

Consideration of coping strategies for patients suffering from systemic lupus erythematosus: reflection for a personalised practice of patient education

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Abstract Objective

Systemic lupus erythematosus (SLE) is a chronic autoimmune multi-organ disease with an unpredictable course. SLE causes functional disability, changes in body appearance, and psychological distress. When faced with SLE, patients have to implement coping strategies. Therefore, the aim of this study was to describe patients' coping strategies, consider the implications for a personalised practice of patient education and evaluate patients' adherence to HCQ treatment.

Methods

One hundred and fifty-eight SLE patients receiving hydroxychloroquine (HCQ) treatment entered a prospective, non-comparative, longitudinal study aimed at describing patients' coping strategies and evaluating their adherence to the HCQ regimen. Coping strategies were evaluated using an abbreviated French version of the WCC-27 exploring 3 dimensions of coping: problem-centered coping, emotion-centered coping and search for social support. Adherence was assessed by the MASRI, the MMAS-8 and also objectively assessed by the patient's serum level of HCQ. Data collected at study entry also included disease activity: SLEDAI, and disease extent: SLICC damage index. The prevalence of anxious and depressive symptoms was evaluated with the HADS. Quality of life was evaluated using the LupusQoL questionnaire.

Results

Patients were clustered using an unsupervised hierarchical classification based on coping strategies. Four clusters of patients were individualised. The cluster of patients with low problem-centered coping, high emotion-centered coping and the lowest search for social support had worse quality of life and more psychological distress. We did not find any inter-cluster differences in terms of compliance to HCQ.

Conclusion

Patients' knowledge is not the only parameter to consider for a personalised educational therapy: psychological parameters such as coping must also be considered to ensure the best possible quality of life. For educational therapy purposes, it is important not to group patients with the same coping style; heterogeneous groups will enable patients to share their experiences and learn from the coping strategies of others.

Key words

coping strategies, SLE, adherence, anxiety, patient education

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Introduction

Systemic lupus erythematosus (SLE) is a chronic inflammatory disease (1). Conventional treatments for SLE rely on hydroxychloroquine (HCQ) (2). A national study showed that around 10% of lupus patients are not compliant regarding HCQ (3).

SLE can cause patients considerable psychological distress (4) and has repercussions in all arenas of life (5). The World Health Organization defines Quality of Life as an individual's perception of their position in life (6). Health-related quality of life (HRQOL) of SLE patients is significantly worse at an earlier age in comparison to patients with other chronic diseases and psychological parameters have to be considered for more personalised medicine (7). It has been proven that living with SLE affects emotional balance (8). Despite the advances in overall SLE prognosis, patients' quality of life has not improved (9).

Coping strategies encompass all the cognitive and behavioural processes that a subject interposes between himself and a stressful event, in order to master the impact of this event. The concept of coping relies to a transactional approach to stress in which the stress depends not only on the subject and the stressful event but also on the transaction between the subject and his/her environment (10). Coping strategies focused on the problem are associated with good mental health (11), and emotion-coping strategies directed toward disengagement predict poor adjustment over time (12). This study presents the results of the ESSTIM (Prospective evaluation of antimalarial treatment and observance of patients with systemic lupus) study, the purpose of which was to describe patients' coping strategies, consider the implications for a personalised practice of patient education and evaluate patients' adherence to HCQ treatment. This study defined subgroups of coping styles of SLE patients and relationships with psychological distress.

Our results may have practical implications since some patients could certainly derive great benefit from patient education (13).

Methods

The ESSTIM study was conducted in part of the Hauts-de-France region and was a prospective, non-comparative, longitudinal, multicentre study in adult subjects with SLE treated with HCQ. Patients were included during a routine visit.

Upon entry to the study, subjects had to be suffering from SLE (ACR criteria) (14), be treated with HCQ and be covered by the French Health Insurance System. Patients were asked to complete questionnaires designed to evaluate their coping skills, anxious and depressive symptoms, quality of life, and compliance at the day of inclusion.

