Educational needs in people with Ankylosing Spondylitis and Psoriatic Arthritis: a cross-sectional study

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Running title: Educational needs in Spondyloarthritis

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Abstract:

Objective: To assess the educational needs of people with Ankylosing Spondylitis (AS) and Psoriatic Arthritis (PsA), test differences across patient subgroups and identify factors independently associated with their educational needs.

Methods: This was a cross-sectional analytic study. Patients with AS and PsA completed the Portuguese version of the Educational Needs Assessment Tool (PortENAT). Data were Rasch-transformed before descriptive and inferential analyses were undertaken. Univariable and multivariable analyses were used to determine differences between patient subgroups and factors independently associated with their educational needs.

Results: The study included 121 patients with AS and 132 with PsA. The level of educational needs varied by diagnostic group, but higher needs for both subgroups were reported regarding the "Disease process", "Feelings" and "Managing pain" domains. Overall, patients with AS had a higher level of educational needs than those with PsA. In both disease groups, female gender was independently associated with higher educational needs. In the PsA group, a shorter disease duration was independently associated with higher educational needs in the following domains: "Managing pain", "Movement" and "Feelings".

Conclusion: Educational needs vary by diagnostic group, gender and disease duration. These differences merit consideration in the design of patient education interventions.

Key words: educational needs assessment, patient education, spondyloarthritis, ankylosing spondylitis, psoriatic arthritis.

Introduction

Ankylosing Spondylitis (AS) and Psoriatic Arthritis (PsA) have important and multidimensional impacts upon patient´s lives, derived not only from pain, joint deformity and work disability but also due to interference in simple daily activities, such as self-care (1–3). The holistic management of these conditions involves pharmacological (4,5) and non-pharmacological interventions such as healthy lifestyle choices (e.g. smoking cessation, weight management and diet), physiotherapy and exercise (4,6,7). Patients and health-care professionals have stressed the need for personalisation of treatment according to individual needs, values and resources. Patient education plays a crucial role in empowering patients as partners in achieving the desirable standards of care (8).

The Educational Needs Assessment Tool was developed in the UK (9) and later adapted and validated into Portuguese (PortENAT) (10) and other languages for use in seven rheumatic diseases, including AS and PsA (11). The clinical utility of this tool has been evaluated by patients and clinicians (12) and it has been shown to help deliver effective needs-based patient education in rheumatoid arthritis (RA) (13).

Three studies have summarised the educational needs of patients with Spondyloarthritis (SpA) (14–16). Two (14,15) were conducted in Sweden and one in Austria (16). One (14) found that patients with SpA (AS and undifferentiated Spondyloarthritis - USpA) had considerable educational needs, especially concerning “Self-help”, “Feelings”, and the “Disease process”; and the other (15) validated ENAT to assess educational needs in USpA, and showed that higher disease activity was associated with higher levels of educational needs. The Austrian study (16), showed that educational needs vary by diagnostic group (PsA, RA, and osteoarthritis), disease activity and personal characteristics. The results of the above studies are interesting but may not be

generalizable to other countries, due to differences in culture, healthcare systems and the way patient education is delivered. In addition, none of them assessed the factors independently associated with educational needs, using multivariable analyses.

The objectives of this study were to (i) assess the self-reported educational needs of patients with AS and PsA, (ii) study the differences between patient subgroups and (iii) identify factors independently associated with educational needs in patients with these conditions.

Materials and methods

Study design and settings

This was a cross-sectional study carried out in an outpatient clinic of a university hospital in the centre region of Portugal. The study was conducted in accordance with the declaration of Helsinki and was approved by the local ethics committee (HUC-09-010). Voluntary informed consent was obtained from all patients prior to any study procedures.

Participants

Consecutive patients from the rheumatology clinics meeting the following inclusion criteria were invited to participate: (i) age ≥ 18 years old, (ii) a clinical diagnosis of AS or PsA by a rheumatologist, and (iii) ability to complete the questionnaire unaided. The exclusion criteria were (i) having any other clinically significant comorbid rheumatic disease, (ii) unwillingness to participate.

