RHEUMATOLOGY

Original article

Psychological profiles in patients with Sjögren's syndrome related to fatigue: a cluster analysis

Ninke van Leeuwen^{1,2}, Ercolie R. Bossema¹, Hans Knoop³, Aike A. Kruize², Hendrika Bootsma⁴, Johannes W. J. Bijlsma² and Rinie Geenen^{1,2}

Abstract

Objective. Fatigue is a highly prevalent and debilitating symptom in the autoimmune disease SS. Although the disease process plays a role in fatigue, psychological factors may influence fatigue and the ability to deal with its consequences. Profiles of co-occurring psychological factors may suggest potential targets for the treatment of fatigue. The aim of this study was to identify psychological profiles in patients with SS and the accompanying levels of fatigue.

Methods. Three hundred patients with primary SS (mean age 57 years, 93% female) completed questionnaires on fatigue (multidimensional fatigue inventory), physical activity cognitions (TAMPA-SK), illness cognitions, cognitive regulation, emotion processing and regulation [Toronto Alexithymia Scale 20, Emotion Regulation Questionnaire (ERQ), Berkeley Expressivity Questionnaire], coping strategies (Brief COPE) and social support.

Results. Principal axis factor analysis (oblimin rotation) yielded six psychological factors: social support, negative thinking, positive thinking, emotional expressivity, avoidance and alexithymia (i.e. the inability to differentiate emotions). Using cluster analyses, these factors were grouped in four psychological profiles: functional (39%), alexithymic (27%), self-reliant (23%) and dysfunctional (11%). Irrespective of the psychological profile, the level of fatigue was substantially higher in patients than in the general population. Patients with a dysfunctional or an alexithymic profile reported more fatigue than those with a self-reliant profile.

Conclusion. Our study in SS yielded four psychological profiles that were differentially associated with fatigue. These profiles can be used to examine determinants and prognosis of fatigue as well as the possibility of customizing cognitive behavioural interventions for chronic fatigue.

Key words: Sjögren's syndrome, fatigue, psychology, coping, cognitive behavioural therapy, clusters, subtypes.

Introduction

The systemic autoimmune disease SS is characterized by lymphocytic infiltration of exocrine glands. Key symptoms are dryness of the eyes (keratoconjunctivitis sicca) and mouth (xerostomia) [1]. Moreover, 57–74% of patients

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report clinically significant levels of fatigue [2–5]. Although the inflammatory process is a precipitating and possible maintaining factor of fatigue, associations of clinical and laboratory variables with fatigue are mostly absent [3, 6, 7].

Psychological factors may influence fatigue and the ability to deal with its consequences [4, 8, 9]. Examples of such factors are negative cognitions such as catastrophizing and helplessness [2, 10], emotions such as depression and fear of movement (kinesiophobia) [2, 4, 8], behavioural variables such as avoidance of physical activity [11] and social factors such as a lack of social support or overprotective responses of other people [12, 13]. Some psychological factors co-occur, which may suggest a common underlying mechanism [14] and may indicate the most appropriate treatment of fatigue for a subgroup

¹Department of Clinical and Health Psychology, Utrecht University, ²Department of Rheumatology and Clinical Immunology, University Medical Center Utrecht, Utrecht, ³Expert Centre for Chronic Fatigue, Radboud University Nijmegen Medical Centre, Nijmegen and ⁴Department of Rheumatology and Clinical Immunology, University Medical Center Groningen, Groningen, The Netherlands

Correspondence to: Ninke van Leeuwen, Department of Clinical and Health Psychology, Utrecht University, Heidelberglaan 1, PO Box 80.140, 3508 TC Utrecht, The Netherlands. E-mail: N.vanLeeuwen@uu.nl

of patients [15]. Profiles of co-occurring psychological factors have been specified for breast cancer [16], sarcoidosis [17, 18], FM [19, 20] and chronic fatigue syndrome [21], but not for patients with SS.