To evaluate coping skills, SLE patients answered the abbreviated French version of the Ways of Coping Checklist (WCC-27) (15), exploring three dimensions of coping: problem-centered coping (10 items referring to efforts to find solutions), emotion-centered coping (9 items referring to feelings of guilt) and search for social support (8 items referring to informal and material support but also emotional support) (15).

Stress at SLE diagnosis announcement was self-rated on a 3-point verbal scale (low, medium, high). Using a self-questionnaire, patients were asked if they were convinced of being sick and if they thought that their treatment was doing more harm than good. Answers were reported on a 4-point verbal scale ("yes, yes most of the time, no most of the time, no"). Patients also self-rated if they felt sufficiently informed about the disease, its potential evolution, its complications and treatments using a 5-point Likert scale ("not at all, a little bit, mildly, for a great part, definitely yes").

To evaluate objectively the adherence to HCQ, blood samples were drawn from the patient at two visits 3 to 6 months apart and the blood HCQ concentration was determined by central laboratory analysis in the Toxicology Laboratory of Lille Regional University Hospital by high performance liquid chromatography technique. Poor adherence to HCQ was defined as subjects with a serum level of HCQ <200 mg/L.

Compliance was also evaluated by the MASRI questionnaire (Medication Adherence Self-Report Inventory) (16), a

score close to 80 reflecting good compliance, and by the MMAS-8 (8-item Morisky Medication Adherence Scale), a score above 6 reflecting better compliance (17–20). In addition, patients rated their perceived benefits of treatment on a 0–10 verbal numeric scale, with high scores reflecting high benefits of treatment. Factors potentially related to treatment compliance were documented, including demographics, smoking status, history of SLE, history of treatment with HCQ.

Disease activity was assessed by the SLE Activity Index (SLEDAI) (21) and extent of SLE by the Systemic Lupus International Collaborative Clinics/American College of Rheumatology (SLICC) damage index (22). Physician global assessment (PGA) was scored on a 0–2 verbal numeric scale, with a high score reflecting the most impairment.

Quality of life was measured by the French version of the LupusQoL questionnaire (23), a tool exploring 8 dimensions of quality of life. Scores range from 0 to 100, with a higher score indicating better quality of life (24).

The HADS questionnaire (Hospital Anxiety and Depression Scale) (25) was used to detect anxious and depressive symptoms. Scores above 7 (26), for each category, reveal anxious or depressive symptoms.

Ethics

This study was conducted in accordance with Guidelines for good clinical practice issued by the International Conference on Harmonization and the European directives 2001/20/CE and in compliance with local regulations.

The study protocol was approved by the *Comité de Protection des Personnes* (CPP) of Lille. A voluntary, signed and dated informed consent form was obtained prior to any study-related activity.

Statistics

The results are summarised as mean $\pm$ standard deviation (SD), numbers and percentage. Based on the responses to the WCC-27, clustering analysis was performed. The number of clusters was chosen on the values of R square, Cluster Cubic Criterion and pseudo-F sta-

Table I. Patients' characteristics.

	Overall n=158
Age (years)	42.2 $\pm$ 12.6
Female gender	136 (86.1%)
Education	
• Middle school	20 (13.8%)
• High school	65 (44.8%)
• University	60 (41.4%)
Current smokers	40 (25.3%)
Fibromyalgia	6 (3.8%)
Sjögren's syndrome	21 (13.3%)
Antiphospholipid syndrome	26 (16.5%)
SLEDAI score	2.7 $\pm$ 3.7
PGA score	0.4 $\pm$ 0.5
SLICC damage index	0.3 $\pm$ 0.7
Duration of treatment with HCQ (years)	9.6 $\pm$ 6.7
Concomitant treatments	
• Corticosteroids	86 (54.4%)
• Immunosuppressive drugs	42 (26.6%)
• Biologics	3 (1.9%)
Total number of pills to be taken each day	6.2 $\pm$ 4.3
Poor adherence to HCQ*	17 (11.7%)
Sufficiently informed about the disease and treatment	
• Not at all	2 (1.3%)
• A little bit	4 (2.6%)
• Mildly	14 (9.0%)
• For a great part	81 (51.9%)
• Definitely yes	55 (35.3%)
• Missing	1
Sufficiently informed about the complications	
• Not at all	4 (2.6%)
• A little bit	10 (6.4%)
• Mildly	37 (23.7%)
• For a great part	66 (42.3%)
• Definitely yes	39 (25.0%)
• Missing	1
LupusQoL scores	
• Physical health	72.5 $\pm$ 23.9
• Pain	72.0 $\pm$ 26.4
• Planning	79.2 $\pm$ 24.8
• Intimate relationships	81.0 $\pm$ 26.1
• Burden to others	66.7 $\pm$ 28.0
• Emotional health	71.3 $\pm$ 23.0
• Body image	76.6 $\pm$ 24.2
• Fatigue	63.4 $\pm$ 25.1

