EXTENDED REPORT

Improvement of coping abilities in patients with systemic lupus erythematosus: a prospective study

M Haupt*, S Millen*, M Jänner, D Falagan, R Fischer-Betz, M Schneider

Objective: To evaluate a novel specific psychological intervention aimed at improving coping in patients with systemic lupus erythematosus (SLE).

Methods: 34 community living SLE patients were recruited for the study. Intervention was undertaken in groups of up to eight patients and in two blocks over six months each. Eight patients were enrolled as a waiting list group. The 18 group sessions focused on information about the disease and specific problems of SLE patients, combining psychoeducative and psychotherapeutic elements. Psychological and medical evaluations were conducted at baseline and after three, six, and 12 months, using validated instruments.

Results: The 34 SLE patients (91% female, mean age 42 years) improved significantly over a six month period on most of the psychological measuring instruments applied, such as depression, anxiety, and overall mental burden. The waiting list group showed no significant changes.

Conclusions: Conceptualised psychoeducational support may produce a significant and sustained improvement in coping skills of SLE patients and hence in their quality of life.

Deproving on its course and on the patient’s individual situation, systemic lupus erythematosus (SLE) can lead to a wide range of physical, mental, and social problems. These include fatigue,1,2 sleeplessness,3–10 cognitive dysfunction,11 neuropsychiatric symptoms,12 lack of self efficiency or control over the disease,13,14 reduced stress threshold,15 depression16–19 or anxiety20 or both,20 and a poorer quality of life than healthy subjects.22 There are indications that involvement of the central nervous system entails an increased risk of suicide.23

The course of the disease and the mental wellbeing of SLE patients are influenced by the kinds of coping strategies,24–26 social support,27–29 and the ability to deal with stress and negative emotions.30,31 The published data on the episode precipitating effect of stress in SLE patients are contradictory.11–13

Adequate coping strategies, social support, and the ability to deal with stress and negative emotions can enhance mental and physical wellbeing in SLE patients. Various studies have underscored the need for supplementary psychological support.11,13,19,20,30,34–36

Approaches published to date for providing SLE patients with supplementary psychological support can be divided into psychoeducational interventions and those based on psychotherapeutic counselling. Psychoeducational concepts are found in patient training programmes—focused on providing information on symptoms and therapeutic approaches—37–40 or giving greater emphasis to the coping response to illness and everyday life—and in self-management courses.41,42 Approaches based on psychotherapeutic counselling include telephone counselling43–46 and short term group psychotherapy based on the concept of brief supportive-expressive group psychotherapy.37,47

In the present explorative study, we developed a group intervention tailored to the specific needs of SLE patients, integrating psychoeducational elements while retaining the fundamental nature of short term group psychotherapy. We assumed that such an integrative intervention would be of greater benefit to SLE patients than former singular therapeutic approaches. The effects of this newly developed psychological intervention on depressive symptoms and anxiety were investigated in this present study. Improved coping ability over six months was therefore the primary aim.

METHODS

The group intervention was conducted at the department of rheumatology, Heinrich-Heine-University, Düsseldorf from 1 April 2002 to 31 March 2003.

Patients were recruited to the study through the following channels: outpatient department of rheumatology, Heinrich-Heine-University, Düsseldorf; private rheumatological practices; local rheumatology hospitals; and the German Lupus Erythematosus Self Help Group.

All patients gave their written informed consent. The ethics committee of Düsseldorf University raised no objections to the proposed group intervention.

Inclusion criteria were the presence of SLE according to American College of Rheumatology (ACR) criteria, minimum age 18 years, minimum disease duration three months, stable health situation, low disease activity at enrolment, and an abnormal rating in at least one subscale of the symptom checklist 90, revised version (SCL-90-R).

Exclusion/discontinuation criteria were hospital admission because of an acute episode, diagnosed psychiatric disorders, severe speech problems, predictable failure to attend group sessions regularly, more than four sessions missed, ongoing external psychotherapy, ongoing participation in a clinical study, pregnancy, dementia, and life threatening concomitant disease.