The significance of clusters of psychological variables for fatigue levels has been indicated in several studies [16-19, 21]. Among others, patients with sarcoidosis [17] and breast cancer [16] with high levels of fatigue reported more psychological problems (i.e. depression, anxiety, emotional instability), interpersonal problems, pain and sleeping problems than patients with mild or intermittent fatigue. Moreover, the effectiveness of cognitive behavioural interventions aimed at the treatment of chronic fatigue syndrome [21] and FM [19] was shown to differ for patients with different psychological profiles. Overall these studies suggest that psychological profiles are of relevance to fatigue.

The aim of this study was to identify psychological profiles in patients with primary SS and the accompanying levels of fatigue. In analogy to studies in patients with chronic pain [19, 20], we expected to find an adaptive coping profile with functional cognitions, coping behaviour and social support; a dysfunctional profile with maladaptive cognitions and coping; and an interpersonally distressed profile with low social and personal support. Patients with a dysfunctional or interpersonally distressed profile were expected to have higher fatigue levels than those with a functional profile [19, 21-24]. The identification of psychological profiles in patients with SS can be used in research of factors influencing fatigue and to tailor interventions to the individual characteristics that maintain fatigue.

Methods

Participants

Patients diagnosed with primary SS according to the criteria of the American-European Consensus Group on Classification Criteria for SS [1] were selected from a larger population of patients with sicca (dryness) symptoms (n = 937) from the Departments of Rheumatology and Clinical Immunology of the University Medical Centres (UMCs) in Utrecht (n = 667) and Groningen (n = 270), The Netherlands. Patients were invited by their rheumatologist to participate in a questionnaire study. Of the 937 questionnaires that were sent, 470 completed guestionnaires were returned (50% response), of which 300 were from patients who fulfilled the criteria for primary SS. Excluded patients had secondary SS (n=34), non-Sjögren's sicca syndrome (n = 115) or did not have a diagnosis of SS (n=21). Patients who did not want to participate (n = 467) were asked to complete and return a non-participation form with questions on demographic characteristics. Compared with the patients who completed the questionnaires, the patients who completed a non-participation form (n = 132) had a lower education level ($\chi^2 = 20.2$, P < 0.001) and were more often single $(\chi^2 = 9.9, P = 0.04)$, but they did not differ in age (t = -1.6, t)

P = 0.10), gender ($\chi^2 = 0.3$, P = 0.61) or ethnicity ($\chi^2 = 6.5$, P = 0.17).

The study was conducted according to the principles of the Declaration of Helsinki (October 2008). All participants provided written informed consent. The Medical Ethics Committee of the UMC Utrecht decided that their approval was not necessary for this non-invasive study.

Measures

The survey included validated questionnaires on fatigue, physical activity cognitions, illness cognitions, cognitive regulation, emotion processing and regulation, coping strategies and social support. The general fatigue dimension of the Multidimensional Fatigue Inventory (MFI) [25] was used to measure fatigue. The scale consists of four items (e.g. I feel fit). Cronbach's α in the current study was 0.89.

The Tampa Scale of Kinesiophobia (TSK) [26] consists of 17 items measuring two aspects of fear of injury caused by physical exercise: activity avoidance (e.g. Afraid of injuring oneself if one exercises) and somatic focus (e.g. My body is telling me I have something dangerously wrong). Cronbach's α was 0.81 and 0.70, respectively.

The Illness Cognition Questionnaire (ICQ) [27] consists of 18 items assessing three specific illness cognitions: disease-related helplessness (e.g. My illness frequently makes me feel helpless), acceptance (e.g. I have learned to accept the limitations imposed by my illness) and perceived benefits (e.g. Dealing with my illness has made me a stronger person). Cronbach's α varied from 0.84 (perceived benefits) to 0.90 (acceptance).

