van reumatische aandoeningen.

De bevindingen van dit onderzoek suggereren dat het nodig is om goed gedoseerd actieve training, met name bestaande uit cardiorespiratoire oefeningen te integreren in het behandelbeleid, zowel bij individuele als groepsoefentherapie. Een deel van de mensen met axSpA zal met de juiste instructie in staat zijn om zelfstandig (zonder supervisie) te oefenen en bewegen volgens beweegrichtlijnen.

Hoofdstuk 5 geeft een overzicht van een in het kader van dit proefschrift uitgevoerd kwalitatief onderzoek onder mensen met axSpA, dat ten doel had hun 'beliefs' ten aanzien van bewegen en cardiorespiratoire beweegactiviteiten te exploreren. Daartoe werden vijf semigestructureerde focusgroepen georganiseerd, waaraan in totaal 24 mensen met axSpA deelnamen. De uitkomsten werden geanalyseerd met een gestructureerde, thematische kwalitatieve inhoudsanalyse.

De analyse van de zogenaamde 'behavioural beliefs' liet zien dat de deelnemers een positieve houding hadden ten aanzien van bewegen: deelnemers noemden veel lichamelijke, psychologische en sociale voordelen, en maar weinig risico's van bewegen. Het conceptuele verschil tussen bewegen in het algemeen en cardiorespiratoire training, en hoe cardiorespiratoire training de verhoogde kans op cardiovasculaire aandoeningen kan verlagen, was sommige deelnemers echter niet duidelijk. De genoemde 'normative beliefs' omvatten de overtuigingen van relevante anderen (partner, andere mensen met axSpA en reumatologen) die van invloed kunnen zijn op het gedrag. Ten aanzien van 'control beliefs' werden bewegen in het algemeen en cardiorespiratoire training beide genoemd als effectieve zelfmanagementstrategieën om met de ziekte om te gaan. De ervaring leert dat het hebben van veel zelfdiscipline en het ter beschikking hebben van technische hulpmiddelen zoals wearables nuttig kunnen zijn bij het bevorderen en behouden van gezond beweeggedrag. Daarnaast spelen fysiotherapeuten hierin een belangrijke rol, waarbij zij onder andere invloed kunnen uitoefenen op de eerdergenoemde 'normative beliefs'. In de toekomst zouden fysiotherapeuten nog vaker kunnen worden ingezet om mensen met axSpA te stimuleren hun mogelijkheden op het gebied van een actieve leefstijl te benutten.

Hoofdstuk 6 beschrijft een onderzoek naar een meetinstrument dat gebruik kan worden bij het uitgebreide assessment dat nodig is om een beweegprogramma dat toegesneden is op de mogelijkheden van een individuele patiënt met axSpA te kunnen opstellen. De rompmusculatuur is van bijzonder belang bij deze patiëntengroep, omdat ontstekingen en verminderde mobiliteit invloed hebben op de dynamische stabilisatie van de wervelkolom. Een zekere mate van rompstabiliteit, in termen van spierkracht en spieruithoudingsvermogen, is nodig bij activiteiten in het dagelijks leven en sportbeoefening. Het beoordelen van de spierkracht van de rompmusculatuur is echter lastig en er bestond geen geschikte beoordelingsmethode voor mensen met axSpA die deelnemen aan groepsoefentherapie.

Het doel van het onderzoek was om de *Core Strength Endurance test battery* (CSE), die voorheen bij sporters werd gebruikt, aan te passen voor gebruik bij mensen

met axSpA, leidend tot de zogenaamde adapted CSE (aCSE). Daarbij werd de intrabeoordelaarsbetrouwbaarheid bepaald en de associatie met drie ziektespecifieke factoren, namelijk functionele status, zelfgerapporteerde pijn en perceptie van spierkracht. Hiertoe werd een cross-sectioneel onderzoek uitgevoerd onder 62 mensen met axSpA die deelnamen aan groepsoefentherapie en 13 fysiotherapeuten die als supervisor van deze groepen fungeerden. De aCSE werd afgenomen en na 7-14 dagen herhaald om de intrabeoordelaarsbetrouwbaarheid van de supervisors te bepalen. De betrouwbaarheid werd berekend met behulp van de intraclass-correlatiecoëfficiënt (ICC).

