Dealing with emotions when the ability to cry is hampered: emotion processing and regulation in patients with primary Sjögren's syndrome

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Abstract

Objectives

The hampered ability to cry in patients with Sjögren's syndrome may affect their ways of dealing with emotions. The aim of this study was to examine differences in emotion processing and regulation between people with and without Sjögren's syndrome and correlations of emotion processing and regulation with mental well-being.

Methods

In 300 patients with primary Sjögren's syndrome and 100 demographically matched control participants (mean age 56.8 years, 93% female), emotion processing (affect intensity and alexithymia, i.e. difficulty identifying and describing feelings), emotion regulation (cognitive reappraisal, suppression and expression of emotions), and mental well-being were assessed.

Results

Criteria for clinical alexithymia applied to 22% of the patients and 12% of the control participants; patients had significantly more difficulty identifying feelings than control participants. No other significant differences in emotion processing and emotion regulation were found. In patients, the emotion processing styles affect intensity and alexithymia ($0.32<r<0.51$) and the emotion regulation strategy suppression of emotions ($r=0.13$) significantly correlated with worse mental well-being, which is about similar to control participants.

Conclusion

Processing and regulating emotions in patients with Sjögren's syndrome does not deviate from normal with one exception: a relatively large number of patients is alexithymic. As in the general population, in patients with Sjögren's syndrome the more intense and deficient processing and regulation of emotions is associated with worse mental well-being. This study indicates that, except for selected patients, processing and regulation of emotions is not a key therapeutic issue for the majority of patients with Sjögren's syndrome.

Key words

Sjögren's syndrome, crying, emotions, alexithymia, quality of life

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Received on August 18, 2011; accepted in revised form on November 28, 2011.

Funding: This work was supported by the Dutch Arthritis Association (grant no. DAA 0701029).

Competing interests: none declared.

Introduction

Hallmark symptoms of the chronic autoimmune disorder Sjögren's syndrome are dryness of eyes (keratoconjunctivitis sicca) and mouth (xerostomia) (1). Many patients also experience disabling fatigue and a reduced quality of life (2-4). Sjögren's syndrome is characterised by lymphocytic infiltration of exocrine glands. The resulting reduced tear production may affect patients' ability to cry (5-7). Crying is considered to have at least two functions in dealing with emotions (8-10). Firstly, it is a distress signal, *i.e.* a powerful emotional expression that elicits attention and support from the social environment. Secondly, it is an arousal-reduction mechanism that contributes to psychological and physiological recovery when experiencing distress. It is as yet unexplored whether the hampered ability to cry in patients with Sjögren's syndrome affected their ways of dealing with emotions.

People employ "emotion processing styles" and "emotion regulation strategies" to deal with their emotions (11). Emotion processing styles refer to relatively automatic appraisals of events, which determine the type and strength of emotional experiences (12). Two emotion processing styles are "affect intensity", which is the strength with which both positive and negative emotions are experienced (12-14), and "alexithymia", which encompasses difficulty identifying and describing feelings and focusing on external events rather than inner experiences (14, 15). Emotion regulation strategies refer to the intentional behaviours and thoughts by which people influence or control when and how specific emotions are experienced and expressed (16). Three emotion regulation strategies are "cognitive reappraisal", which is thinking about a potentially emotion-eliciting situation in a way that changes its emotional impact (16), "suppression of emotions", which is the inhibition of outward signs of inner feelings (17), and "expression of emotions", which is the sharing of inner feelings in both interpersonal and intrapersonal forms (such as in a diary) (18). Processing and regulating emotions in patients with Sjögren's syndrome has not been examined up to now. Reduced tear production may have changed patients' ways of processing emotions, because arousal-reduction through crying is hampered. Moreover, the ways of regulating emotions may be changed because expressing distress through crying is hindered. By comparing emotion processing and regulation of people with and without Sjögren's syndrome, it will be shown whether it is worthwhile to therapeutically focus on dealing with emotions in Sjögren's syndrome.