Results are expressed as mean $\pm$ SD, numbers and percentages. Percentages are calculated on the number of observed data. PGA: Physician Global Assessment.

* Poor adherence is defined by blood HCQ concentration <200 mg/L at visit 1 or visit 2.

tistic (27). The elbow method based on values of R square looks at the percentage of variance explained as a function of the number of clusters. We used the Ward method for clustering observations.

Demographics, history of SLE and treatment, blood HCQ concentrations, self-administered MASRI and MMAS-8 scores, quality of life, information level about the disease and its therapy, and HADS scores were compared between

clusters using chi squared statistics and variance analysis (ANOVA). Adjusted pair-wise comparisons were performed if the global test was significant.

Statistical analyses were performed with SAS 9.4 software (SAS Institute, Cary, NC, USA).

Results

Population

One hundred and fifty-eight SLE patients entered the study. Patients' char-

acteristics are summarised in Table I and Table II. Mean age was 42.2 ± 12.6 years and 136 (86.1%) patients were female. Forty (25.3%) patients were current smokers. Based on blood HCQ concentration, 17 (11.7%) patients were poorly adherent at visit 1 or visit 2. Patients with good adherence and patients with poor adherence had similar characteristics (data not shown).

The announcement of SLE diagnosis was a stressful event for most patients. Whereas more than 80% of patients felt they were sufficiently informed about SLE and treatment (answering “for a great part” or “definitely yes”), one third felt insufficiently informed about the potential complications of SLE (“not at all”, “a little bit” or “mildly” responses). At study entry, subjects had a high level of symptoms of anxiety on the HADS questionnaire (8.5 ± 4.5). Quality of life was good for intimate relationships, planning, and body image, mildly impaired for physical health, pain, and emotional health and more severely impaired for fatigue and burden to others (Table I).

Patients' scores on the WCC-27 were as follows: problem-centered coping (items referring to efforts to solve the problem) 29.4 ± 5.0 (ranging from 17 to 40 for a maximum of 40), emotion-centered coping (referring to hope) 22.1 ± 5.9 (ranging from 4 to 35 for a maximum of 36) and search for social support (informal, material and emotional support) 22.2 ± 5.1 (ranging from 8 to 32 for a maximum of 32). Expressed as percentages of the maximum score, problem-centered coping was $73.5\% \pm 12.6\%$, emotion-centered coping was $61.4\% \pm 16.4\%$, and search for social support was $69.5\% \pm 16.0\%$ (Table II).

Clustering

Based on the coping strategies, four clusters were identified (Fig. 1-2).

- Cluster 1 (n=38) had the highest score for problem-centered coping, a low score for emotion-centered coping but the highest score for search for social support.
- Cluster 2 (n=77) had a high score for problem-centered coping, a high score for emotion-centered coping

Table II. Psychological characteristics of patients.

	Overall n=158
Stress level scores at SLE diagnosis announcement	
• Low	20 (13.6%)
• Mild	52 (35.4%)
• High	75 (51.0%)
Coping strategy scores	
– Problem-centered coping (/40)	29.4 ± 5.0
– Emotion-centered coping (/36)	22.1 ± 5.9
– Search for social support (/32)	22.2 ± 5.1
HADS anxiety score	8.5 ± 4.5
HADS depression score	4.8 ± 3.8

Results are expressed as $m \pm SD$, number and percentages. Percentages are calculated on the number of observed data. HADS: Hospital Anxiety Depression Scale.

and a high score for search for social support.