De intrabeoordelaarsbetrouwbaarheid (ICCs (95% BI)) voor de ventrale (0,54 (0,35-0,74)), laterale (0,52 (0,33-0,70)) en dorsale (0,71 (0,58-0,86)) spiergroepen van de romp was matig tot aanzienlijk. Om de associatie tussen het krachthoudingsvermogen van de ventrale, laterale en dorsale rompsspieren en de ziektespecifieke factoren vast te stellen, werden Pearson correlatiecoëfficiënten berekend. Op basis van deze bevindingen werd geconcludeerd dat de aCSE een haalbaar en betrouwbaar beoordelingsinstrument is om rompkracht te meten bij mensen met axSpA. Deze methode kan worden gecombineerd met andere relevante methoden om cardiorespiratoire conditie, beweeglijkheid (van de wervelkolom) en neuromotore activiteiten te meten. De combinatie omvat daarmee een betaalbaar, praktisch, en toch uitgebreid instrumentarium voor het assessment van deelnemers aan groepsoefentherapie voor mensen met axSpA. Daaruit bleek dat geen van de aCSE-parameters significant was gecorreleerd met de ziektespecifieke factoren.

Het doel van de SVMB was om het tot dan toe gehanteerde concept voor groepsoefentherapie te herzien volgens state-of-the-art maatstaven. Om deze reden werd de EULAR aanbevelingen voor lichamelijke activiteit van mensen met inflammatoire artritis en artrose uit 2018 vertaald naar een nieuw concept voor groepsoefentherapie, "BeFit" geheten. Vervolgens werden vijf belangrijke implementatieactiviteiten uitgevoerd: a) trainen van de begeleidende fysiotherapeuten; b) integreren van correct gedoseerde oefeningen in alle oefendomeinen (dat wil zeggen: cardiorespiratoir, spierkracht, lenigheid, neuromotore of functionele/balansoefeningen); c) geven van educatie en beweegadvies; d) uitvoeren van halfjaarlijkse conditietests; en e) aanbieden van individuele oefeningen (naast groepstrainingen). Door dit concept toe te passen binnen de groepsoefentherapie, zou het programma niet alleen in overeenstemming zijn met de principes van oefentherapie voor mensen met axSpA maar ook met de beweegrichtlijnen voor de algemene bevolking.

Hoofdstuk 7 beschrijft de ontwikkeling van een implementatiestrategie-op-maat voor BeFit en een pilotonderzoek om deze strategie te evalueren bij vier oefengroepen. Na zes maanden testen van BeFit, werd de implementatie geëvalueerd vanuit het perspectief van de patiënt, de fysiotherapeut en de organisatie. In totaal namen 30 mensen met axSpA en vier fysiotherapeuten hieraan deel.

Vanuit het patiëntperspectief was de primaire uitkomst de mate waarin het aanbevolen

oefen- en beweeggedrag werd nageleefd. Dit werd beoordeeld op basis van het aantal in het elektronische beweeglogboek vermelde trainingssessies, opgesplitst naar oefendomein, over een periode van 6 maanden. De secundaire uitkomsten waren de haalbaarheid van en de tevredenheid over het nieuwe concept voor oefentherapie, gemeten op een schaal van 0 tot 10. Om de effectiviteit van de geïndividualiseerde beweegadviezen te evalueren was de tertiaire uitkomst de conditieverbetering van de patiënten, bepaald aan de hand van gemeten fitnessparameters. Vanuit het perspectief van de fysiotherapeut was de primaire uitkomst de mate waarin de concepten waarop het programma was gebaseerd werden gevolgd. Om dit vast te kunnen stellen werd een logboek bijgehouden. De secundaire uitkomsten waren de kwaliteit en haalbaarheid van en de tevredenheid over de behandeling. Deze aspecten werden geëvalueerd met behulp van semigestructureerde interviews. Op organisatieniveau werd gekeken of BeFit geaccepteerd werd en of het een vaste plek kreeg binnen de structuur van de organisatie.