Emotion processing and emotion regulation have been associated with maladjustment to chronic diseases (19). High affect intensity, alexithymia, and suppression of emotions are considered risk factors for psychological adjustment (15, 17, 20, 21), whereas cognitive reappraisal and expression of emotions are found to be helpful (22-26). These relations of emotion processing and emotion regulation with adjustment outcomes have been found in various rheumatic diseases, such as rheumatoid arthritis (27-29), systemic lupus erythematosus (30) and fibromyalgia (31, 32), and are likely to be found in patients with Sjögren's syndrome. In addition, it is possible that some ways of processing and regulating emotions are especially troublesome in patients with Sjögren's syndrome. Notably, patients who cannot use tears to express emotions to their social environment (the first function of crying) may specifically experience adjustment problems when they do not use other ways of expressing emotions that may lead to attention and support from others. Moreover, having high affect intensity may be especially troublesome in patients with Sjögren's syndrome, because more easily aroused people may be more in need of an arousal-reduction mechanism, the second function of crying.

The aim of our study was to examine differences in emotion processing and emotion regulation between people with and without Sjögren's syndrome, and to examine in both groups whether the processing and regulation of emotions is associated with mental well-being. Because of the reduced tear production

in Sjögren's syndrome, we expected differences in emotion processing and emotion regulation between people with and without Sjögren's syndrome, but we did not have empirical grounds for specific hypotheses about the direction of these differences. However, in agreement with other chronic diseases (15, 27, 32, 33), we did expect higher levels of alexithymia in Sjögren's syndrome. Furthermore, in addition to the generally observed associations of emotion processing and emotion regulation with mental well-being, we hypothesised that especially in patients with Sjögren's syndrome high affect intensity and low expression of emotions are associated with worse mental well-being.

Patients and methods

Patients

Patients diagnosed with primary Sjögren's syndrome (pSS) according to established criteria (1) were selected from a larger sample of patients with sicca symptoms (n=937) from the Departments of Rheumatology and Clinical Immunology of the University Medical Center (UMC) Groningen (n=270) and the UMC Utrecht (n=667), The Netherlands. Since comorbidities are common in primary Sjögren's syndrome (34), patients with comorbidities were not excluded from the study in order to obtain a representative sample. Patients were invited to participate in a questionnaire study. Patients who did not want to participate could complete and return a "non-participation form" with questions on demographic characteristics.

As a control sample, we acquired people from a representative community sample of 179 people from the general population outside the health care setting but comparable to the patient sample with regard to country, age, gender, and socioeconomic status. Participants in the control sample were allowed to have whatever health problems that can occur in a representative sample with as only exclusion criterion that they did not have the diagnosis Sjögren's syndrome. From the sample of 179 people, we selected one control participant to three patients with Sjögren's syndrome using gender, age, and education level (as a proxy of socioeconomic status) as matching criteria. This yielded a well-matched control sample of 100 participants. The Medical Ethics Committee of the UMC Utrecht decided that their approval was not necessary for this non-invasive study. All participants completed an informed consent form.

Methods

The questionnaire included questions on demographics and medical characteristics such as disease duration, comorbidities, and medication, and commonly-used, well-validated questionnaires of emotion processing styles, emotion regulation strategies, and mental well-being. Hypothyroidism (34, 35), lymphoma and other extraglandular manifestations (36) as well as comorbidities not specifically related to Sjögren's syndrome were derived from the patient reports on comorbidities and medication.

– *Dryness*. Patients indicated on three 100 mm visual analogue scales (VAS) the severity during the previous two days of oral (dry mouth) and ocular (dry eyes, feeling of sand/gravel in eyes) dryness between the extremes "not troublesome" (0 mm) and "extremely troublesome" (100 mm).

