

The Educational Needs of Patients with Undifferentiated Spondyloarthritis

- validation of the ENAT questionnaire and needs assessment

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Short title

Educational needs in USpA

Key words

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Abstract

Objectives

To validate the Swedish version of the educational needs assessment tool (SwENAT) in undifferentiated spondyloarthritis (USpA) and use it to study educational needs of patients with USpA.

Methods

This was a cross-sectional study recruiting a random sample of patients with USpA from a hospital register in Sweden. Educational needs data were collected together with disease activity and function indices (BASDAI and BASFI). Rasch analysis was utilized to evaluate the construct validity, internal consistency and unidimensionality of the SWENAT before studying differences in educational needs between patient subgroups (gender, age and disease severity).

Results

Complete responses were obtained from 77 patients (48 women), mean (SD) age 50 (12) years, disease duration was 16 (11) years, BASDAI 4.9 (1.9) and BASFI 3.1 (2.3). The SwENAT satisfied the requirements of Rasch model ($\chi^2=11.488$; $p=0.119$) including strict unidimensionality. Overall, the mean (SD) SwENAT score was 86 (32), women reported higher needs than men in the domains of pain, mean (SD) 13.1 (6.8) vs. 10.1 (6.0), $p = 0.05$; movement, mean (SD) 13.0 (5.5) vs. 9.9 (5.7), $p = 0.02$ and self-help, mean (SD) 17.0 (5.8) vs. 14.1 (5.0), $p = 0.03$. Higher disease activity (BASDAI >4) was associated with higher educational needs, mean (SD) 92.6 (31.9) vs. 73.7 (29.4), $p = 0.02$.

Conclusions

Our data suggest that the SwENAT is valid in USpA. Women and patients with higher disease activity are more likely to have high levels of educational needs, therefore special attention and strategies to target patient education are warranted.

Key words

patient education, arthritis, outcome measures, undifferentiated spondyloarthritis, needs assessment.

Introduction

Undifferentiated spondyloarthritis (USpA) is a subgroup of Spondyloarthritis (SpA) sharing some common features with ankylosing spondylitis (AS) such as inflammatory axial pain, asymmetrical peripheral arthritis, enthesitis, and extra-articular manifestations (Dougados and Hochberg 2002, Dougados et al. 1998). The diagnosis of USpA is used in all Swedish healthcare clinics, in accordance with the International Classification of Disease (ICD-10) (www.who.int/classifications/icd/en/).

Patient education is an integral part of the management of rheumatic diseases and supported by the European League Against Rheumatism (EULAR) recommendations (Zangi et al. 2015). Educational needs have been well studied in people with rheumatoid arthritis (RA), and other sub-groups of spondyloarthritis (SpA). For example, in RA, needs-based education has been shown to have effects in self-efficacy and some aspects of health status (Ndosi et al. 2016). Educational needs of patients with other SpAs, have been outlined (Haglund et al. 2017, Dragoi et al. 2013) although no intervention studies have been published. However, the educational needs of people with undifferentiated spondyloarthritis (USpA) have not been well studied.

Patient education should be patient-centred to support disease management, enhance self-efficacy and patient empowerment (Newman et al. 2004, Zangi et al. 2015). A patient-completed questionnaire tailored to facilitate a discussion concerning educational needs in patients with rheumatoid arthritis (RA) was developed in early 2000 in the UK: the educational needs assessment tool (ENAT) (Hardware et al. 2004). The ENAT has since been validated in seven rheumatic diseases: rheumatoid arthritis (RA), ankylosing spondylitis (AS), fibromyalgia syndrome (FMS), psoriatic arthritis (PsA), systemic lupus erythematosus (SLE), scleroderma (SSc) and osteoarthritis (OA) (Ndosi et al. 2011, Ndosi et al. 2014) and cross-culturally adapted to different European languages including also Swedish (Ndosi et al. 2011, Ndosi et al. 2014, Cruz et al. 2014, Sierakowska et al. 2015). While the ENAT is now considered as a generic tool to assess educational needs of people with rheumatic diseases, and it has been translated into Swedish, the evidence of its validity in USpA was lacking. The aim of this study was twofold: 1) to validate the educational needs assessment tool (ENAT) in people with USpA and 2) to use the ENAT to study the educational needs of people with USpA.