Assessments

All participants completed the PortENAT in its original form, i.e., the Portuguese version of ENAT used for European validation of this tool (10). This questionnaire

contains 39 items, grouped into 7 domains: “Managing pain” (7 items), “Movement” (5 items), “Feelings” (4 items), “Disease process” (7 items), “Treatments” (7 items), “Self-help measures” (6 items), and “Support systems” (4 items). Each item is assessed using a 0-4 Likert Scale from “not at all important” to “extremely important”. This gives a total score range of 0 to 156, higher scores representing higher educational needs.

From the first page of PortENAT we collected patient-reported information about personal characteristics (age, gender, disease duration (years) and educational background (three ordinal options: basic, secondary or higher)) plus an indication of their overall needs for information about their rheumatic disease (four ordinal options from “I do not want to know anything” to “I want to know everything”). Further details of the PortENAT and its validation can be found elsewhere (10). Patients completed the PortENAT before a regular clinic appointment.

Data Analysis

Following completion of the PortENAT, the raw scores were transformed into interval-level data (ordinal-to-interval measure conversion table is published elsewhere (10)) and summarised descriptively before further analyses. As the ENAT domains have different maximum scores, mean percentages of the maximum score were determined and used to compare between domains.

For univariable analyses, we used independent t-tests to evaluate differences in educational needs between gender (female vs male) and educational background (patients with “basic education” vs those with “secondary or higher education”). To investigate the relationship between educational needs and the independent continuous variables (age and disease duration) correlation statistics were used.

Multivariable analyses (multiple linear regression, enter method) were performed for each disease, using PortENAT scores (domain and total scores) as dependent variables and forcing age (years, continuous), gender (female vs male), educational background ("basic education" vs "secondary or higher education") and disease duration (years, continuous) in the model as theoretically important independent variables.

We present parameter estimates with their associated 95% confidence intervals (CI) and p-values. Results were considered statistically significant for p-values <0.05. We used IBM SPSS Statistics for Windows, Version 22.0. Armonk, NY: IBM Corp. in all analyses.

Results

Population characteristics

Table I presents the demographic and needs of information for each diagnostic group. Of the 280 patients that were invited, 253 returned the questionnaire (90.4% response rate), 121 with AS and 132 with PsA. The rate of complete data (no missing items) was 91.7% (n=111) and 88.6% (n=117) in the AS and PsA groups, respectively. Responses to the screening question indicated that the majority of patients wanted to know "everything" about their disease and only 6.7% and 10.9% of patients with AS and PsA, indicated that they did not want any information.

Comparison of educational needs by diagnostic group

Table II presents the scores of educational needs by diagnostic group. Patients with AS expressed, overall, a higher level of educational needs than those with PsA, reaching statistical significance in the domains of "Treatments", "Self-help measures" and "Support systems".

Associations of educational needs with socio-demographic factors and disease characteristics (univariable analyses)

Table III presents the results of the univariable analyses in each diagnostic group: (III. a.) differences in perceived educational needs by gender and educational background; (III. b.) correlation between educational needs and age or disease duration. Significant differences are outlined below:

In AS:

Gender: Female patients had higher educational needs than their male counterparts in the domains of "Feelings", "Self-help measures", "Managing pain" and "Movement".

Educational background: Patients with a lower educational background had higher educational needs than their counterparts on the domains of "Movement" and "Feelings".

Age: A significant negative correlation was found between age and educational needs on the domain of "Self-help measures": being young was weakly correlated (r=-0.25) to having higher educational needs.

In PsA:

Gender: Female patients had higher educational needs than their male counterparts in the domains of "Feelings", "Self-help measures" and "Disease Process".

Educational background: Patients with higher educational background had higher educational needs than their counterparts regarding "Feelings" and "Self-help measures".

Age: negative significant weak correlations ($0.2 < r < 0.3$) were found between age and educational needs on "Managing pain", "Disease process" and "Self-help measures" domains.

Disease duration: having shorter disease duration was weakly but significantly correlated ($0.2 < r < 0.3$) with higher educational needs regarding "Managing pain", "Movement", "Disease process" and "Self-help measures".