Test procedures

The following standardised instruments were used within the framework of the study: symptom checklist 90, revised version (SCL-90-R); anxiety; depression; social support; everyday coping; everyday life; hospital anxiety; and depression; disease activity; German version; self registration scale; SF-36; self registration scale; SF-36 item general health; SLE, systemic lupus erythematosus; SUSA, System lupus international collaborating clinics.

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Abbreviations: ACR, American College of Rheumatology; ECLAM, European consensus lupus activity measurement; FAL, everyday life questionnaire; FKV, Freiburg questionnaire on coping with illness; HADS-D, hospital anxiety and depression scale—German version; KKG, questionnaire for registration of control convictions relating to illness and health; SCL-90-R, symptom checklist 90, revised version; SESA, self acceptance registration scale; SF-36, short form 36 item general health questionnaire; SLE, systemic lupus erythematosus; EUCC, system lupus international collaborating clinics.
version (SCL-90-R); the short form 36 item general health questionnaire (SF-36); the hospital anxiety and depression scale–German version (HADS-D); the questionnaire for registration of control convictions relating to illness and health (KKG); the Freiburg questionnaire on coping with illness (FKV); self acceptance registration scale (SESA); and the everyday life questionnaire (FAL) with selected sub-scales49–55; for description see the appendix, which can be viewed as a supplemental file on the journal website (www.annrheumdis.com/supplemental). These were applied at baseline, after three months, at the end of the intervention after six months, and at a 12 month follow up. All tests used were in the form of self rating questionnaires which were filled in at home by the group participants without assistance.

The ECLAM (European consensus lupus activity measurement), a validated instrument of lupus activity,57 was used for activity (time points 0, 3, 6, and 12 months), and the system lupus international collaborating clinics (SLICC)/ACR58 for damage (time points 0 and 12 months).

At baseline, the previous history and present case records of each patient, including current treatment, were recorded. To ensure that the participants’ drug treatment was kept as consistent as possible, the patients were provided with a study pass.

**Intervention**

The primary objective set for the psychological intervention was improvement of coping abilities of SLE patients. Concrete single targets were improved handling and control of the illness, reduced disease related and disease affecting anxieties and depression, a reduced overall mental burden, and improved interaction with relatives, partners, and other healthy persons. These dimensions were measured by FKV, SESA, HADS-D, and SCL-90-R.

Further aims were reduced disease activity and an improvement in health related quality of life, as rated by ECLAM and SF-36.

An overview of the most important psychosocial stress areas of SLE patients was gained by carrying out a comprehensive search of published reports, attending outpatient appointments, and pursuing intensive interchange with rheumatologically qualified physicians and with members of the German Lupus Erythematosus Self Help Group. This enabled some crucial problems experience by SLE patients to be formulated as a basis for the design of the following aspects.

**Psychoeducational interventions**: Information on symptoms, course, prognosis, and therapeutic options was given to the participants (two sessions). They collected relevant topics for further detailed information, such as efficacy and safety of pharmacological substances or correlation of psychosocial sequelae of the disease with disease outcome (one session). A greater part of this psychoeducational intervention was dedicated to the assessment and handling of the disease (three sessions). In addition, development and sustainability of social contacts and competence was target topic in further sessions (three sessions).

**Psychotherapeutic interventions**: These interventions consisted of sessions directed at identification and management of

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**Table 1** Characteristics of intervention group (IG) and waiting list group (WG) probands and of the total sample on entry into the study