The Cognitive Emotion Regulation Questionnaire-short (CERQ-short) [28] consists of 18 items assessing nine aspects of cognitive emotion regulation: self-blame (e.g. I think that basically the cause must lie within myself), acceptance (e.g. I think that I have to accept that this has happened), rumination (e.g. I often think about how I feel about what I have experienced), positive refocusing (e.g. I think of pleasant things that have nothing to do with it), refocus on planning (e.g. I think about a plan of what I can do best), positive reappraisal (e.g. I think that I can become a stronger person as a result of what has happened), putting into perspective (e.g. I think that it hasn't been too bad compared with other things), catastrophizing (e.g. I keep thinking about how terrible it is what I have experienced) and other blame (e.g. I feel that basically the cause lies with others). Cronbach's α varied from 0.67 (acceptance) to 0.82 (positive refocusing).

The Toronto Alexithymia Scale (TAS-20) [29] consists of 20 items assessing three aspects of alexithymia: difficulty identifying feelings (e.g. I am often confused about what emotion I am feeling), difficulty describing feelings (e.g. It is difficult for me to find the right words for my feelings) and externally oriented thinking (e.g. Looking for hidden meanings in movies or plays distracts from their enjoyment). Cronbach's α varied from 0.61 (externally oriented thinking) to 0.85 (difficulty identifying feelings).

The Emotion Regulation Questionnaire (ERQ) [30] consists of 10 items measuring two emotion regulation strategies: cognitive reappraisal (e.g. When I want to feel less negative emotion I change what I'm thinking about) and suppression (e.g. I control my emotions by not expressing them). Cronbach's α was 0.78 and 0.74, respectively.

The Berkeley Expressivity Questionnaire (BEQ) [31] consists of 20 items measuring three dimensions of emotional expressivity: impulse strength (e.g. I experience my emotions very strongly), expression of negative emotions (e.g. No matter how nervous or upset I am, I tend to keep a calm exterior) and expression of positive emotions (e.g. I laugh out loud when someone tells me a joke that I think is funny). Cronbach's α varied from 0.50 (expression of negative emotions) to 0.75 (impulse strength).

Four two-item scales of the Brief COPE [32], covering constructs that were not included in the CERQ, were used to measure four coping strategies: self-distraction (e.g. l've been turning to work or other activities to get my mind off things), active coping (e.g. l've been taking action to try to make the situation better), denial (e.g. l've been saying to myself 'this isn't real') and behavioural disengagement (e.g. l've given up trying to deal with it). Cronbach's α varied from 0.55 (behavioural disengagement) to 0.70 (self-distraction).

The social support list (SSL) [33] consists of 41 items measuring seven dimensions of social interaction: everyday emotional support (e.g. Does it ever happen to you that people are affectionate to you?), problem-oriented social support (e.g. Does it ever happen to you that people give you good advice?), esteem support (e.g. Does it ever happen to you that people ask you for advice?), instrumental support (e.g. Does it ever happen to you that people give you a lift?), social companionship (e.g. Does it ever happen to you that people just call you up or just chat to you?), informative support (e.g. Does it ever happen to you that people let you know what they expect from you?) and negative interactions (e.g. Does it ever happen to you that people don't keep their appointments with you?). Cronbach's a varied from 0.70 (informative support) to 0.88 (emotional support with problems).

Statistical analysis

SPSS for Windows version 20.0 (IBM, Armonk, NY) was used in analyses. A P-value <0.05 was considered significant. The 33 psychological questionnaire scale scores (not including the general fatigue scale of the MFI) were used as input in a higher-order principal axis factor analysis with oblimin rotation to reduce the number of psychological variables. Factor analysis requires variables to have roughly normal score distributions [34, 35]. Twentyseven of the 33 scales had a skewness of the score distribution <1. Because correlations are the input data in factor analysis, we checked the six scales with a skewness between 1.2 (CERQ behavioural disengagement) and 2.9 (CERQ other blame) for multivariate outliers using Cook's distances. The maximal Cook's distance was 0.85 and thus never exceeded 1. Therefore all 33 scales were included in the factor analysis. Criteria used for excluding scales in the factor analysis were a factor loading of <0.40 or a loading of >0.32 on two or more factors [36]. The scree plot and interpretability of the factor solution were used to select the number of factors. Standardized *z*-scores were computed for each patient on each scale using the mean and s.p. of the patient group; factor scores were calculated by averaging the *z*-scores belonging to a specific factor. Cronbach's α was used to examine the internal consistency of these factors.