- Cluster 3 (n=34) had an intermediate score for problem-centered coping, the lowest score for emotion-centered coping and a low score for search for social support.
- Cluster 4 (n=8) had the lowest score for problem-centered coping, the highest score for emotion-centered coping and the lowest score for search for social support. (Table III and Fig. 2).

Subjects in cluster 4 had a specific profile: they were the youngest subjects of the population, had been more stressed at SLE diagnosis announcement, were more convinced of being sick, were more convinced that the treatment was doing more harm than good and did not feel sufficiently informed about the evolution of the disease and about the complications than other clusters. Assessing the benefits of treatment, they rated them lower than other subjects (5.7 ± 1.3). They scored lower for all dimensions of quality of life, had significantly more anxious symptoms than cluster 1 and cluster 3 on the HADS questionnaire (12.6 ± 5.1) and a significantly higher score for depressive symptoms than cluster 1 and cluster 3 (8.3 ± 5.6).

Subjects in cluster 2 were close to those of cluster 4 in terms of the psychological evaluation. Forty-two (59.2%) felt high stress at SLE diagnosis. Subjects in cluster 2 had significantly higher score for anxiety than those in cluster 1 and cluster 3 (9.7 ± 4.3) on the HADS questionnaire. Their quality of life was impacted in all domains.

Subjects in cluster 3 rated the benefits of treatment more highly than those in cluster 2 (7.9 ± 1.0). They felt a low level of stress at SLE announcement. They reported significantly fewer anxious symptoms (5.7 ± 4.2) than cluster 2 and cluster 4. They had the best quality of life as evaluated with lupusQoL questionnaire.

Subjects in cluster 1 had felt stressed at SLE diagnosis announcement, with 21 (56.8%) reporting high stress. They scored 7.4 ± 3.8 for anxious symptoms on the HADS questionnaire. They had average quality of life in all domains.

Clinical features, duration of treatment and monthly dose of HCQ were not different between clusters. Whereas the percentage of poorly adherent patients ranged from 10.8% to 14.5% in clusters 1 to 3, all subjects in cluster 4 were adherent, without statistical difference between groups (Table III).

Discussion

This analysis focused on coping styles among SLE patients. Patients were assessed during a routine visit. To better analyse coping style, it was important to consider non-flaring patients or not hospitalised patients. We described four clusters of patients defined according to their coping strategy. We discovered relationships between coping, psychological distress and perceived benefits of treatment. This suggests that a heterogeneity of coping strategies could be beneficial when forming patient education groups. These findings could lead to deem the heterogeneity of coping strategies for an efficient patient education.