– *Emotion processing styles*. Affect intensity was assessed with the impulse strength scale of the Berkeley Expressivity Questionnaire (BEQ) (37), which consists of six items (*e.g.* "I experience my emotions very strongly"), rated from 1 (strongly disagree) to 7 (strongly agree). Three aspects of alexithymia were assessed with the Toronto Alexithymia Scale-20 (TAS-20) (38). "Difficulty identifying feelings" consists of seven items assessing the ability to identify feelings and to distinguish them from the somatic sensations that accompany emotional arousal (*e.g.* "I am often confused about what emotion I am feeling"). "Difficulty describing feelings" consists of five items assessing the ability to describe feelings to other people (*e.g.* "I am able to describe my feelings easily"). "Externally oriented thinking" consists of eight items assessing the tendency to focus on outer events rather than inner experiences (*e.g.* "I prefer to analyse problems rather than just describe them"). The items of the TAS-20 were rated from 1 (strongly disagree) to 5 (strongly agree).

– *Emotion regulation strategies*. Cognitive reappraisal and suppression of emotions were measured with the two scales of the Emotion Regulation Questionnaire (ERQ) (17). The six-item scale "cognitive reappraisal" measures the ability to achieve or maintain a positive mood (*e.g.* "When I want to feel less negative emotion I change what I'm thinking about"). The four-item scale "suppression" measures the ability to inhibit emotion-expressive behaviour (*e.g.* "I control my emotions by not expressing them"). Items were rated from 1 (strongly disagree) to 7 (strongly agree). Two scales of the BEQ (12) were used for assessing expression of negative and positive emotions. Expression of negative emotions was measured with six items (*e.g.* "No matter how nervous or upset I am, I tend to keep a calm exterior") and expression of positive emotions was measured with four items (*e.g.*, "I laugh out loud when someone tells me a joke that I think is funny"). The items were rated from 1 (strongly disagree) to 7 (strongly agree).

– *Mental well-being*. The RAND 36-item Health Survey (RAND-36) (39) was used to measure mental well-being with the mental component summary score (40).

Statistical analyses

SPSS for Windows version 16.0 was used. A p-value <0.05 was considered to be significant. The continuous data were screened for deviations from normal distributions. The maximum skewness of the score distributions was -0.6 in the group with Sjögren's syndrome and -1.1 in the control group, except for the three scores of dryness in the control group, of which the skewness varied from 1.5 to 2.1.

To examine differences between the groups with and without Sjögren's syndrome we used χ^2-tests with respect to frequencies (gender, education level, marital status, work status, and comorbidity), Mann-Whitney U-tests with respect to continuous variables with

a non-normal score distribution (dryness), and independent samples *t*-tests for continuous variables with a normal score distribution (age, emotion processing styles, emotion regulation strategies, and mental well-being). To examine the magnitude of group differences, Cohen's *d* effect sizes were computed. Effect sizes of 0.2, 0.5, and 0.8 represent small, medium, and large group differences (41).

Partial correlation coefficients, adjusted for age, gender, and education level, were calculated to determine whether emotion processing and emotion regulation were correlated with mental well-being. Correlations of 0.1, 0.3 and 0.5 represent small, medium, and large correlations (41).

Results

Participants

From the 937 questionnaires that were sent to patients with sicca symptoms of the UMC Utrecht and the UMC Groningen, 132 non-participation forms were returned (14% response) and 470 completed questionnaires (50% response); 300 from patients who fulfilled the criteria of primary Sjögren's syndrome and 170 from patients who were excluded because they had secondary Sjögren's syndrome (n=34) or had sicca symptoms without the diagnosis primary Sjögren's syndrome (n=136). As compared to the patients who completed the questionnaires, the patients who filled out a non-participation form had a lower education level (χ^2=20.2, p<.001). The reported reasons for non-participation were: no diagnosis of primary Sjögren's syndrome (n=33), no severe symptoms of dryness or fatigue (n=15), participation in another study (n=12), lack of time or mental ability (n=30), and other reasons (n=21). A few reported no reason (n=21).