Identification of the psychological profiles consisted of two steps [37, 38]. First, factor scores were grouped using hierarchical cluster analysis with Ward's method to identify the number of profiles. This number of profiles was determined by interpreting the agglomeration schedule indicating the changes in distances between the clusters and the dendrogram showing the optimal fit index. Next, *k*-means cluster analysis was performed to optimize the results.

To interpret the (dis)functionality of the psychological profiles, standardized deviation scores were computed for each patient on each scale not excluded following the factor analysis, using the mean and s.p. of a control group from the general population (n = 100), which was matched to the Sjögren's group on age, gender and education level [8]. Because there were no scores of the control group available for the ICQ and TSK, scores for these scales were standardized using the mean and s.p. of the Sjögren's group. The standardized deviation scores and z-scores were then averaged across the scales belonging to a psychological factor and across profiles. Means <0.20 were considered as not deviating from normal (i.e. neutral), scores ≥ 0.20 and < 0.50 were considered small, scores \ge 0.50 and <0.80 were considered medium and scores ≥ 0.80 were considered large deviations from normal [39].

To examine differences between the Sjögren's subgroups with different psychological profiles, Fisher's exact tests were used for gender, marital status and work status; χ^2 tests were used for education level, comorbidities related to SS (extraglandular manifestations) and co-morbidities not related to SS (other comorbidities); and univariate analyses of variance were used for age, psychological factors and fatigue. With the Fisher's exact tests and χ^2 tests, the significance of differences between subgroups were analysed using the *z*-score of the difference between the observed and expected value; a *z*-score of >1.96 was considered significant [34]. With the univariate analyses of variance, post hoc comparisons between the subgroups were performed using Bonferroni correction.

Results

Participants

Participants with missing values (13 in factor analysis and 3 in cluster analysis) were listwise deleted from the analyses. The demographic and medical characteristics of the 297 patients who were included in the cluster analyses are shown in Table 1 in the Total column.

TABLE 1 Demographic and medical characteristics of the total patient group and subgroups with different psychological profiles

Characteristics	Total (n = 297)	Functional profile (<i>n</i> = 117)	Alexithymic profile (n = 80)	Self-reliant profile (n = 68)	Dysfunctional profile (n = 32)	Comparisons of patient subgroups
Age, mean (s.ɒ.), years Gender, <i>n</i> (%)	56.6 (13.5)	54.2 (12.3)	58.8 (14.9)	55.6 (13.5)	61.8 (12.0)	<i>F</i> =3.8, <i>P</i> =0.01 FET=6.9, <i>P</i> =0.06
Female	276 (93)	112 (96)	71 (89)	61 (90)	32 (100)	
Male	21 (7)	5 (4)	9 (11)	7 (10)	0 (0)	
Education ^a , <i>n</i> (%)						χ ² =46.8, <i>P</i> < 0.001
Low	72 (24)	11 (9)	28 (35)	15 (22)	18 (58)	
Medium	110 (38)	43 (37)	28 (35)	33 (49)	6 (19)	
High	113 (38)	63 (54)	23 (30)	20 (29)	7 (23)	
Marital status, n (%)						FET = 5.3, P = 0.81
Single	20 (7)	6 (5)	6 (8)	4 (6)	4 (12)	
With partner	236 (79)	97 (83)	60 (74)	56 (82)	23 (73)	
Divorced	15 (5)	5 (4)	6 (8)	3 (5)	1 (3)	
Widowed	26 (9)	9 (8)	8 (10)	5 (7)	4 (12)	
Work status, n (%)						FET = 22.4, P = 0.001
Unemployed	100 (35)	36 (32)	33 (42)	20 (30)	11 (37)	
Employed <30 h/week	77 (27)	35 (31)	12 (15)	28 (42)	2 (6)	
Employed ≥30 h/week	29 (10)	15 (13)	6 (8)	5 (7)	3 (10)	
Retired	77 (27)	28 (24)	25 (32)	13 (19)	11 (37)	
Co-morbidity, n (%)						
Extraglandular manifestations	100 (34)	45 (39)	25 (31)	19 (28)	11 (34)	$\chi^2 = 2.4, P = 0.49$
Other comorbidities	129 (43)	50 (43)	38 (48)	22 (32)	19 (59)	$\chi^2 = 7.3, P = 0.06$

^aEducation: low: primary school or lower vocational secondary education; medium: intermediate general secondary education or intermediate vocational education; high: higher general secondary education, higher vocational education or university education. FET: Fisher's exact test, two-tailed.