Factors independently associated with educational needs (multivariable analyses)

Results of multiple linear regression analyses are presented in Table IV.

In AS, gender was independently associated with educational needs: being female was independently associated with high educational needs on the domains of "Managing pain", "Movement" and "Feelings". Age, disease duration and educational background were not independently associated with educational needs on any domain.

In PsA, being female was independently associated with higher educational needs in the domain of "Feelings" and having shorter disease duration was independently associated with higher educational needs on the domains of "Managing pain", "Movement" and "Disease Process". Age and educational background were no longer associated with educational needs on any domain.

Discussion

AS and PsA are the two best-studied SpA subtypes so far (17), notwithstanding little is known about the educational needs of these patients, as only a few publications have addressed this topic (14,16). Our cross-sectional study suggests that these patients have important educational needs, which vary by diagnostic group. The main factors independently associated with educational needs were gender in both AS and PsA and disease duration in PsA.

Patients with AS reported, overall, a higher level of educational needs than those with PsA (Table II). The reasons underlying these differences are not clear. Our results

suggest that the content of educational interventions should pay special attention to "Disease process", "Feelings" and "Managing pain" in both AS and PsA, as these domains were considered more important than others. As participants with AS had higher educational needs than those with PsA ("Treatments", "Self-help measures" and "Support systems") perhaps educational interventions for the two diagnostic groups should be separate (disease-specific). Nevertheless, as our study was performed using the data collected in the context of the European validation of ENAT tool (not designed to formally compare diagnostic groups), these differences between AS and PsA need further confirmation, particularly, in studies ensuring comparability of cohorts regarding other factors potentially influencing educational needs (e.g. disease activity).

After considering all factors in multivariable analyses (Table IV), only gender and disease duration remained independently associated with educational needs. Gender was the only factor independently associated with educational needs in both diagnostic groups. This association was more evident in AS, where being female was independently associated with higher educational needs in three domains: "Managing pain", "Movement" and "Feelings". Other international studies using the ENAT have reported similar gender differences in AS and PsA (11, 13), although they were based on univariable analyses only. Our data add robustness to this evidence by controlling for other factors. Recent evidence suggests that female patients with AS have functional MRI signals consistent with central chronic pain (18). Together with our findings, this highlights the special importance of addressing "Managing pain" in patient education for patient subgroup. In PsA, being female was independently associated with higher educational needs on the "Feelings" domain only.

In the PsA dataset, disease duration was independently associated with educational needs: shorter disease duration was associated with higher levels of educational needs in

"Managing pain", "Movement" and "Disease process" domains, mirroring the associations found in the univariable analysis. Previous studies reported no association between disease duration and educational needs in AS and PsA (14,16). However, this may be explained by methodological limitations of those studies as they used univariable analysis only and disease duration was dichotomized as shorter/longer (cut-off of ≤/> 10 years in AS (14) and ≤/> 25th percentile of disease duration in PsA (16)). Our study used multivariable analyses and disease duration was analysed as a continuous variable (i.e. taking advantage of the entire scale), thus providing more robust conclusions.

Strengths of our study are: the few missing data; the use of an instrument (ENAT questionnaire) with strong construct validity and reliability, cross-cultural validity, allowing for cross-cultural comparisons (11); age and disease duration were included in the analysis as continuous variables, taking advantage of the entire scale, instead of "artificially" creating cut-offs to dichotomize these variables; and, for the first time, the use of multivariable analysis to determine factors independently associated with educational needs in AS and PsA.

Our results should be interpreted in the light of some limitations. Data were collected from a sample of patients attending one single centre, which limits the generalisability of the results. However, as the socio-demographic features are in agreement with expectations for AS and PsA populations (19), our results are likely to provide relevant information at group-level for both diseases, at least in Portugal. Some possible determinants of educational needs, such as disease activity, physical function, comorbidities, treatment, economic status, family support and pre-existing knowledge of the patients were not addressed. Future research should take these factors into account.

In conclusion, our results suggest that educational needs vary by diagnostic group, gender and disease duration. Educators should be aware of these differences and target resources appropriately.

