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Original article

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% 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.

Conclusion. 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 words: physiotherapy, group exercise, hydrotherapy, ankylosing spondylitis

Key messages

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

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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 ~0.1–0.6% according to European disease prevalence data [2, 3]. Axial spondyloarthritis affects men and women equally (1:1 ratio) [4]. Disease onset is usually in early adulthood [5], and therefore axSpA has a large impact on ability to work, and personal and societal costs are high [6, 7].

Drug treatment and physiotherapy, in particular exercise therapy, are the cornerstones of appropriate management of the disease [1, 8]. In particular, the fact that people with axSpA have an increased risk of cardiovascular diseases [9], and evidence shows that axSpA affects flexibility [10], balance [11], muscle strength [12] and cardiorespiratory capacity [13], emphasize the need for exercise. In this respect, it is important to underline that exercise is a subset of physical activity and is 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. Given that usage, content and preferences regarding physiotherapy may 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 [25]. 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 physical therapist, 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, biologics or no drugs; MAO).
- Use of Individual physiotherapy: usage (if ever/currently, 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 exercise 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. This 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 χ^2 or Fisher'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 physical therapists combined to 'yes' vs 'no treatment'; current or past use of GET combined to 'yes' vs 'no'; referral by rheumatologist or referral by general practitioner combined to 'referral by doctor' vs 'direct access'; duration of treatment >5 years and 1–5 years combined to '1 year+' vs '<1 year'; and frequency of individual therapy less than once per week and once per week combined to 'once' vs 'twice or at least three times per week combined to 'twice+'.

The parameters of the logistic regression models are log odds ratios (LOR): $\log O_{\text{NL}}/O_{\text{CH}} = \log O_{\text{NL}} - \log O_{\text{CH}}$ 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 the 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).

More than one-third (36.7%) of participants had used 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 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

*P-value of χ^2 or Mann–Whitney U-test.

ASAS: Assessment of Spondyloarthritis International Society; axSpA: axial spondyloarthritis; CH: Switzerland; NL: The Netherlands.

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 type of therapy	62 (8.6)	17 (8.8)	45 (8.8)

^aOne individual did not answer those questions.

CH: Switzerland; GET: group exercise therapy; NL: the Netherlands.

(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 on home exercises (67.7%).

Use of land- or water-based GET

Participants usually met once a week (median 4 times a month) for 60 min land-based or for 45 min 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).

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 (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 programme 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

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	n = 206	n = 507		
	No (%)	No (%)	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	n = 169	n = 268		Direct vs referral
	No (%)	No (%)	No (%)		
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	n = 89	n = 143		<1 year vs ≥1 year
	No (%)	No (%)	No (%)		
>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	n = 89	n = 141		Once or less vs twice or more
	No (%)	No (%)	No (%)		
<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	n = 180	n = 418		
	No (%)	No (%)	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)
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	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)

*P-value of Mann–Whitney U , χ^2 or Fisher's exact tests.

CH: Switzerland; GET: group exercise therapy; GP = general practitioner; MC: multiple choice; NL: The Netherlands.

TABLE 4 Use and content of land- or water-based group exercise therapy by Dutch and Swiss patients

	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 month, n	n = 168	n = 18	n = 150		
Median (range)	4 (1–10)	4 (1–4)	4 (1–10)	0.95	n.c.
Duration of session, min	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 month, 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, min	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)

*P-value of Mann–Whitney *U*, χ^2 or Fisher's exact tests.

CH: Switzerland; GET: group exercise therapy; MC: multiple choice; n.c.: not calculated; NL: The Netherlands.

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 ~1 h, in the evening, but not at weekends (Table 5).

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 available only in Dutch, physical therapists may work according to international general management recommendations for axSpA [1, 17, 31–33] and use experiences from other rheumatic conditions, such as OA [34] or RA [35]. Some axSpA guidelines clearly state that active

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 about how to get information on axSpA	n = 651	n = 153	n = 498		
	No (%)	No (%)	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	n = 201	n = 507		
	No (%)	No (%)	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	n = 197	n = 507		
	No (%)	No (%)	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	n = 199	n = 486		
	No (%)	No (%)	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 telephone application	130 (18.9)	34 (17.0)	96 (19.7)	0.84	1.01 (0.62, 1.59)
Personalized programme	250 (36.4)	50 (25.1)	200 (41.1)	<0.001	0.62 (0.41, 0.91)
Personal programme with guidance by an expert by email, Internet or telephone application	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 programme	291 (42.4)	71 (35.6)	220 (45.2)	0.02	0.74 (0.51, 1.06)
Supervised exercise preferred (MC)	n = 670	n = 190	n = 480		
	No (%)	No (%)	No (%)		
Individual exercise programme with face-to-face supervision by physical therapist	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 programme 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 centre) 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	n = 90	n = 355		
	No (%)	No (%)	No (%)		
<1 h	47 (10.3)	11 (12.2)	36 (10.1)	n.c.	n.c.
1 h	313 (70.3)	50 (55.5)	263 (74.0)		
1.5 h	61 (13.7)	17 (18.9)	44 (12.4)		
>1.5 h	24 (5.3)	12 (13.3)	12 (3.3)		
Frequency per week	n = 440	n = 85	n = 355		
	No (%)	No (%)	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)		
Three times	50 (11.3)	7 (8.2)	43 (12.1)		
More than three times	9 (2.0)	2 (2.3)	7 (1.9)		
Time of the day	n = 503	n = 84	n = 419		
	No (%)	No (%)	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	n = 84	n = 356		
	No (%)	No (%)	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)		

(continued)

TABLE 5 Continued

Knowledge about disease and exercise	Total	NL	CH	P-value*	Adjusted odds ratio (95% CI)
Supervisor should be expert in	n = 439	n = 85	n = 354		
	No (%)	No (%)	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 it that supervising physical therapist is expert specifically in axSpA?	n = 515	n = 159	n = 356		
	No (%)	No (%)	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)		

*P-value of Mann-Whitney U-test, χ^2 test or Fisher's exact test.

axSpA: axial spondyloarthritis; CH: Switzerland; MC: multiple choice; n.c.: not calculated; NL: The Netherlands.

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 to home exercise [10]. Moreover, a group setting was found to foster adherence to exercise [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 afore-mentioned 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 physical therapist 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 physical therapist.

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, physical therapists' 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 physical therapists 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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Supplementary data

Supplementary data are available at *Rheumatology Advances in Practice* online.

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