Psychological factors

Factor analysis of the 33 scales yielded a Kaiser-Meyer-Olkin measure of sampling adequacy of 0.82, indicating that the squared partial correlations between the items were small compared with the squared correlations between the items and that the factor analysis yielded distinct and reliable factors [40]. Bartlett's test of sphericity was significant (χ^2 =3882.70, *P* < 0.001), indicating that the variables in the correlation matrix are uncorrelated and should be rejected [40]. Therefore factor analysis was appropriate.

Eight factors had an eigenvalue >1.0 (the Kaiser criterion). The scree plot indicated a solution between five and eight factors. In terms of the interpretability of factors, the solution with seven factors was best; one factor was deleted in this solution because it involved only one item with a factor loading of <0.40. The eight-factor solution was rejected because three factors included one item. With six or fewer factors, the factor alexithymia disappeared, although it reflected a consistent construct.

Six of the 33 scales were not included in the final factor solution; three scales (i.e. CERQ other blame, Brief COPE self-distraction and SSL negative interactions) had a factor loading of <0.40 and three scales (i.e. ERQ suppression, ICQ acceptance and TAS-20 externally oriented thinking) loaded >0.32 on two or more factors [36]. The remaining 27 scales loading on the six factors are shown

in Table 2. The internal consistency of all factors was adequate ($\alpha \ge 0.70$) except for negative thinking ($\alpha = 0.64$).

Psychological profiles

In the hierarchical cluster analyses, the agglomeration coefficients and dendrogram suggested a four-cluster solution, with the clusters representing functional [n = 117(39%)], alexithymic [n = 80 (27%)], self-reliant [n = 68(23%)] and dysfunctional [n = 32 (11%)] profiles.

Fig. 1 shows the psychological profiles comprising the six psychological factors. Patients with a functional profile mostly reported scores opposite to patients with a dysfunctional or an alexithymic profile. Since emotional expressivity included the expression of both positive and negative emotions, the composition of this variable will differ for patients in the functional *vs* the dysfunctional and alexithymic groups. Patients with a self-reliant profile showed a mixed pattern of scores. Table 3 shows the factors that significantly differentiated the four subgroups.

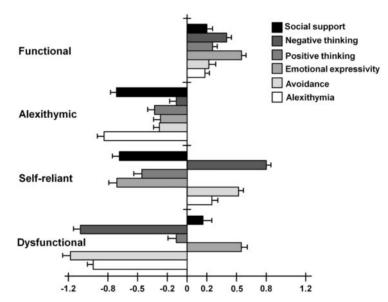
The demographic and medical characteristics of the patients with the four psychological profiles are shown in Table 1. Post hoc comparisons of subgroups showed that patients with a dysfunctional profile were older than patients with a functional profile. Patients with an alexithymic or dysfunctional profile were more often less educated and patients with a functional profile were more often more highly educated. Patients with a self-reliant

Factor	Internal consistency ^c	Psychological scales
Social support	0.88	Problem-oriented social support, instrumental support, esteem support, everyday support, social companionship, informative support (SSL)
Negative thinking	0.64	Rumination, self-blame, catastrophizing (CERQ-short)
Positive thinking	0.80	Positive reappraisal (CERQ-short), perceived benefits (ICQ), refocus on planning, putting into perspective, positive refocusing (CERQ-short), active coping (Brief COPE), acceptance (CERQ-short), cognitive re- appraisal (ERQ)
Emotional expressivity	0.70	Expression of positive emotions, impulse strength, expression of nega- tive emotions (BEQ)
Avoidance	0.72	Activity avoidance, somatic focus (TSK), helplessness (ICQ)
Alexithymia	0.72	Difficulty describing feelings, difficulty identifying feelings (TAS-20), denial, behavioural disengagement (Brief COPE)