Demographic and medical characteristics of the patients with Sjögren's syndrome who were included in the study (n=300) and of the control participants (n=100) are shown in Table I. There were no significant differences in age, gender, education level, marital status, and comorbidities, but compared to control participants the patients with Sjögren's syndrome were more often unemployed, more often had extraglandular manifestations, and reported more dryness of mouth and eyes and a sand/gravel sensation in the eyes. The category "other diseases" included many different diseases, with 6 patients with Sjögren's syndrome indicating to have another rheumatic disease (3 fibromyalgia, 2 osteoarthritis, 1 did not indicate the specific rheumatic disease), and 8 control participants indicating a rheumatic disease (2 fibromyalgia, 2 osteoarthritis, 1 polymyalgia rheumatica, 3 did not indicate the specific rheumatic disease).

Patients with Sjögren's syndrome had worse mental well-being than control participants (mean=44.9, SD=11.0 in patients with Sjögren's syndrome and mean=49.5, SD=9.1 in the control group; t=-4.15, p<0.001, small effect size of d=-0.42).

Table I. Demographic and medical characteristics of patients with Sjögren's syndrome and control participants.

Characteristics	Sjögren's syndrome (n=300)	Control participants (n=100)	Comparison	*p*-value
Age in years, mean (SD)	56.8 (13.6)	56.8 (13.7)	t=0.006	0.99
Gender, n (%)				
female	279 (93)	91 (93)	χ^2=0.002	0.96
male	21 (7)	7 (7)		
Education level, n (%)*			χ^2=0.32	0.85
low	73 (24)	27 (27)		
middle	112 (38)	35 (35)		
high	113 (38)	38 (38)		
Marital status, n (%)			χ^2=1.07	0.79
single	22 (7)	5 (5)		
with partner	236 (79)	78 (78)		
divorced	15 (5)	6 (6)		
widowed	27 (9)	11 (11)		
Work status, n (%)†			χ^2=26.54	<0.001
employed >30 hours a week	29 (10)	21 (21)		
employed <30 hours a week	77 (26)	40 (40)		
unemployed	101 (35)	11 (11)		
retired	79 (27)	25 (25)		
other	7 (2)	3 (3)		
Extraglandular manifestations, n (%)	100 (33)	11 (11)	χ^2=18.66	<0.001
Lymphoma	14 (5)	0 (0)		
Muscle and joint complaints	37 (12)	7 (7)		
Thyroid involvement	21 (7)	4 (4)		
Raynaud's phenomenon	12 (4)	1 (1)		
Neuropathy	12 (4)	1 (1)		
Renal involvement	4 (1)	0 (0)		
SLE/scleroderma/dermatomyositis	7 (2)	0 (0)		
Other glandular symptoms	19 (6)	0 (0)		
Comorbidities, n (%)	130 (43)	41 (41)	χ^2=0.17	0.68
Cancer	13 (4)	3 (3)		
Cardiovascular disease	50 (17)	21 (21)		
Osteoporosis	13 (4)	3 (3)		
Diabetes	11 (4)	4 (4)		
Mental problems	27 (9)	6 (6)		
Pulmonary disease	33 (11)	3 (3)		
Other diseases	37 (12)	14 (14)		
Dryness, median (percentile 25–75)				
Dryness of the eyes	6.3 (3.8–8.0)	0.4 (0.1–1.4)	U=3086.50	<0.001
Sandy sensation of the eyes	4.6 (1.3–7.5)	0.3 (0.0–1.3)	U=6208.50	<0.001
Dryness of the mouth	6.6 (3.9–8.5)	0.6 (0.1–2.2)	U=5059.50	<0.001

*Education level, low: primary school or lower vocational secondary education; middle: intermediate general secondary education or intermediate vocational education; high: higher general secondary education, higher vocational education, or university education.

†The significance of the group difference in work status between patients with Sjögren's syndrome and control participants was examined without the category "other".

SLE: systemic lupus erythematosus.

Emotion processing and emotion regulation

Table II shows the mean scores of the patients with Sjögren's syndrome and the control participants at emotion processing styles and emotion regulation strategies.

With regard to emotion processing styles, patients with Sjögren's syndrome had more difficulty identifying feelings than control participants (the effect size of the difference is medium). Almost twice as many patients with Sjögren's syndrome (22%) than people in the control group (12%) fulfilled the criterion of clinical alexithymia (38) (χ^2=4.78, p=0.03).