<table>
<thead>
<tr>
<th></th>
<th>IG* (n = 26)</th>
<th>WG (n = 8)</th>
<th>Total sample (n = 34)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Female</td>
<td>24</td>
<td>92.3</td>
<td>7</td>
</tr>
<tr>
<td>Male</td>
<td>2</td>
<td>7.7</td>
<td>1</td>
</tr>
<tr>
<td><strong>Educational qualification</strong></td>
<td></td>
<td></td>
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<tr>
<td>Junior high school</td>
<td>10</td>
<td>38.5</td>
<td>4</td>
</tr>
<tr>
<td>Senior high school</td>
<td>5</td>
<td>19.2</td>
<td>3</td>
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<tr>
<td>Polytechnic/University</td>
<td>9</td>
<td>34.6</td>
<td>0</td>
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<td><strong>Polytechnic/University Degree</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>7.7</td>
<td>1</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
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<td></td>
</tr>
<tr>
<td>Single</td>
<td>5</td>
<td>19.2</td>
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<tr>
<td>Partnership</td>
<td>5</td>
<td>19.2</td>
<td>2</td>
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<tr>
<td>Married</td>
<td>14</td>
<td>53.8</td>
<td>5</td>
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<tr>
<td>Divorced</td>
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<td>7.7</td>
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<tr>
<td><strong>Duration of illness</strong></td>
<td></td>
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<tr>
<td>Less than 1 year</td>
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<td>15.4</td>
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<tr>
<td>1 to 5 years</td>
<td>14</td>
<td>53.8</td>
<td>1</td>
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<td>5 to 10 years</td>
<td>3</td>
<td>11.5</td>
<td>1</td>
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<tr>
<td>More than 10 years</td>
<td>5</td>
<td>19.2</td>
<td>6</td>
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<td><strong>SHG/C192 membership</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>16</td>
<td>61.5</td>
<td>3</td>
</tr>
<tr>
<td>No</td>
<td>10</td>
<td>38.5</td>
<td>5</td>
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</table>

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>SD</th>
<th>Mean</th>
<th>SD</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (years)</strong></td>
<td>40.15</td>
<td>12.96</td>
<td>47.63</td>
<td>11.19</td>
<td>41.91</td>
<td>12.81</td>
</tr>
<tr>
<td>Disease activity</td>
<td>1.27</td>
<td>1.15</td>
<td>0.63</td>
<td>0.74</td>
<td>1.12</td>
<td>1.15</td>
</tr>
<tr>
<td>Chronic changes</td>
<td>0.46</td>
<td>0.91</td>
<td>1.25</td>
<td>0.89</td>
<td>0.68</td>
<td>0.95</td>
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</table>

*Without WG.
†German Lupus Erythematosus Self Help Group.
The software used for data analysis was the Statistical Package for the Social Sciences (SPSS, version 11.0).

**RESULTS**

Overall, 115 patients were asked to participate; Seventy three refused for various reasons—for example, they had no interest in participating in a scientific study. Four patients did not fulfill the psychopathological inclusion criterion (SCL-90 R). The final intervention cohort comprised 38 patients. Four patients (10.5%) discontinued the intervention prematurely (one had a lupus flare, one found the travelling inconvenient, and two found the group setting unhelpful). There were no significant differences between the drop outs and the long term participants with respect to their demographic characteristics. Further inspection of medical and psychological data did not yield significant differences between participants and refusers.

We were able to use the datasets on 34 SLE patients for course measurements. Eight of the 34 patients who participated in the second intervention phase functioned initially as a waiting list group (WG): their psychological and medical test findings on initial contact were compared with the results at baseline. At study entry, WG did not differ substantially from the treatment group of patients (IG) (table 1) despite a longer disease duration (p<0.05). Twenty eight of the 34 subjects were German; the other six originated from various other countries but had a good command of the German language.

**Measurement of the psychological course**

In view of the exploratory nature of the study, a adjustment according to Bonferroni–Holm was not applied.

Overall, significant effects of the intervention in terms of a reduction in mental burden, an increase in positive resources, or a decline in dysfunctional behaviour, emotions, and cognitions were recorded (table 2).

Three months after the start of the intervention, significant changes were recorded at the 5% level on the following test scales: insecurity in social contact (SCL-90-R), social functioning (SF-36), depressive coping with the illness (FKV), and social life (FAL). Significant changes at the 1% level were detected on the following scales: somatisation, depression, anxiety, aggression, paranoid thinking, and overall mental burden (all SCL-90-R), general perception of health, emotional role function, and mental wellbeing (all SF-36) as well as depression (HADS-D). After six months, on completion of the group intervention, a marked increase in significant changes was recorded. Only the somatisation scale (SCL-90-R) showed no further significant improvement over the baseline value.

Six months after completion of the intervention, most significant changes persisted or increased further, and for the first time improvement in physical role function (SF-36) and control of the disease by doctors and by self (KKG) were recorded at the 5% level.