De door de patiënten gerapporteerde naleving van de beweegadviezen werd onvoldoende bevonden (43%). Mogelijk kwam dit door technische problemen met het logboek. De mate waarin de fysiotherapeuten het nieuwe beweegconcept volgden, werd als voldoende beoordeeld. Vanuit alle drie de perspectieven werd het nieuwe concept in het algemeen gezien als haalbaar en als een zinvolle aanvulling op het beweegaanbod inclusief het zelfstandig oefenen. De aanbevolen frequentie van het aanbieden een individueel oefen- en beweegadvies (eens per kwartaal) en de afname van de conditietests (eens per halfjaar) werd door zowel de patiënten als de fysiotherapeuten als te hoog en te weinig flexibel ervaren. In het algemeen was de acceptatie van BeFit en de tevredenheid over dit concept in de implementatiepilot voldoende. Desondanks lijkt het op grond van de bevindingen noodzakelijk om een aantal aanpassingen te doen om opschaling op nationaal niveau haalbaar te maken. Deze aanpassingen zijn in hoofdstuk 7 in detail beschreven, zodat zij niet alleen aan de SVMB maar ook aan andere, soortgelijke, toekomstige implementatie-onderzoeksprojecten ten goede kunnen komen.

Algemene Discussie

De EULAR aanbevelingen voor lichamelijke activiteit van mensen met inflammatoire artritis en artrose uit 2018, en de literatuurstudie en meta-analyse die daaraan ten grondslag liggen, dragen bij aan het empirische bewijs voor de effectiviteit van niet-farmacologische zorg voor mensen met RMDs. Er is sterk bewijs (Hoofdstuk 3) dat lichamelijke activiteit volgens beweegrichtlijnen voor de algemene bevolking binnen de vier oefendomeinen (cardiorespiratoire conditie, spierkracht, flexibiliteit en neuromotoriek/functioneel/balans) effectief, veilig en haalbaar is voor mensen met RMDs (Hoofdstuk 2). De EULAR aanbevelingen benadrukken belangrijke aspecten waarmee bij beweeginterventies voor mensen met RMDs rekening moet worden gehouden. Mensen met RMDs kunnen ziektespecifieke of andere beperkingen hebben die vragen om aanpassingen van beweegadviezen aan hun individuele

behoefden, voorkeuren, capaciteiten en de beschikbare voorzieningen en middelen. In de toekomst zal moeten worden vastgesteld worden of verdere verfijning van de richtlijn, in de vorm van extra, ziektespecifieke aanbevelingen, nodig is in om de toepassing ervan in de dagelijkse praktijk te vergemakkelijken.

Daarnaast zijn er nog andere relevante kennishiaten, zoals meer inzicht in welke interventiestrategieën het meest effectief zijn om lichamelijke activiteit ook op de lange termijn te bevorderen, wat de haalbaarheid is van beweeginterventies die alle vier de domeinen van beweging omvatten, en welke methoden voor het objectief beoordelen van de effecten van oefenen en bewegen het meest geschikt, valide en bruikbaar zijn in de klinische praktijk. Gelukkig is er al veel onderzoek gedaan op het gebied van beweeginterventies en beweeggedrag, en zal vooral door een goede afstemming en samenwerking tussen onderzoekers en onderzoeksgroepen, vooruitgang worden geboekt.

Implementatie van de EULAR aanbevelingen in de klinische zorg vergt een systematische aanpak, op basis van implementatie-theorie. Dit proefschrift beschrijft de vertaling van de EULAR aanbevelingen in BeFit, een concept voor groepsoefentherapie voor mensen met axSpA. Tevens wordt een pilot implementatiestudie van BeFit beschreven (Hoofdstuk 7). De pilot was gebaseerd op het implementatiemodel van Grol & Wensing (1), waarbij gebruik gemaakt werd van een zogenaamd “hybride designtype 3”.