Methods

Design and Patients

This was a single centre, analytical cross-sectional study. Data on patients' characteristics and their educational needs were collected together with other outcomes to study the validity of the ENAT in USpA and assess the association between educational needs and variables of interest (age, gender and disease activity). Data were collected from a regional rheumatology centre in the South of Sweden.

Patients were selected from the hospital register which included patients diagnosed with USpA at least once over the last ten years between 2002 and 2012. The inclusion criteria included: (i) diagnosis of USpA according to the ICD-10 code (M46.0, M46.1, M46.8, and M46.9) (www.who.int/classifications/icd/en/) (ii) age between 18 and 85 years. 210 patients who fulfilled the inclusion criteria were randomly selected and having consented to the study, they were given a postal survey collecting demographic data and data on disease activity, physical function and educational needs.

Measures

Disease activity was collected with the Bath Ankylosing Spondylitis Disease Activity Index (BASDAI) (Garrett et al. 1994) and physical function was assessed with the Bath Ankylosing Spondylitis Functional Index (BASFI) (Calin et al. 1994). The total score for each of the indices ranges between 0–10, where a higher score in the BASDAI indicates a more severe disability due to AS and a higher score in BASFI indicates a more severe limitation of function due to AS. Both indices are outcome measures validated in SpA.

Educational needs were assessed with the Swedish version of the ENAT (SwENAT) (Bergsten 2007, Ndosi et al. 2014)) and the data was then utilized to assess the construct validity, internal consistency, unidimensionality and response bias of the SwENAT using Rasch analysis. In addition to demographic details, the SwENAT has 39 items which are grouped into seven domains, each with varying number of items: Managing pain (6), Movement (5), Feelings (4), Disease process (7), Treatments (7), Self-help measures (6) and Support systems (4). In each domain, respondents are asked to rate the question: "How important is it for you to know more about ..." for all items in that domain. Each item is rated using five-point Likert scales with the descriptors: "not at all important" = 0, "fairly important" = 1, "a little important" = 2, "very important" = 3 and "extremely important" = 4. The total SwENAT score is obtained

by summing up all domain scores (pain 0-24, movement 0-20, feelings 0-16, disease 0-28, treatments 0-28, self-help 0-24 and support 0-16) and ranges between 0 (no needs) and 156 (the highest level of needs). Examples of items in the “movement” domain include devices to help do practical things, ways to make lifting easier, ways to save energy, getting enough rest and sleep and ways to do things which wear joints less.

Data analysis

To assess differences between patient subgroups, the data were categorised by gender, age (median split) and disease activity (BASDAI split at 4.0). Rasch analysis was used to test the validity of the ENAT in USpA. ENAT items were assessed for fit to the Rasch model, using a set of fit statistics. Fit to the model implies construct validity, reliability and statistical sufficiency. The expected values for perfect model fit are presented at the bottom of Table 2. Rasch analysis involves multiple testing, therefore, the p-values for fit statistics were Bonferroni-adjusted to the alpha level (i.e. $p = 0.05/\text{number of tests carried out}$) (Bland and Altman 1995). After adequate fit to the model was established, a strict test of unidimensionality suggested by Smith (2002) was carried out to assess if there is any multidimensionality in the scale. Having satisfied the requirements of the Rasch models, the ENAT data which is by nature ordinal was transformed into interval scores before further analyses were carried out. Rasch analysis was carried out using the Master’s Partial Credit Model parameterization (Masters 1982) in RUM2030 software, RUMM Laboratory Pty Ltd.

We then studied the educational needs of patient sub-groups using independent t-tests. For these analyses, SPSS version 21 (IBM, Chicago, Illinois, USA) was used and in hypothesis testing, p-value ≤ 0.05 was considered statistically significant.

Ethical approval

The study was approved by the Regional Ethics Board (Dnr 2012/328), and all included patients signed an informed consent. The study adhered to the Helsinki declaration.