TABLE 2 Psychological factors resulting from higher-order principal axis factor analysis with 33 psychological scales^{a,b}

^aFactors are described in order of their appearance in the factor analysis and psychological scales in order of their factor loadings. ^bSix scales were not included in the factor solution because of a factor loading <0.40 or a loading >0.32 on two or more factors. ^cCronbach's α . BEQ: Berkeley Expressivity Questionnaire; CERQ-short: Cognitive Emotion Regulation Questionnaire-short; ERQ: Emotion Regulation Questionnaire; ICQ: Illness Cognition Questionnaire; SSL: Social Support List; TAS-20: 20-item Toronto Alexithymia Scale; TSK: Tampa Scale of Kinesiophobia.

Fig. 1 The four psychological profiles comprising six psychological factors



The factor scores reflect standardized deviations from the general population for all factors but avoidance. A positive score reflects high social support, low negative thinking, high positive thinking, high emotional expressivity, low avoidance and low alexithymia.

profile more often had a part-time job compared with patients with an alexithymic or dysfunctional profile.

Fatigue

Fig. 2 displays the levels of general fatigue in the control group from the general population [8] and in the patient subgroups with different psychological profiles. All the patient subgroups reported higher fatigue levels than the control group (all *P*-values <0.001) and also differed from each other in fatigue level (F=7.6, P < 0.001). Patients with an alexithymic or dysfunctional profile

reported more fatigue than those with a self-reliant profile (P < 0.001 and P = 0.001, respectively). Patients with a functional, an alexithymic or a dysfunctional profile did not differ from each other in fatigue level ($P \ge 0.08$).

Discussion

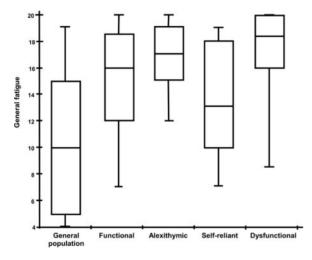
Four psychological profiles were identified in patients with SS: functional, alexithymic, self-reliant and dysfunctional. Fatigue in patients with any of the psychological profiles was substantially higher than in the general population.

Factor	Difference ^a	F (P)
Social support	Functional, dysfunctional > self-reliant, alexithymic	37.8 (<0.001)
Negative thinking	Self-reliant < functional < alexithymic < dysfunctional	92.2 (<0.001)
Positive thinking	Functional, dysfunctional > alexithymic, self-reliant	29.7 (<0.001)
Emotional expressivity	Dysfunctional, functional > alexithymic > self-reliant	58.1 (<0.001)
Alexithymia	Self-reliant, functional < alexithymic, dysfunctional	78.1 (<0.001)
Avoidance	Self-reliant < functional < alexithymic < dysfunctional	65.2 (<0.001)

TABLE 3 Differences in psychological factors between the subgroups

^aSignificant results of post hoc comparisons using Bonferroni correction.

Fig. 2 General fatigue in control participants and in patients grouped according to psychological profile



The box represents the 25th-75th percentile, the band inside the box is the median and the whiskers outside the box represent the 10th and 90th percentiles.

Patients with a self-reliant profile reported less fatigue than those with an alexithymic or dysfunctional profile.

In previous studies identifying psychological profiles [19, 21–24], one profile reflected an overall adaptive coping repertoire in patients with a chronic disease, as did our functional profile. Also one or two profiles were clearly maladaptive in previous studies, as were our dysfunctional and alexithymic profiles. A rather unique finding of our study is the self-reliant profile reflecting low scores in terms of social support and emotional expressivity next to low scores on negative thinking and avoidance. This profile, with its more reserved, solitary behaviour indicating no cognitive behavioural maladjustment, appears to reflect an introverted personality.