To determine possible predictors of the degree of mental change, the following variables were investigated within the framework of a regression analysis: age, sex, education, duration of the disease, marital status, membership in the self help group, number of group sessions, participation in the information evening for relatives/partners, number of one to one discussions, and disease activity. The focus was on a correlation with the anxiety and depression scales, where, however, no significant predictors were found.

**Measurement of the medical course**

The measurement of the medical course of the overall sample (n = 34) revealed no significant changes at any assessment. Changes in drug treatment and dosage were only observed in
three IG patients relating to their non-steroidal anti-inflammatory drug (NSAID) use.

### Waiting list group

The average waiting time from initial contact to baseline for the eight waiting list group members was 132 days (minimum 12, maximum 188). During this period, SF-36 revealed an improvement in physical functioning and a deterioration in general perception of health (both p<0.05).

### Course of the intervention

The overall participation rate was 85.6%, 5.1% of which was disease induced. The patients attended an average of 15 group sessions (minimum 12, maximum 18). Three patients attended fewer than 14 sessions (12/12/13).

Table 3 shows the results of an anonymised concluding evaluation by those taking part in the intervention (five point Likert scale: higher rating = better assessment).

**DISCUSSION**

The psychological group intervention presented here resulted in improvements in the mental health of SLE patients, suggesting that the intervention could be effective even over a longer period.

The primary target criterion of the study—improved coping—was achieved: coping with the disease was improved by a long term reduction in the dysfunctional strategies of “depressive coping” and “playing down/wishful thinking”. In the control convictions relating to illness and health, a

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### Table 2 Subscales/psychological course measurements (n = 34)