Contributors AM and PMM collected the data. MN, MLM and RJOF designed the study. MLM and RJOF analysed the data. MLM prepared the first version of the manuscript. MN and JAPS supervised and contributed to all steps of the work. All authors critically interpreted the results, reviewed the draft versions and gave their approval of the final version of the manuscript.

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Competing interests None.

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Table I. Demographic and self-perceived information needs by diagnostic group.

		AS (n=121)	PsA (n=132)
Male, n (%)		70 (57.9)	65 (49.2)
Age, years, mean (SD)		47.3 (13.2)	53.8 (12.8)
Disease duration*, years, mean (SD)		15.6 (11.8)	14.4 (10.2)
Educational background*	Basic, n (%)	33 (27.7)	65 (52.8)
	Secondary, n (%)	62 (52.1)	45 (36.6)
	Higher, n (%)	24 (20.2)	13 (10.6)
How much information?*	None, n (%)	8 (6.7)	14 (10.9)
	Some things, n (%)	22 (18.3)	40 (31.3)
	A lot of things, n (%)	16 (13.3)	13 (10.2)
	Everything, n (%)	74 (61.7)	61 (47.7)

AS, Ankylosing Spondylitis; PsA, Psoriatic Arthritis; SD, standard deviation

*Percentages of patients with missing data were ≤3.0%, except for Educational background in patients with PsA (6.8%) and Disease duration in AS (6.6%) and PsA (9.1%).

Table II. Comparison of educational needs between patients with AS and PsA.

Domain (score range)#	AS (n=121)			PsA (n=132)			Difference		
	N	Mean (SD)**	Mean as % of maximum##	N	Mean (SD)**	Mean as % of maximum	MD (95% CI)	t-statistic	p-value
1. Managing pain (0-24)	121	14.3 (5.2)	59.6%	130	13.3 (6.4)	55.4%	1.00 (-0.46 to 2.46)	1.360	0.175
2. Movement (0-20)	121	10.6 (3.8)	53.0%	131	10.5 (4.8)	52.5%	0.12 (-0.95 to 1.19)	0.227	0.821
3. Feelings (0-16)	121	9.5 (3.8)	59.4%	130	9.5 (3.5)	59.4%	0.05 (-0.86 to 0.96)	0.108	0.914
4. Disease process (0-28)	121	18.2 (5.5)	65.0%	130	17.6 (6.2)	62.9%	0.58 (-0.88 to 2.04)	0.786	0.433
5. Treatments (0-28)	112	14.6 (5.2)	52.1%	119	12.9 (5.2)	46.1%	1.68 (0.32 to 3.03)	2.444	**0.015**
6. Self-help measures (0-24)	121	14.8 (5.3)	61.7%	131	12.8 (6.1)	53.3%	1.98 (0.57 to 3.40)	2.759	**0.006**
7. Support systems (0-16)	120	9.3 (3.6)	58.1%	131	7.3 (3.8)	45.6%	2.00 (1.08 to 2.92)	4.284	**<0.001**
Total PortENAT score (0-156)	111	88.6 (23.2)	56.8%	117	79.7 (26.4)	51.1%	8.88 (2.37 to 15.39)	2.688	**0.008**

Higher scores mean higher level of educational needs.

Determined as: (mean value of the domain*100) / maximum value of the domain. This percentage allows easier comparison between domains.

AS, Ankylosing Spondylitis; PsA, Psoriatic Arthritis; MD, mean difference (AS scores minus PsA scores); PortENAT, Portuguese Educational Needs Assessment Tool.

**Rasch-transformed PortENAT scores.

Table III. Educational needs of both diagnostic groups by gender, educational background, age and disease duration (univariable analyses).