Aan de basis van de implementatiestudie lagen drie onderzoeken (Hoofdstukken 4-6) die er op gericht waren om de huidige situatie te analyseren en het ontwikkelingsproces van de implementatieactiviteiten te ondersteunen. Deze diepgaande analyse van de context is een sterk punt van de implementatiestudie. Bovendien waren de belangrijke stakeholders, in het bijzonder mensen met axSpA, fysiotherapeuten en de SVMB, betrokken bij het onderzoek. Als een andere implementatiemethode was gebruikt dan die van Grol & Wensing, bijvoorbeeld de PRACTIS-methode (*Practical planning for Implementation and Scale-up*) (2), die speciaal is ontworpen voor het plannen en opschalen van beweeginterventies, was er mogelijk in de beginfase van het onderzoek nog meer en beter samengewerkt tussen alle belanghebbenden en was de implementatie van BeFit succesvoller verlopen. Hoewel de fysiotherapeuten en de meeste deelnemers aan de pilot-oefengroepen geïnteresseerd waren in het nieuwe concept en bereid waren hun gebruikelijke zorg aan te passen, kan het zijn dat andere oefengroepen niet zo innovatief ingesteld zijn en het belang van verandering niet inzien. Een belangrijke verandering voor de fysiotherapeuten was hun nieuwe rol als adviseur op het gebied van lichamelijke activiteit. Bevordering van bewegen is weliswaar een kernelement van fysiotherapie (3), maar sommige fysiotherapeuten beschikken mogelijk nog niet over de benodigde communicatievaardigheden, gedragsveranderingstechnieken en/of gedetailleerde kennis van beweegrichtlijnen om BeFit succesvol in de praktijk te kunnen integreren.

Het focusgroeponderzoek naar ‘beliefs’ van mensen met axSpA ten aanzien van algemene lichamelijke activiteit en cardiorespiratoire training liet zien dat bewegen belangrijk is als

strategie voor patiënten om zo goed mogelijk met hun ziekte om te kunnen gaan. Het conceptuele verschil tussen lichamelijke activiteit en cardiorespiratoire training was voor sommige deelnemers echter niet duidelijk. Aangezien axSpA geassocieerd is met een verhoogd risico op cardiovasculaire aandoeningen, is de conclusie dat patiënten en fysiotherapeuten het verschil tussen deze twee concepten beter moeten begrijpen en moeten weten hoe ze het beste de cardiorespiratoire training kunnen uitvoeren. Daarnaast is een aandachtspunt dat de meeste deelnemers waren niet op de hoogte waren van het verhoogde risico op cardiovasculaire aandoeningen bij axSpA patiënten (Hoofdstuk 4). Uit het vragenlijstonderzoek (Hoofdstuk 4) werd duidelijk dat de meeste mensen met axSpA gebruik maken van fysiotherapie, individueel en/of in groepsverband. Fysiotherapeuten zijn dus bij uitstek in de positie om de gezondheidsvaardigheden van patiënten te verbeteren zodat zij lichamelijke activiteit kunnen inzetten als zelf-managementstrategie bij het omgaan met de ziekte. Bewegingactiviteiten moeten zorgvuldig worden gepland aan de hand van individuele doelen die regelmatig opnieuw moeten worden geëvalueerd door middel van – bij voorkeur objectieve – beoordelingscriteria. In Hoofdstuk 6 wordt een betrouwbare en eenvoudig uit te voeren methode beschreven om de kracht van de rompmusculatuur te meten bij mensen met axSpA. Deze test zou kunnen worden ingezet bij een periodiek assessment dat bij mensen met axSpA zou moeten worden uitgevoerd om hun beweegdoelen en bewegingsprogramma vast te stellen en waar nodig aan te passen.