A rationale underlying our study was that psychological profiles might indicate factors influencing fatigue. Most importantly, fatigue levels of subgroups of patients with distinct psychological profiles are high for any of the psychological profiles. This suggests that over and above the psychological factors that were examined in this study, other factors are responsible for fatigue in patients with SS. However, previous studies have indicated that endocrine variables and clinical and laboratory parameters reflecting expression of disease [7], autonomic nervous system variables [4] or dryness [41] are also not clearly related to fatigue. Our study did indicate that fatigue was higher in patients with a dysfunctional or an alexithymic profile than in patients with a self-reliant profile. In patients with chronic pain, effects of cognitive behavioural therapy are greater in patients with a maladaptive rather than an adaptive coping strategy [20]. In analogy, a treatment aimed at reducing fatigue by psychological means could be more effective in patients with a dysfunctional or alexithymic profile than in other patients.

One study indicated that patients with SS exhibit a distinct pattern of personality traits and high levels of psychological distress compared with healthy people [42], while another study indicated that processing and regulating emotions in patients with SS mostly does not deviate from normal [43]. Whether psychological characteristics deviate from normal or not, there are large individual differences in these factors that may influence fatigue. Our study focused on cognitive and behavioural variables that are influenced by personality traits but that have also been shown to be—to a certain extent—amenable to change in psychological interventions. Therefore our study clarifies psychological profiles that could be of use in interventions.

With the current knowledge and evidence, cognitive behavioural therapy combined with physical exercise training is the mainstay of intervention in cases of chronic fatigue [44, 45]. However, previous studies have indicated that knowing the psychological profiles of patients may help to customize treatment [21, 24]. It is theoretically obvious and empirically indicated that restructuring of negative thinking will probably be especially fruitful in patients with a dysfunctional profile [20, 46, 47]. For the three other psychological profiles it is much more difficult to indicate the appropriate treatment. Patients with an alexithymic profile are especially deviant with respect to high alexithymia and low social support. In the literature there is a lack of concrete suggestions on how to diminish alexithymia's maladaptive impact by regulating one's emotions [48]. Perhaps interventions that use cognitive reappraisal, such as cognitive behavioural therapy, are more effective in treating people with alexithymia than emotionfocused interventions [48-50]. Furthermore, there is no evidence to indicate the most appropriate intervention for patients with a self-reliant profile. The patients belonging to

this cluster appear on average to be more introverted but have appropriate cognitive behavioural skills, as do patients with a functional profile. With current knowledge and evidence, the recommended intervention in patients with a healthy psychological profile is the combination of a physical exercise programme [8, 51] and cognitive behavioural interventions that specifically aim at fatigue, maintaining cognitions and behaviours. Studies examining the differential effects of the psychological profile clusters as found in the current study are urgently needed in SS and in other chronic diseases.

Our study is the first to identify psychological profiles in SS. The next step is to examine whether these profiles are predictive of the outcome of cognitive behavioural therapy for chronic fatigue. The clarification of psychological profiles may ultimately provide clues to customize therapies to subgroups of patients. As this study is cross-sectional, causal inferences and clear implications about customizing treatment cannot be given. The strengths of this study were the large sample size of patients with primary SS diagnosed by a rheumatologist and the comparison with a well-matched control group.

This study in patients with SS identified four psychological profiles that can be used to examine whether therapy is differentially effective in subgroups of patients in order to customize treatment. While cognitive behavioural therapy and physical exercise training are the advised therapies for chronic fatigue at the moment, the effectiveness of therapeutic interventions in fatigue may be improved when the heterogeneity of patients is taken into account [21, 52]. Future studies in SS should examine whether the observed psychological profiles are predictive of the outcome of cognitive behavioural therapy for chronic fatigue and, if so, whether customized therapies are more effective.

Rheumatology key messages

- Four psychological profiles reflect heterogeneity in SS: functional, alexithymic, self-reliant and dysfunctional.
- In patients with SS, all psychological profiles showed higher than normal fatigue levels, especially the alexithymic and dysfunctional profiles.
- The psychological profiles can be used in research and possibly to customize interventions targeting fatigue in patients with SS.

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