<table>
<thead>
<tr>
<th>Subscales/psychological course measurements</th>
<th>Baseline</th>
<th>3 Months</th>
<th>6 Months</th>
<th>Follow up (12 months)</th>
</tr>
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<tbody>
<tr>
<td>Medical care</td>
<td>10.88 (3.06)</td>
<td>11.56 (2.52)</td>
<td>11.12 (2.52)</td>
<td>11.32 (2.36)</td>
</tr>
<tr>
<td>Physical function</td>
<td>67.79 (21.57)</td>
<td>70.00 (24.83)</td>
<td>65.74 (26.26)</td>
<td>70.88 (23.40)</td>
</tr>
<tr>
<td>Pain</td>
<td>45.09 (24.55)</td>
<td>48.56 (26.94)</td>
<td>49.94 (26.24)</td>
<td>54.44 (29.94)</td>
</tr>
<tr>
<td>Social functioning</td>
<td>55.26 (8.04)</td>
<td>54.09 (6.97)</td>
<td>53.00 (7.64)</td>
<td>53.24 (8.78)</td>
</tr>
<tr>
<td>SF-36</td>
<td>85.47 (8.37)</td>
<td>85.47 (8.37)</td>
<td>85.47 (8.37)</td>
<td>85.47 (8.37)</td>
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<tr>
<td>SCL-90</td>
<td>62.38 (10.05)</td>
<td>58.97 (8.84)</td>
<td>60.24 (10.28)</td>
<td>58.79 (10.88)</td>
</tr>
<tr>
<td>Somatisation</td>
<td>50.41 (8.37)</td>
<td>50.41 (8.37)</td>
<td>50.41 (8.37)</td>
<td>50.41 (8.37)</td>
</tr>
<tr>
<td>Anxierty</td>
<td>33.26 (5.71)</td>
<td>35.15 (5.71)</td>
<td>35.15 (5.71)</td>
<td>35.15 (5.71)</td>
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<tr>
<td>Compulsion</td>
<td>55.59 (7.44)</td>
<td>55.59 (7.44)</td>
<td>55.59 (7.44)</td>
<td>55.59 (7.44)</td>
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<tr>
<td>Insecurity</td>
<td>49.24 (7.76)</td>
<td>49.24 (7.76)</td>
<td>49.24 (7.76)</td>
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<tr>
<td>Depression</td>
<td>44.38 (14.70)</td>
<td>44.38 (14.70)</td>
<td>44.38 (14.70)</td>
<td>44.38 (14.70)</td>
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<tr>
<td>Anxiety</td>
<td>57.53 (27.20)</td>
<td>57.53 (27.20)</td>
<td>57.53 (27.20)</td>
<td>57.53 (27.20)</td>
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<tr>
<td>HADS-D</td>
<td>7.18 (3.72)</td>
<td>6.09 (3.05)</td>
<td>5.53 (3.47)</td>
<td>5.71 (4.06)</td>
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<tr>
<td>Depression</td>
<td>7.26 (4.60)</td>
<td>5.97 (3.95)</td>
<td>5.38 (3.67)</td>
<td>5.41 (3.99)</td>
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<tr>
<td>Anxiety</td>
<td>7.26 (4.60)</td>
<td>5.97 (3.95)</td>
<td>5.38 (3.67)</td>
<td>5.41 (3.99)</td>
</tr>
<tr>
<td>Control conviction: self</td>
<td>49.50 (34.44)</td>
<td>38.79 (30.77)</td>
<td>42.85 (32.31)</td>
<td>40.26 (33.74)</td>
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<tr>
<td>Control conviction: doctors</td>
<td>81.68 (22.08)</td>
<td>77.41 (26.81)</td>
<td>74.53 (29.49)</td>
<td>74.82 (26.62)</td>
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<tr>
<td>Control conviction: chance/fate</td>
<td>88.82 (21.03)</td>
<td>86.78 (17.91)</td>
<td>87.97 (16.44)</td>
<td>86.66 (20.80)</td>
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<tr>
<td>SF-36</td>
<td>85.47 (8.37)</td>
<td>85.47 (8.37)</td>
<td>85.47 (8.37)</td>
<td>85.47 (8.37)</td>
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<td>FKV</td>
<td>2.45 (1.77)</td>
<td>2.24 (1.71)</td>
<td>2.14 (1.80)</td>
<td>2.05 (1.65)</td>
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<tr>
<td>Depressive coping</td>
<td>3.41 (7.3)</td>
<td>3.40 (8.3)</td>
<td>3.45 (8.5)</td>
<td>3.46 (7.2)</td>
</tr>
<tr>
<td>Active problem oriented coping</td>
<td>3.23 (7.18)</td>
<td>3.26 (7.2)</td>
<td>3.35 (6.3)</td>
<td>3.24 (6.5)</td>
</tr>
<tr>
<td>Distraction/self encouragement</td>
<td>2.86 (7.79)</td>
<td>2.85 (8.3)</td>
<td>2.92 (8.7)</td>
<td>2.88 (9.2)</td>
</tr>
<tr>
<td>Religiousness/search for meaning</td>
<td>2.61 (9.8)</td>
<td>2.40 (10.1)</td>
<td>2.25 (8.8)</td>
<td>2.22 (8.8)</td>
</tr>
<tr>
<td>SESAM</td>
<td>108.74 (20.06)</td>
<td>111.00 (19.05)</td>
<td>113.06 (19.26)</td>
<td>115.91 (18.03)</td>
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<tr>
<td>Self acceptance</td>
<td>32.18 (7.42)</td>
<td>34.18 (7.11)</td>
<td>33.29 (7.89)</td>
<td>34.94 (7.19)</td>
</tr>
<tr>
<td>Social life</td>
<td>31.26 (7.94)</td>
<td>34.56 (6.11)</td>
<td>34.65 (5.87)</td>
<td>35.15 (5.71)</td>
</tr>
<tr>
<td>Medical care</td>
<td>10.88 (3.06)</td>
<td>11.56 (2.52)</td>
<td>11.12 (2.52)</td>
<td>11.32 (2.52)</td>
</tr>
</tbody>
</table>

**Table 3 Anonymised concluding evaluation of the intervention by the probands**

<table>
<thead>
<tr>
<th>Mean (SD), n = 34</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information on the illness</td>
</tr>
<tr>
<td>Help in coping with the illness</td>
</tr>
<tr>
<td>Interchange with other patients</td>
</tr>
<tr>
<td>Regular group sessions</td>
</tr>
<tr>
<td>Expert group leaders</td>
</tr>
<tr>
<td>Disease specific topics</td>
</tr>
<tr>
<td>Feedback on test results</td>
</tr>
<tr>
<td>Own contribution to research</td>
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reduction in the rating of the doctor’s influence was revealed at the follow up. This might be interpreted as an indication of a long term development of greater independence on the part of the patients in handling their illness. During the intervention period, a continuous reduction in anxiety and depression, and a reduction in overall mental burden, were observed. These effects were still detectable, though less pronounced, at the follow up measurement. In addition, significant improvements in social contact were also of a long term nature.