Results

Out of the 210 patients that were randomly selected and assigned to receive the postal survey, 77 (37%) responded and returned the questionnaires. Their mean (SD) age was 50 (12) years, disease duration, 16 (11) years and 48 (62%) were women. Their mean (SD) BASDAI was 4.9 (1.9) and BASFI was 3.1 (2.3), Table 1. Non-responders had a mean age of 48 (SD 13) years, and 49% were women.

Rasch analysis of the ENAT

The initial results of Rasch analysis revealed lack of fit to the Rasch model when the individual items were used; $\chi^2 = 91.918$; $p < 0.001$. Initial lack of fit was due to item-item correlations (local dependence) which also had artificially inflated the internal consistency (PSI-0.962). See table 2, analysis 1. When items corresponding to each domain were analysed as a unit, i.e. the ENAT as a 7-subscale questionnaire, the requirements of Rasch model were satisfied, $\chi^2 = 11.488$; $p = 0.119$ including strict unidimensionality, that is only 3.2% of independent t-tests on the latent estimates derived from two independent sets of items lie outside the ± 1.96 range (Smith 2002). In addition, the internal consistency of the scale remained high (PSI = 0.913). See table 2. There was no differential item functioning by age, gender or disease activity.

Educational needs

The mean ENAT total score for patients with USpA was 86 (SD 32). Women reported higher educational needs than men in the domains of pain, mean 13.1 (SD 6.8) vs. 10.1 (SD 6.0), $p = 0.05$, in movement mean 13.0 (SD 5.5) vs. 9.9 (SD 5.7), $p = 0.02$ and in self-help, mean 17.0 (SD 5.8) vs. 14.1 (SD 5.0), $p = 0.03$. Higher disease activity (BASDAI > 4) was associated with higher educational needs, mean 92.6 (SD 31.9) vs. 73.7 (SD 29.4), $p = 0.02$. There was no significant difference in educational needs between age groups. See Table 4.

Discussion

The SwENAT has been validated in USpA thus enabling an accurate estimation of the educational needs. We found substantial educational needs among this random sample of patients with USpA in Sweden, particularly with respect to pain and movement. Studying subgroups we found that people with worse self-reported disease activity reported higher educational needs in almost all areas. Also, women were more likely to report higher educational needs compared to men in some areas. These findings support the importance of targeting educational interventions to all patients with USpA, bearing in mind that women and patients with high disease activity may express more needs than other subgroups of patients (Zangi et al. 2015).

The findings indicated extensive educational needs in patients with USpA who had higher scores overall than that found for patients with systemic sclerosis (SSc) (Schouffoer et al. 2016) but similar to those reported by Dutch patients with systemic lupus erythematosus (SLE) (Zirkzee et al. 2014). These findings may suggest that patients with USpA may not access as much patient education as

those with SSc.

Patients with USpA reported worse disease activity than previously reported in those with AS (Haglund et al. 2012). In the present study patients with worse disease severity reported higher educational needs than patients with lower disease severity, suggesting extensive educational needs. We also found some gender differences in patients with USpA, where women reported higher educational needs than men in three of seven subscales (pain, movement and self-help), but not in the total ENAT score. Women with USpA have been found to report worse pain intensity, pain distribution and function compared to men (Haglund et al. 2012) and health professionals should strive to recognize these needs. However, no differences were found between gender in the total ENAT scores, which is similar to findings in Dutch patients with SSc or with RA (Meesters et al. 2009, Schouffoer et al. 2016). Age was not associated with educational needs in USpA, contrary to findings in the Dutch study where younger patients with RA had more educational needs in the subscales pain and feelings than older patients had (Meesters et al. 2009).

Our findings provide further evidence to support the validity of the ENAT as a generic questionnaire in rheumatic diseases. Previous work validated the tool in rheumatoid arthritis, ankylosing spondylitis, fibromyalgia syndrome, psoriatic arthritis, systemic lupus erythematosus, scleroderma and osteoarthritis (Ndosi et al. 2014, Ndosi et al. 2011, Cruz et al. 2014, Sierakowska et al. 2015). This work has extended this to USpA albeit in Sweden only.

