Implementation of physical activity recommendations in people with axial spondyloarthrtis

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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 (is 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 supervisior [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, [a]one 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 ration (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 (%)**		
Education					
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 ration (95% CI)
Instruction on home exercises	405 (67.7)	121 (67.2)	284 (67.9)	0.51	0.87 (0.58-1.30)
Exercises					
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)
Other physiotherapy treatment					
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 No (%)**	**n= 90 No (%)**	**n=272 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 ration (95% CI)
Land-Based GET					
Current or past land-based GET	**n=712 No (%)**	**n=205 No (%)**	**n =507 No (%)**	Yes vs. no	Yes vs. 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 ration (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 No (%)**	**n=57 No (%)**	**n=134 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 No (%)**	**n=205 No (%)**	**n=507 No (%)**	yes vs. no	yes vs. 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 No (%)**	**n=34 No (%)**	**n=116 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 ration (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 ration (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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