A reduction in disease activity, a secondary objective of the intervention, could not be detected by ECLAM. This may be caused by the inclusion criterion “low disease activity”, aimed at ensuring continuous attendance at the group sessions, or our observation period may not have been sufficient to register effects of improved coping on the course of the disease. However, our data are in accordance with studies by Dobkin et al. and Sohng. Six month follow up assessments within the framework of other studies revealed significant improvements in various medical aspects, but without the disease activity of the probands being investigated.

Another secondary objective, improvement in the health related quality of life, was achieved in essential selective aspects. For instance, general perception of health, vitality, social functioning, emotional role function, and mental well-being were improved throughout the intervention and in part at the follow up measurement.

In comparison with existing offers of support for SLE patients, the present intervention is closest in its structure and objectives to the study design of Dobkin et al. Despite a concept successfully used with cancer patients and uniformly trained group leaders, Dobkin and colleagues achieved no significant improvements in the 58 members of the intervention group in comparison with their control group, either from the mental or from the physical aspect. This may have reflected the fact that the Canadian trial had specified no psychopathological findings as an inclusion criterion. However, each proband of our intervention had to record a clinically atypical value on at least one SCL-90-R scale to enable a potential therapeutic benefit of the group sessions to be detected. It is also conceivable that the contents of the intervention by Dobkin et al., which had originally been developed for cancer patients, failed fully to meet the specific needs of SLE patients.

However, with respect to a secondary objective of the same study—reduced illness intrusiveness—Edworthy et al. achieved statistically significant effects. For example, the areas (1) relationships and personal development (family relationships, other social relationships, self expression) and (2) intimacy (relationship with spouse, sex life) underwent a marked improvement. These effects were not significant until the six or 12 month follow up. The development of the present intervention was based on the following considerations: in view of the complexity and diversity of potential psychosocial problems in SLE patients, an integrative psychosocial approach seemed inadequate, even though a recent study reported significant effects on couple communication and self efficacy; with a telephone based intervention, the advantages of a group setting are lost; and the brief supportive expressive group psychotherapy approach was not originally developed for SLE patients and failed, despite the relevant adaptation, to produce the desired success.

In view of the important role of social support, it was considered essential to integrate key attachment figures. Factors supporting the concept selected for the present study are the low drop out rate, the high level of participation in the accompanying information session for relatives, and the very positive evaluation of its adequacy by the patients (table 3).

In comparison with the baseline psychological findings, several significant changes were recorded after only half of the intervention period, whereas maximum effects were not achieved until the end of the six month intervention (table 2). The time frame of the study thus appears to do greater justice to the complex problems of SLE patients than shorter interventions, and this is also supported by the predominant stability of the attained effects at the six month follow up.

Weaknesses of the present study are primarily in its small sample size and small waiting list group which has not been rigorously followed up and which does not fulfil standard criteria for a control group. However, the sample size is relatively large for a single centre study, considering the rare nature of the disease and the amount of time that had to be invested by the probands. The fact that a correction of the α level was not applied in the data analysis seems justified in view of the exploratory nature of the study.

In summary, the results of this newly developed intervention aimed at improving the coping abilities of SLE patients are promising. In comparison with reported psychological intervention, the current study is based on a longer psychoeducational approach with a focus not just limited to information and practical aspects of coping with the illness, addressing patients who have documented serious psychological problems. What is now needed is replication within the framework of a confirmatory study with a larger sample and a randomised control group approach, possibly with a longer term follow up of the achieved effects.

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The appendix can be viewed on the journal website: www.annrheumdis.com/supplemental

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Psychosocial issues in SLE


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