The following limitations may lower the external validity of our study: (i) a low response rate (ii) the sample was randomly chosen from a hospital register and included patients who were given the diagnosis of USpA at least once over the last ten years, which may present a risk for misclassification of diagnosis (iii) patients with USpA are often treated in primary care but our sample was derived from a specialist hospital register which might indicate a worse disease severity in general. Further studies are needed to study the educational needs of patients treated in a primary care setting.

Conclusion

The validity of the ENAT has been extended to USpA, supporting it as a generic tool for assessing educational needs in people with rheumatic diseases. Our data suggest that in USpA, women and patients with higher disease activity are more likely to have high levels of educational needs, implying that these groups should get special attention in educational interventions.

Author contributions

All authors have fulfilled the ICMJE authorship criteria.

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Table 1. BASDAI and BASFI by gender and age groups, n=77; numbers are means (SD).

| | Men | Women | Age 18-50 years | >51-85 years |
|----------------|------------|--------------|------------------------|------------------------|
| | n=29 | n=48 | n=42 | n=35 |
| BASDAI (0-10*) | 4.2 (1.6) | 5.3 (2.0) | 4.9 (2.1) | 4.9 (1.7) |
| BASFI (0-10*) | 2.4 (2.0) | 3.6 (2.4) | 2.7 (2.2) | 3.6 (2.4) |

* 0=best possible score and 10=worst possible score

Table 2. Results of Rasch analysis of the SwENAT for USpA.

| Analysis | Item Fit Residual | | Person Fit Residual | | Chi Square Interaction | | PSI | Sample Size | Test of Strict Unidimensionality* |
|---------------------------------|--------------------------|----------|----------------------------|----------|-------------------------------|--------------|-----------------|--------------------|--|
| | Mean | SD | Mean | SD | Value (df) | p | | | |
| Analysis 1 (individual items) | 0.365 | 1.433 | -0.16 | 2.108 | 91.918 (39) | <0.001 | 0.962 | 73 | Proportion of significant independent T-Tests (CI) |
| Analysis 2 (7 sub-scales) | 0.457 | 0.739 | -0.281 | 1.119 | 11.488 (7) | 0.119 | 0.913 | 73 | |
| <i>Expected for perfect fit</i> | <i>0</i> | <i>1</i> | <i>0</i> | <i>1</i> | | <i>0.050</i> | <i>>0.85</i> | | <i>Lower bound CI <0.05</i> |

*Unidimensionality test suggested by Smith (2002) -.

Table 3. Conversion chart from raw to transformed scores – SwENAT for USpA.