The two groups did not significantly differ with respect to the other emotion processing styles and with respect to emotion regulation strategies.

Correlations of emotion processing and regulation with mental well-being

Table III shows the correlations of emotion processing styles and emotion regulation strategies with mental well-being in the group with Sjögren's syndrome and in the control group.

In the group with Sjögren's syndrome, all emotion processing styles except externally oriented thinking were significantly correlated with mental well-being. Worse mental well-being was observed in patients with higher affect intensity (medium correlation), more difficulty identifying feelings (large correlation), and more difficulty describing feelings (medium correlation). With respect to emotion regulation strategies, only more suppression of emotions was correlated with worse well-being (small correlation).

In the control group, also all emotion processing styles except externally oriented thinking were significantly correlated with mental well-being (all medium correlations). In this group, no significant correlations were found between emotion regulation strategies and mental well-being.

Table II. Emotion processing styles and emotion regulation strategies in patients with Sjögren's syndrome and control participants.

	Sjögren's syndrome (n=300)		Control participants (n=100)				
	Mean	SD	Mean	SD	*t*	*p*-value	*d*
Emotion processing styles							
Affect intensity	4.45	1.16	4.51	1.04	-0.45	0.65	0.06
Alexithymia							
- difficulty identifying feelings	16.94	6.39	14.31	5.06	4.21	<0.001	-0.52
- difficulty describing feelings	12.95	4.28	12.43	4.21	1.06	0.29	-0.12
- externally oriented thinking	20.06	4.64	19.64	4.61	0.78	0.44	-0.09
Emotion regulation strategies							
Cognitive reappraisal	4.63	1.02	4.76	1.06	-1.14	0.26	0.13
Suppression	3.55	1.16	3.59	1.19	-0.30	0.77	0.03
Expression of emotions							
- expression of negative emotions	3.93	0.91	3.81	0.78	1.23	0.22	-0.16
- expression of positive emotions	5.16	1.06	5.16	0.99	-0.03	0.98	0.00

Table III. Partial correlations of emotion processing styles and emotion regulation strategies with mental well-being.

	Sjögren's syndrome (n=300)		Control participants (n=100)	
	r	(*p*-value)	r	(*p*-value)
Emotion processing styles				
Affect intensity	-0.32	(<0.001)	-0.37	(<0.001)
Alexithymia				
- difficulty identifying feelings	-0.51	(<0.001)	-0.46	(<0.001)
- difficulty describing feelings	-0.32	(<0.001)	-0.33	(0.001)
- externally oriented thinking	-0.11	(0.08)	-0.06	(0.57)
Emotion regulation strategies				
Cognitive reappraisal	0.09	(0.14)	-0.01	(0.90)
Suppression	-0.13	(0.03)	-0.08	(0.47)
Expression of emotions				
- expression of negative emotions	0.01	(0.86)	-0.10	(0.32)
- expression of positive emotions	0.00	(0.99)	-0.13	(0.22)

Correlations were adjusted for age, gender and education level.

Discussion

Patients with Sjögren's syndrome had higher scores on difficulty identifying feelings than control participants, but did not deviate on the other emotion processing styles and emotion regulation strategies. In patients and control participants, worse mental well-being was correlated with the emotion processing styles affect intensity and the alexithymia components difficulty identifying and describing feelings. In patients only, worse mental well-being was also correlated with the emotion regulation strategy suppression of emotions.

The comparison of emotion processing and regulation between people with and without Sjögren's syndrome did yield only one difference. As has been found in rheumatoid arthritis (27), fibromyalgia (32) and other chronic pain conditions (15, 33), alexithymia – specifically difficulty identifying feelings – was relatively high in patients with Sjögren's syndrome. That alexithymia tends to be high in these divergent diseases suggests that alexithymia might be due to the general burden of a chronic disease instead of being caused by inability to cry. Our hypothesis that reduced tear production could have changed the ways of processing and regulating emotions in patients with Sjögren's syndrome was not confirmed. This suggests that emotion processing and regulation is not a key issue to therapeutically focus on in the total group of patients.