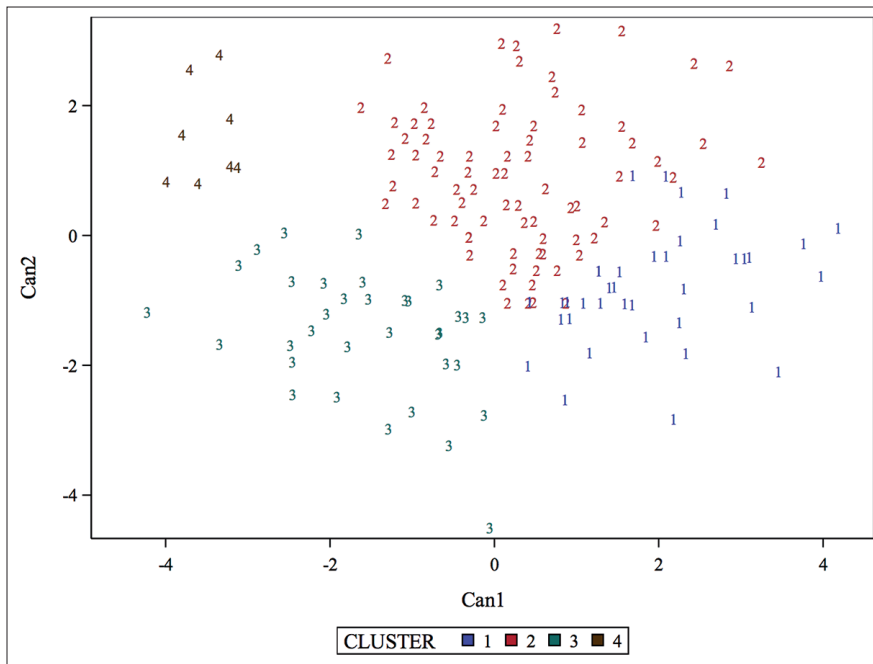
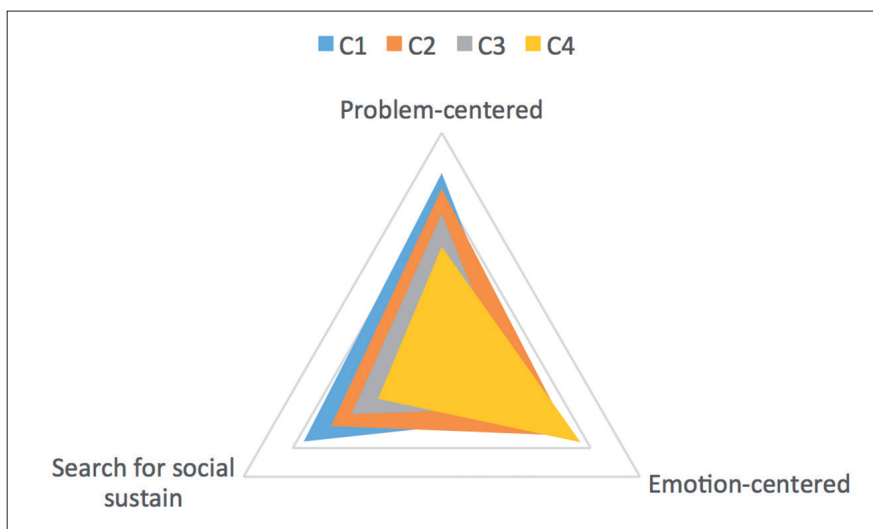


Fig. 1. Dispersion of clusters.



	Problem-centered	Emotion-centered	Search for social support
Cluster 1	HIGHEST	LOW	HIGHEST
Cluster 2	HIGH	HIGH	HIGH
Cluster 3	AVERAGE	LOWEST	LOW
Cluster 4	LOWEST	HIGHEST	LOWEST

Fig. 2. Representation of coping strategies by cluster.

Coping is defined as the constantly evolving cognitive and behavioural efforts to manage specific requirements. These are strategies to control aversive situations (28). For some authors, determinants of coping are dispositional (29), while for others, coping is de-

termined by situational characteristics (30). Classically, three main coping meta-strategies are distinguished: emotion-centered coping, problem-centered coping and search for social support. Some authors use the dichotomy of engaging/active for problem-

centered coping or disengaging/passive for emotion-centered coping. This classification (31) values judgments on the adaptability of the coping strategies. The only important point about a coping strategy is its effectiveness if it allows the person to control the situation. We found four clusters depending on the predominant strategy of coping, with no correlation with disease activity ($p=0.80$). Cluster 4 comprised only a small number of patients. This cluster was characterised by emotion-centered coping. Cluster 4 patients felt more anxious, depressed and had the worst quality of life. They had good compliance with treatment but felt the least benefits. Emotion-centered coping could be the cause or the consequence of the stress they felt at SLE diagnosis announcement. Nonetheless, this response is maladaptive since it leads to a high prevalence of anxious symptoms. One reason for these patients having developed this kind of inadequate coping could be found in the sense of coherence (SOC), a global orientation to one's inner environment which determines the link between stressors, coping and health (32). SOC has a major influence on quality of life for women with SLE (33), as an independent variable for the mental and physical component summary of the SF36, a questionnaire of quality of life (33). The aim of patient education is to improve a patient's quality of life (34). Patients in cluster 4 would certainly derive great benefit from patient education.