| Raw scores | Transformed scores | | | | | | |
|------------|--------------------|----------|----------|-----------|------------|-----------|---------|
| | Pain | Movement | Feelings | Arthritis | Treatments | Self-Help | Support |
| 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 |
| 1.0 | 0.9 | 1.0 | 1.2 | 0.5 | 0.8 | 0.8 | 1.4 |
| 2.0 | 1.6 | 1.9 | 2.2 | 0.9 | 1.4 | 1.4 | 2.5 |
| 3.0 | 2.1 | 2.8 | 2.9 | 1.4 | 2.0 | 2.2 | 3.4 |
| 4.0 | 2.5 | 3.6 | 3.6 | 1.8 | 2.3 | 2.7 | 4.1 |
| 5.0 | 2.8 | 4.1 | 4.2 | 2.0 | 2.7 | 3.2 | 4.8 |
| 6.0 | 3.2 | 4.8 | 4.9 | 2.5 | 3.1 | 3.7 | 5.5 |
| 7.0 | 3.5 | 5.7 | 5.6 | 2.7 | 3.5 | 4.2 | 6.3 |
| 8.0 | 4.1 | 6.4 | 6.5 | 3.2 | 3.7 | 4.6 | 7.1 |
| 9.0 | 4.4 | 7.4 | 7.5 | 3.2 | 4.1 | 5.3 | 8.0 |
| 10.0 | 4.8 | 8.8 | 8.5 | 3.6 | 4.3 | 5.8 | 8.9 |
| 11.0 | 5.3 | 10.5 | 9.5 | 4.1 | 4.7 | 6.4 | 9.8 |
| 12.0 | 5.8 | 11.9 | 10.7 | 4.3 | 5.3 | 7.2 | 10.7 |
| 13.0 | 6.5 | 12.8 | 11.7 | 4.5 | 5.7 | 8.3 | 11.6 |
| 14.0 | 7.2 | 13.8 | 13.0 | 5.0 | 6.1 | 9.9 | 12.7 |
| 15.0 | 8.3 | 14.7 | 14.4 | 5.4 | 6.9 | 11.5 | 14.2 |
| 16.0 | 9.9 | 15.3 | 16.0 | 6.1 | 7.6 | 12.8 | 16.0 |
| 17.0 | 11.5 | 16.2 | | 7.0 | 9.0 | 13.9 | |
| 18.0 | 12.9 | 17.2 | | 9.9 | 11.0 | 15.0 | |
| 19.0 | 14.1 | 18.4 | | 12.2 | 12.7 | 16.0 | |
| 20.0 | 15.5 | 20.0 | | 14.0 | 13.9 | 17.1 | |
| 21.0 | 16.9 | | | 15.4 | 15.3 | 18.4 | |
| 22.0 | 18.5 | | | 16.7 | 16.4 | 19.8 | |
| 23.0 | 21.0 | | | 17.8 | 17.6 | 21.6 | |
| 24.0 | 24.0 | | | 19.2 | 19.0 | 24.0 | |
| 25.0 | | | | 20.8 | 20.4 | | |
| 26.0 | | | | 22.4 | 22.1 | | |
| 27.0 | | | | 24.8 | 24.5 | | |
| 28.0 | | | | 28.0 | 28.0 | | |

Table 4. Educational needs in people with USpA; data presented as mean (SD) in ENAT domain scores and ENAT total scores, n=77

| | Men n=29 | Women n=48 | p | Age 18-51 yrs n=42 | Age ≥51 yrs n=35 | p | BASDAI 0- 4 n=24 | BASDAI ≥4 n=53 | p |
|----------------------------------|-------------|---------------|-------------|--------------------------|------------------------|------|------------------------|----------------------|--------------|
| Pain (0-24) | 10.1 (6.0) | 13.1 (6.8) | 0.05 | 12.5 (7.1) | 11.5 (6.1) | 0.52 | 9.4 (5.8) | 13.1 (6.7) | 0.02 |
| Movement (0-20) | 9.9 (5.7) | 13.0 (5.5) | 0.02 | 11.6 (6.0) | 12.1 (5.3) | 0.73 | 9.1 (5.7) | 13.0 (5.4) | 0.005 |
| Feelings (0-16) | 8.7 (4.4) | 10.6 (4.7) | 0.08 | 9.8 (4.4) | 10.0 (5.0) | 0.82 | 8.4 (4.6) | 10.6 (4.6) | 0.06 |
| Disease (0-28) | 15.2 (7.9) | 17.8 (7.3) | 0.14 | 16.2 (7.6) | 17.6 (7.7) | 0.43 | 16.1 (7.9) | 17.1 (7.5) | 0.62 |
| Treatments (0-28) | 12.0 (7.8) | 14.0 (8.0) | 0.31 | 12.6 (8.0) | 14.1 (7.8) | 0.42 | 10.0 (6.6) | 14.8 (8.1) | 0.01 |
| Self-help (0-24) | 14.1 (5.0) | 17.0 (5.8) | 0.03 | 16.3 (6.0) | 15.4 (5.2) | 0.50 | 14.7 (6.0) | 16.5 (5.4) | 0.18 |
| Support (0-16) | 7.3 (4.3) | 8.1 (4.1) | 0.41 | 7.5 (4.0) | 8.2 (4.4) | 0.52 | 6.0 (4.2) | 8.7 (3.9) | 0.008 |
| ENAT total scores (0-156) | 78.3 (33.1) | 91.5 (30.9) | 0.10 | 84.3 (31.6) | 89.3 (33.2) | 0.52 | 73.7 (29.4) | 92.6 (31.9) | 0.02 |

Bold values indicate significant p-values