High affect intensity was expected to be associated with worse mental well-being (13, 14, 17, 20) and to be especially troublesome in patients with Sjögren's syndrome. Although indeed an associa-

tion between high affect intensity and worse mental well-being was found in patients and control participants alike, our results did not show that high affect intensity is especially detrimental in patients with Sjögren's syndrome. Individuals with high affect intensity are expected to benefit from emotion-expression interventions, since the expression of strong emotions reduces emotional intensity by mechanisms of habituation and gaining insight (42-48). To confirm this suggestion, for selected people with or without Sjögren's syndrome high on affect intensity clinical experimental research is needed.

Also alexithymia was hypothesised to be associated with worse psychological adjustment (14, 15, 21). Our study confirmed that more difficulty identifying and describing feelings is associated with worse mental well-being in patients and control participants. People who have problems with identifying emotions and differentiating between emotions are susceptible to experience bodily arousal that cannot be explained, and this may lead to a negative affective state and insufficient clues on how to regulate emotions (32). Notably, in people with difficulty identifying feelings, emotion-focused interventions may lead to confusion and more emotional arousal (21, 49). It has been suggested that for these people cognitive-behavioural therapy and education in recognition, labelling, and adequately regulating emotions are useful, but evidence for this idea is still too scarce. Too strong therapeutic inferences are not allowed, because our design was cross-sectional and the optimal intervention to treat alexithymia is still largely unknown. Our study only tentatively indicates that it may be useful to target deficient emotion processing in selected patients with high alexithymia.

Emotion regulation strategies were expected to be associated with mental well-being (16-18, 22-26), especially expression of emotions. It is easier to therapeutically target relatively conscious and intentional emotion regulation strategies than largely automatic emotion processing styles. However, our results do not suggest that either cognitive reappraisal or expression of emotions is beneficial for mental well-being and thus need therapeutic attention, and only weak support in patients with Sjögren's syndrome was found for an association between emotional suppression and lower mental well-being, which is in agreement with other studies (17, 25). Our results do also not support the idea that preventing the urge to cry by suppression of emotions may be good for mental well-being, because it prevents the pain that by some patients is said to accompany crying without tears. Overall, our study did not yield strong support for the hypothesis that some emotion regulation strategies might be better for mental well-being than others.

Previous suggestions that crying is hampered in Sjögren's syndrome (5-7) have not been thoroughly examined yet. It is possible that crying with reduced tear production still brings relief to the person and still is a distress signal to the environment. Moreover, although most people in the general population feel better after crying (8) and rheumatoid arthritis patients who more easily cry as an emotional expression display a better control of disease activity (50), alexithymia has been associated with worsened mood after crying (51) and crying did not lead to alleviation of depression (52). As yet, the psychological consequences of reduced tear production in Sjögren's syndrome are unexplored. More research about crying in Sjögren's syndrome is welcome, although our study does not suggest that the processing and regulation of emotions is seriously disturbed.

This is the very first study to examine processing and regulation of emotions in patients with Sjögren's syndrome. The large sample of patients diagnosed with primary Sjögren's syndrome and the large sample of control participants demographically well-matched to the patient group are strengths of our study. The conclusions of the study are hampered by not using observations next to the self-report measures, by its cross-sectional nature which prevents causal interferences, and by the absence of a control group with a comparable burden of the disease but no hindered tear production.

To summarise, processing and regulating emotions in patients with Sjögren's syndrome generally does not deviate from normal with one exception: a relatively large number of patients is alexithymic. Processing emotions more intensely or more deficiently and regulating emotions by more suppression is associated with worse mental well-being; virtually alike in patients and control participants. This study indicates that, except for selected patients who have problems with processing and regulating emotions, dealing with emotions is not a key therapeutic issue for the majority of patients with Sjögren's syndrome.

Acknowledgements

We thank the rheumatologists and staff of the UMC Utrecht and UMC Groningen for their help in the recruitment of patients, and students of the Department of Psychology of Utrecht University for their help with the data collection.

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