Coping efforts are triggered by the nature of the stressor. Emotional coping can be useful in the short term. Problem-based coping is really effective if the situation is controllable (28). Faced with an uncontrollable event, the subject's repeated efforts are useless and an avoidant emotional strategy may be appropriate. This could explain the prevalence of symptoms of anxiety and average scores for quality of life in patients of cluster 1. SLE is a chronic disabling disease with a complex clinical presentation and course. This is why, even when the subject is developing problem-centered coping approach, the stress caused by the unpredictable course can lead to anxiety. This illus-

trates the importance of diversifying coping responses. Sessions of patient education can be group sessions leading to the development of social support. Problem-focused coping targets causes of stress in practical ways which tackle the problem or stressful situation, consequently reducing the stress. A patient education program emphasizes an approach centered on the mobilisation of the person's own resources and the sharing of solutions between peers. This group of patients, with a predominantly problem-focused coping strategy could become expert patients (35). This encourages health professionals to acknowledge patients' expertise and to consider them as a valuable resource for other patients (36).

In cluster 2, patients developed all three coping strategies. They did not have the best quality of life and reported symptoms of anxiety. Subjects who are clear and attentive to their emotions, and who continue to actively process and express their emotions, are not moving towards the resolution of their problem. They are becoming over vigilant, which can lead to rumination (37). It is important to consider coping but it is also important to modulate the stressor. In the case of SLE, the stressor is the disease itself so the clinician has to promote resilience (38). A trauma is an event of life which is defined by its intensity, the incapacity for the subject to respond to it adequately (39). The aim of patient education is to help a patient to accept living with his/her disease. Thus, patient education promotes the concept of auto-normativity as defined by Barrier (40). Considering the acceptance to live with a chronic disease, the stressor is no longer there and the concept of coping no longer takes place.

This hypothesis could explain the results of cluster 3. These patients had an intermediate score for problem-centered coping, the lowest score for emotion-centered coping and a low score for search for support. Asked about their stress level at SLE diagnosis, they reported less stress than patients in other clusters. The stress caused by the diagnosis announcement may possibly have long-term consequences. Thus, the announcement of the diagnosis can

Table III. Clusters based on coping strategies.