III. a. Comparison of educational needs in each diagnostic group by gender and educational background.

ENAT Domains (range)			Pain (0-24)	Movement (0-20)	Feelings (0-16)	Disease process (0-28)	Treatments (0-28)	Self-help (0-24)	Support (0-16)	Total score (0-164)
AS	Gender	Male, mean (SD)	13.3 (4.8)	9.7 (3.6)	8.6 (3.8)	17.6 (5.6)	14.0 (5.1)	14.0 (5.2)	8.8 (3.6)	83.4 (23.1)
		Female, mean (SD)	15.6 (5.5)	11.8 (3.9)	10.9 (3.3)	19.1 (5.5)	15.4 (5.2)	16.0 (5.3)	10.1 (3.5)	96.0 (21.5)
		p-value	**0.013**	**0.004**	**<0.001**	0.148	0.154	**0.039**	0.053	**0.004**
	Educational background	Basic, mean (SD)	13.6 (3.9)	11.0 (3.3)	10.6 (3.1)	17.6 (5.6)	15.5 (3.9)	13.2 (4.6)	9.6 (3.2)	89.6 (18.4)
		Above*, mean (SD)	14.5 (5.9)	8.6 (3.7)	8.0 (4.2)	17.8 (5.2)	12.9 (6.5)	14.4 (6.2)	8.2 (3.1)	82.2 (26.5)
		p-value	0.498	**0.012**	0.009	0.888	0.076	0.415	0.098	0.228
PsA	Gender	Male, mean (SD)	12.3 (6.5)	10.0 (4.8)	8.3 (3.3)	16.5 (6.1)	12.8 (5.3)	11.5 (6.3)	6.6 (3.5)	75.8 (28.6)
		Female, mean (SD)	14.0 (6.0)	10.8 (4.6)	10.6 (3.3)	18.6 (6.0)	13.0 (5.2)	14.0 (5.5)	7.9 (3.9)	83.7 (23.6)
		p-value	0.121	0.312	**<0.001**	**0.048**	0.839	**0.018**	0.056	0.102
	Educational background	Basic, mean (SD)	11.9 (6.9)	9.7 (5.0)	9.0 (3.6)	17.2 (6.6)	12.5 (5.4)	11.7 (6.3)	7.3 (4.3)	73.6 (26.7)
		Above*, mean (SD)	15.7 (5.7)	12.4 (4.3)	11.4 (4.8)	17.0 (6.1)	14.0 (7.2)	16.8 (6.1)	6.7 (3.4)	93.9 (32.9)
		p-value	0.068	0.073	**0.043**	0.918	0.405	**0.008**	0.672	**0.021**

III. b. Correlation between educational needs, age and disease duration by diagnostic group.

ENAT Domains (range)			Pain (0-24)	Movement (0-20)	Feelings (0-16)	Disease process (0-28)	Treatments (0-28)	Self-help (0-24)	Support (0-16)	Total score (0-164)
AS	Age	*r*	-0.01	0.15	0.02	-0.12	-0.14	-0.25	-0.03	-0.13
		p-value	0.992	0.114	0.846	0.200	0.163	**0.007**	0.764	0.193
	Disease duration	*r*	0.03	0.05	0.02	-0.05	-0.13	-0.14	0.01	-0.07
		p-value	0.778	0.638	0.822	0.582	0.179	0.150	0.960	0.481
PsA	Age	*r*	-0.22	-0.17	-0.14	-0.23	-0.13	-0.26	0.03	-0.28
		p-value	**0.015**	0.063	0.109	**0.009**	0.163	**0.004**	0.758	**0.002**
	Disease duration	*r*	0.28	-0.28	-0.14	-0.27	-0.12	-0.25	-0.03	-0.33
		p-value	**0.002**	**0.002**	0.135	**0.003**	0.204	**0.006**	0.740	**0.001**

AS, Ankylosing Spondylitis; ENAT, Educational Needs Assessment Tool; PsA, Psoriatic Arthritis; r- Pearson's correlation.

*secondary or higher education

Table IV. Multiple linear regression analysis of educational needs (transformed Port-ENAT scores) and all independent variables.