Conclusie

De bijdrage van dit proefschrift aan de al bestaande kennis op het gebied van oefenen en bewegen van mensen met RMDs is dat het een overzicht geeft van het gehele ontwikkelingstraject van de EULAR aanbevelingen voor lichamelijke activiteit van mensen met RMDs (inclusief axSpA), tot en met de implementatie van de concepten van de richtlijn in de groepsoefentherapie voor mensen met axSpA. Volgens de EULAR aanbevelingen is lichamelijke activiteit volgens beweegrichtlijnen voor de algemene bevolking voor mensen met RMDs effectief, veilig en haalbaar. Daarnaast leveren de studies in dit proefschrift meer inzicht in de mogelijkheden en uitdagingen die samenhangen met het implementeren van de nieuwe inzichten op het gebied van lichamelijke activiteit binnen de groepsoefentherapie voor mensen met axSpA.

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Curriculum Vitae

Anne-Kathrin Rausch was born on 12th November 1984 in Offenbach am Main, Germany. After graduating from high school (private Gymnasium Canisianum, Lüdinghausen), she studied physiotherapy at the Hochschule Fresenius Idstein (DE), which was one of the first Universities of Applied Sciences in Germany to offer the opportunity to obtain a Bachelor of Science in European Studies, in cooperation with the Hogeschool Utrecht (NL). During her bachelor studies, she earned the propaedeutic, attaining a teaching licence in the federal state of Hessen. Additionally, she worked at the physiotherapy clinic of the Olympic Centre Frankfurt-Rhein-Main. In 2008, Anne-Kathrin wrote her bachelor thesis on a small study investigating the electromyographic activity of the pelvic floor during horse riding. This experience awoke her interest in research. Consequently, she decided to continue her studies with a Masters' degree. Two years later, after gaining additional clinical experience working as a physiotherapist at an outpatient clinic in Aarau (Switzerland), she registered for an MSc in Physiotherapy at the Zurich University of Applied Sciences (ZHAW). This was the first course of its kind in Switzerland. The part-time programme ran for three years and included two short-term internships at the Maastricht University (NL), Department for Epidemiology and the George Institute for Global Health (AUS), Musculoskeletal Division. At the George Institute, she worked on the PEDro project, led by Anne Mosely, initiating the inclusion of German randomized controlled studies into the Physiotherapy Evidence Database. In 2013, Anne-Kathrin wrote her Master thesis at the University Hospital Zurich (USZ), Department of Pulmonology, supervised by Prof. Dr. Arnoldus van Gestel, on the association between peripheral muscle strength and daily physical activity in patients with chronic obstructive pulmonary disease.

In 2012, Anne-Kathrin started working as a research fellow in the Research & Development department, Institute of Physiotherapy, at the ZHAW. Since then, she has been involved in many research projects related to various fields of physiotherapy, applying qualitative and quantitative methods. Anne-Kathrin's main research focus is on the promotion of physical activity in people with chronic conditions. As a consequence, in 2015, she became a part-time PhD student at the Leiden University Medical Center (LUMC), supervised by Prof. Dr. Thea P.M. Vlieland and Prof. Dr. Karin Niedermann (ZHAW). Her PhD studies have focussed on physical activity promotion in the field of rheumatology. She was introduced into the network of EULAR Health Professionals in Rheumatology (HPR) by both supervisors. Currently, Anne-Kathrin is a member of the EULAR HPR representation committee and HPR liaison in the EULAR patient representation committee (PARE). She has presented her work at many national and international conferences. Anne-Kathrin is member of the editorial board of 'Physioscience' (Thieme), a journal promoting physiotherapy-related research in German. Since Spring 2022, she is responsible for the focus area "physical activity" of the Master of Science in Physiotherapy at the ZHAW.

Anne-Kathrin lives in Zurich, Switzerland, with her husband Stefan and their three children Johanna (2014), Samuel (2015) and Lorenz (2019).

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