	Cluster 1 n=38	Cluster 2 n=77	Cluster 3 n=34	Cluster 4 n=8	p-value
Age (years)	46.5 ± 12.5	40.5 ± 12.9	43.0 ± 11.7	34.1 ± 8.9	0.03
Female gender	31 (81.6%)	72 (93.5%)	25 (73.5%)	7 (87.5%)	0.02
Education					
• Middle school	5 (13.9%)	9 (13.0%)	5 (16.1%)	1 (12.5%)	0.97
• High school	14 (38.9%)	32 (46.4%)	15 (48.4%)	3 (37.5%)	
• University	17 (47.5%)	28 (40.6%)	11 (35.5%)	4 (50.0%)	
Disease duration (years)	12.08 ± 8.43	11.51 ± 7.60	13.01 ± 8.08	10.01 ± 5.81	0.7163
Fibromyalgia	2 (5.3%)	3 (3.9%)	0	1 (12.5%)	0.27
Sjögren's syndrome	7 (18.4%)	9 (11.7%)	4 (11.8%)	1 (12.5%)	0.78
Antiphospholipid syndrome	7 (18.4%)	10 (13.0%)	8 (23.5%)	1 (12.5%)	0.55
SLEDAI score	2.6±4.9	2.9±3.5	2.2±2.5	2.9±3.1	0.80
PGA score					
• 0	21 (59.8%)	36 (46.8%)	20 (58.8%)	3 (37.5%)	0.25
• [0;1]	15 (40.5%)	32 (41.6%)	14 (41.2%)	5 (62.5%)	
• [1;2]	1 (2.7%)	9 (11.7%)	0	0	
SLICC damage index	0.3 ± 0.9	0.3 ± 0.6	0.3±0.6	0	0.72
Stress level at SLE diagnosis announcement					
• Low	4 (10.8%)	5 (7.0%)	9 (28.1%)	2 (28.6%)	0.0001
• Mild	4 (10.8%)	24 (33.8%)	16 (50.0%)	0	
• High	21 (56.8%)	42 (59.2%)	7 (21.9%)	5 (71.4%)	
Coping strategy scores					
• Problem-centered coping (/40)	32.9 ± 3.7	30.2 ± 4.3	25.9 ± 3.6	20.1 ± 2.5	0.72
• Emotion-centered coping (/36)	19.1 ± 3.6	25.7 ± 4.4	15.8 ± 3.9	28.0 ± 3.1	
• Search for social support (/32)	27.8 ± 2.4	22.3 ± 3.6	18.2 ± 3.7	12.9 ± 1.9	
Benefits of treatment (/10)	7.5 ± 2.3	6.7 ± 2.5	7.9 ± 1.0	5.7 ± 1.3	0.01
MASRI score	94.0 ± 10.7	92.8 ± 10.6	91.8 ± 15.5	89.4 ± 11.7	0.74
MASRI < 80	2 (5.3%)	4 (5.2%)	5 (15.2%)	1 (12.5%)	0.25
MMAS-8 total regarding hydroxychloroquine	6.8 ± 1.8	6.6 ± 1.6	6.6 ± 1.7	6.1 ± 2.5	0.75
MMAS-8 ≤ 6	11 (29.0%)	28 (36.4%)	9 (28.1%)	3 (37.5%)	0.78
Plaquenil dose (mg/kg/day)	4.48 ± 1.63	4.54 ± 1.62	3.91 ± 1.47	4.46 ± 1.89	0.29
Poor compliers (based on HCQ blood level)	4 (10.8%)	10 (14.5%)	4 (12.5%)	0	0.78
HADS anxiety score	7.4 ± 3.8	9.7 ± 4.3	5.7 ± 4.2	12.6 ± 5.1	<0.0001
HADS depression score	3.7 ± 3.3	5.5 ± 3.7	3.6 ± 3.1	8.3 ± 5.6	0.001
LupusQoL scores*					
• Physical health	77.1 ± 20.9	66.7 ± 25.1	83.6 ± 15.6	60.2 ± 33.9	0.001
• Pain	77.2 ± 21.8	67.5 ± 27.8	80.8 ± 20.8	53.1 ± 38.8	0.009
• Planning	84.9 ± 19.8	74.5 ± 25.9	87.9 ± 20.2	62.5 ± 37.3	0.005
• Intimate relationship	88.6 ± 17.2	77.3 ± 26.4	86.1 ± 27.6	62.5 ± 37.9	0.04
• Burden to others	77.2 ± 19.7	58.3 ± 27.7	84.3 ± 17.0	30.2 ± 32.7	<0.0001
• Emotional health	80.0 ± 18.0	64.4 ± 21.6	85.5 ± 15.2	39.1 ± 30.5	<0.0001
• Body image	88.3 ± 14.1	71.3 ± 26.0	85.2 ± 15.9	48.7 ± 30.9	<0.0001
• Fatigue	69.0 ± 21.0	60.1 ± 25.0	70.8 ± 22.1	35.2 ± 34.4	0.0008
Convinced of being sick					
• Yes	16 (43.2%)	36 (47.4%)	17 (50.0%)	6 (75.0%)	0.02
• No	7 (18.9%)	3 (4.0%)	3 (8.8%)	1 (12.5%)	
• Yes most of the time	9 (24.3%)	30 (39.5%)	5 (14.7%)	1 (12.5%)	
• No most of the time	5 (13.5%)	7 (9.2%)	9 (26.5%)	-	0.03
• Missing	1	1	-	-	
Treatment is doing more harm than good	3 (8.3%)	12 (16.0%)	-	1 (12.5%)	
• Yes	26 (72.2%)	45 (60.0%)	29 (85.3%)	4 (50.0%)	0.67
• No	-	4 (4.3%)	1 (2.9%)	2 (25.0%)	
• Yes most of time	7 (19.4%)	14 (18.7%)	4 (11.8%)	1 (12.5%)	
• No most of time	2	2	-	-	0.01
• Missing	-	-	-	-	
Sufficiently informed about the disease					
• Not at all	-	2 (2.6%)	-	-	0.67
• A little bit	-	4 (5.2%)	-	-	
• Mildly	1 (2.7%)	8 (10.4%)	4 (11.8%)	1 (12.5%)	
• For a great part	19 (51.4%)	38 (49.4%)	19 (55.9%)	5 (62.5%)	0.01
• Definitely yes	17 (46.0%)	25 (32.5%)	11 (32.4%)	2 (25.0%)	
• Missing	1	-	-	-	
Sufficiently informed about the complications					
• Not at all	-	2 (2.6%)	2 (5.9%)	-	0.01
• A little bit	-	7 (9.1%)	1 (2.9%)	2 (25.0%)	
• Mildly	3 (8.1%)	19 (24.7%)	13 (38.2%)	2 (25.0%)	
• For a great part	22 (59.5%)	29 (37.7%)	11 (32.4%)	4 (50.0%)	0.01
• Definitely yes	12 (32.4%)	20 (26.0%)	7 (20.6%)	-	
• Missing	1	-	-	-	