IV. a. Ankylosing Spondylitis (AS)

Independent variables	Reference category	Pain (0-24)		Movement (0-20)		Feelings (0-16)		Disease Process (0-28)		Treatments (0-28)		Self-Help (0-24)		Support (0-16)		Total ENAT Score (0-164)	
		β 95%CI	p	β 95%CI	p	β 95%CI	p	β 95%CI	p	β 95%CI	p	β 95%CI	p	β 95%CI	p	β 95%CI	p
Gender	Male	0.28 0.87 to 5.07	**0.006**	0.81 0.81 to 3.84	**0.003**	0.32 1.00 to 3.94	**0.001**	0.17 -0.34 to 4.10	0.096	0.10 -1.18 to 3.33	0.345	0.17 -0.22 to 4.02	0.078	0.17 -0.21 to 2.67	0.093	0.25 2.38 to 22.42	**0.016**
Educational background	Basic	0.09 -1.62 to 3.75	0.433	0.03 -1.65 to 2.24	0.762	-0.20 -3.72 to 0.05	0.056	0.01 -2.70 to 2.99	0.921	-0.21 -5.42 to 0.26	0.074	0.10 -1.44 to 3.99	0.355	-0.10 -2.67 to 1.00	0.370	-0.11 -18.54 to 6.61	0.349
Disease duration #		-0.01 -0.10 to 0.09	0.924	-0.08 -0.10 to 0.05	0.474	-0.01 -0.07 to 0.06	0.896	0.03 -0.09 to 0.12	0.816	-0.09 -0.14 to 0.06	0.459	-0.02 -0.11 to 0.09	0.856	-0.03 -0.08 to 0.06	0.787	-0.04 -0.53 to 0.37	0.737
Age #		0.11 -0.06 to 0.14	0.394	0.26 -0.01 to 0.15	0.054	0.00 -0.07 to 0.07	0.998	-0.05 -0.13 to 0.08	0.694	-0.18 -0.18 to 0.04	0.197	-0.13 -0.15 to 0.05	0.286	0.01 -0.07 to 0.07	0.961	-0.08 -0.62 to 0.32	0.540

IV. b. Psoriatic arthritis (PsA)

Independent variables	Reference category	Pain (0-24)		Movement (0-20)		Feelings (0-16)		Disease Process (0-28)		Treatments (0-28)		Self-Help (0-24)		Support (0-16)		Total ENAT Score (0-164)	
		β 95%CI	p	β 95%CI	p	β 95%CI	p	β 95%CI	p	β 95%CI	p	β 95%CI	p	β 95%CI	p	β 95%CI	p
Gender	Male	0.11 -1.05 to 3.94	0.252	0.02 -1.66 to 2.10	0.817	0.34 1.05 to 3.72	**0.001**	0.14 -0.66 to 4.15	0.153	-0.10 -3.35 to 1.27	0.373	0.13 -0.72 to 3.93	0.174	0.17 -0.23 to 2.78	0.097	0.04 -8.86 to 12.92	0.712
Educational background	Basic	0.14 -1.21 to 4.71	0.244	0.12 -1.14 to 3.34	0.331	0.13 -0.71 to 2.48	0.273	-0.07 -3.72 to 2.01	0.555	-0.02 -2.87 to 2.51	0.897	0.16 -0.84 to 4.70	0.169	-0.02 -1.97 to 1.62	0.848	0.07 -8.76 to 16.59	0.541
Age #		0.01 -0.12 to 0.12	0.969	0.01 -0.08 to 0.10	0.831	0.02 -0.04 to 0.09	0.460	-0.07 -0.15 to 0.08	0.572	-0.03 -0.14 to 0.07	0.547	-0.06 -0.14 to 0.08	0.626	0.03 -0.06 to 0.08	0.804	-0.08 -0.65 to 0.35	0.545
Disease duration #		-0.23 -0.26 to 0.01	**0.030**	-0.25 -0.21 to -0.02	**0.017**	-0.10 -0.10 to 0.03	0.324	-0.26 -0.28 to 0.04	**0.012**	-0.11 -0.17 to 0.06	0.333	-0.18 -0.23 to 0.01	0.069	-0.02 -0.08 to 0.07	0.882	-0.28 -1.24 to -0.17	**0.010**

CI, Confidence interval; ENAT, Educational Needs Assessment Tool; AS, Ankylosing Spondylitis; PsA, Psoriatic Arthritis.

Defined as a continuous variable.