Results are expressed as mean ± SD, numbers and percentages. Percentages are calculated on the number of observed data. Poor compliers are defined as subjects with serum level of hydroxychloroquine <200 mg/L at visit 1 or visit 2.

*the upper score corresponds to a better quality of life.

PGA: physician global assessment

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be the first phase of disease appropriation (41). For patients in cluster 3, in the absence of a stressor, there is no need for them to develop a coping strategy. Medical staff should be aware of SLE patients' psychological resources to deal with the stress of the disease, since such traits are strongly independently associated with quality of life (42). Dobkin et al. followed-up 120 female SLE patients during 15 months; global psychological distress, stress and emotion-oriented coping improved with time (43).

Coping style was not correlated in our study with adherence to treatment. We did not find any differences between clusters concerning compliance to HCQ. In a study involving SLE flaring patients, Costedoat-Chalumeau *et al.* (44) reported that HCQ blood levels were <200 mg/L in 14.5% of patients, and undetectable in an additional 7.2%. In our study, the proportion of patients with poor adherence was similar to the proportion (7%) previously reported in a non-flaring SLE population (45). Interestingly, patients in cluster 3 with an intermediate score for problem-centered coping, the lowest score for emotion-centered coping and a low score for search for support felt more benefits of their treatment compared to the other clusters and had less symptoms of anxiety and depression. Psychological factors could influence patients' conception of treatment without modifying intake medicine (46).

Our study has several limitations. The main limitation is that causal influences between coping and health are most likely bidirectional. MacCracken *et al.* (47) provided evidence that cognitive symptoms of anxiety interfere with cognitive coping strategies. This finding reflects the need for prospective, interventional studies to examine coping. Experimental studies evaluating the effects of patient education according to the patient's coping strategy are needed. Additional psychological variables need to be evaluated, such as personality traits, as it is known that optimism impacts on mental and physical well-being (48), or "cognitive hardness", which is described as a personality variable that has both cognitive and behavioural aspects (49). Also, given

the small number of patients in some of our clusters, and especially cluster 4, caution is needed in generalising our results. Nonetheless, cluster 4 appears as an extreme case of psychological distress and further investigations are needed to better explore reasons for this distress. Even if these patients do not appear to constitute a statistically significant group, their level of suffering merits particular attention on the part of health care providers.

Conclusion

Faced with the diagnosis of SLE, patients have to deploy coping strategies. Because each coping strategy can offer solutions, it is important to understand that group heterogeneity is one of the strengths of patient education beyond mere knowledge of the disease.

Key messages

What is already known about this subject?

- Emotion-centered coping is associated with worse quality of life for patients suffering from SLE.
- Patient education aims to improve patients' skills.

What does this study add?

- SLE patients can be clustered by their coping strategies (problem-centered coping, emotion-centered coping, search for social support).
- Patient education could be tailored according to coping strategies.

How might this impact on clinical practice?

- Patient education could be personalised not only of knowledge, but of coping styles.

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