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.
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-scales; 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 measure-ment), a validated instrument of lupus activity, was used for activity (time points 0, 3, 6, and 12 months), and the system lupus international collaborating clinics (SLICC)/ACR 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.

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<table>
<thead>
<tr>
<th>Table 1</th>
<th>Characteristics of intervention group (IG) and waiting list group (WG) probands and of the total sample on entry into the study</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>IG** (n = 26)</td>
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<tr>
<td></td>
<td>n</td>
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<tr>
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<tr>
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<tr>
<td>Mean</td>
<td>SD</td>
</tr>
<tr>
<td>Age (years)</td>
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<tr>
<td>Disease activity</td>
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</tr>
<tr>
<td>Chronic changes</td>
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</tbody>
</table>

*Without WG. 
**German Lupus Erythematosus Self Help Group.
disease related/disease affecting anxieties (three sessions) and at the coping possibilities concerning fatigue and reduction of initiative and motivation in everyday living (two sessions), with structuring day activities and establishing pleasurable contacts. The participants also learned how to cope with stress and the usual everyday problems under conditions of a continuously present illness (two sessions). Coping with pain was a topic in the intervention as well (one session).

At the end of these two parts, a general discussion was conducted to enable participants to highlight problems that were still unresolved or remained unmentioned within the previous sessions (one session).

A rheumatologically qualified physician (RF-B) introduced the contents of the topic with two medical modules from the SLE patient training programme. All further group sessions were run by a graduate psychotherapist (SM). Topic centred discussions were held on the basis of the above mentioned units. The sessions had a semi-open structure in that orientation to the set topic was observed on the one hand while attention was paid to the individual problems confronting the participants on the other. The psychological confrontation with various aspects of coping was supplemented by an ongoing intensive interchange of information including concrete references to issues of everyday and legal relevance. This provided a down to earth, problem oriented approach to the complex topic of coping with illness.

Two intervention units with identical contents were carried out for a period of six months each: some second half probands functioned initially as a waiting list group, undergoing the intervention six months later.

Each intervention unit comprised 18 group sessions of 90 minutes’ duration, the first 12 held once a week, and the other six once a fortnight. All group sessions were held in the late afternoon or early evening in small groups of not more than eight subjects. Each intervention phase was accompanied by an information evening for relatives or partners.

Because of external circumstances, the patients could not be randomised to the individual groups. Job or family situation, travel time, or regular appointments necessitated targeted distribution to appropriate weekdays. In addition, efforts were made to attain group homogeneity with respect to the age of the participants.

In view of the rare occurrence of the disease, it had to be assumed that the waiting list group could be recruited only in the course of the first intervention phase. The precondition for enrolment in the control group was a waiting time of three months or more. Patients reporting during the three months preceding the second group phase took part in the intervention but were no longer included in the waiting list group.

Statistical analysis
The characteristics of the overall sample are described using descriptive statistics. For comparison of the demographic data on the intervention and the control group, as well as on drop outs, consistent characteristics were compared using the t test, and categorised data using a χ² test. The t test was used for the psychological course measurement, and the Wilcoxon test for the medical course measurement. Multivariate testing (general linear model for repeated measurements) was not applied as it was assumed that psychological and somatic variables were not correlated. Possible predictors of a successful treatment outcome were investigated by means of incremental regression.

Correlations were assumed to be significant at p<0.05 error probability, very significant at p<0.01, and highly significant at p<0.001. Owing to the exploratory character of the present study, Bonferroni–Holm adjustments were not applied.

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 fulfil 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). Four patients (10.5%) self reported 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
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

<table>
<thead>
<tr>
<th>Table 2</th>
<th>Subscales/psychological course measurements (n = 34)</th>
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<tbody>
<tr>
<td></td>
<td>Baseline</td>
</tr>
<tr>
<td>SCL-90-R</td>
<td></td>
</tr>
<tr>
<td>Somatisation</td>
<td>62.38 (10.05)</td>
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<tr>
<td>Compulsiveness</td>
<td>60.24 (8.74)</td>
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<tr>
<td>Insecurity</td>
<td>55.39 (8.44)</td>
</tr>
<tr>
<td>Depression</td>
<td>59.38 (8.26)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>58.88 (9.32)</td>
</tr>
<tr>
<td>Aggression</td>
<td>57.82 (8.76)</td>
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<tr>
<td>Phobic anxiety</td>
<td>54.00 (9.52)</td>
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<tr>
<td>Paranoid thinking</td>
<td>53.65 (9.32)</td>
</tr>
<tr>
<td>Psychoticism</td>
<td>53.26 (8.04)</td>
</tr>
<tr>
<td>Overall mental burden (GSI)</td>
<td>59.74 (7.45)</td>
</tr>
<tr>
<td>SF-36</td>
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<tr>
<td>Physical function</td>
<td>67.79 (21.57)</td>
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<tr>
<td>Physical role limitation</td>
<td>32.35 (37.20)</td>
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<tr>
<td>Pain</td>
<td>45.09 (24.55)</td>
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<tr>
<td>General health</td>
<td>39.00 (14.33)</td>
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<tr>
<td>Vitality</td>
<td>36.03 (18.21)</td>
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<tr>
<td>Social functioning</td>
<td>55.12 (25.40)</td>
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<tr>
<td>Emotional role limitation</td>
<td>50.00 (42.04)</td>
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<tr>
<td>Mental health</td>
<td>55.65 (20.76)</td>
</tr>
<tr>
<td>Change in state of health</td>
<td>2.79 (1.12)</td>
</tr>
<tr>
<td>HADS-D</td>
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<tr>
<td>Anxiety</td>
<td>7.18 (3.72)</td>
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<td>Depression</td>
<td>7.26 (4.60)</td>
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<td>KKG</td>
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<td>Control conviction: self</td>
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<td>Control conviction: doctors</td>
<td>81.68 (22.08)</td>
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<tr>
<td>Control conviction: chance/fate</td>
<td>88.82 (21.03)</td>
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<tr>
<td>FKV</td>
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<tr>
<td>Depressive coping</td>
<td>2.45 (1.77)</td>
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<tr>
<td>Active problem oriented coping</td>
<td>3.41 (7.33)</td>
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<tr>
<td>Distraction/self encouragement</td>
<td>3.23 (9.81)</td>
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<td>Religiousness/search for meaning</td>
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<td>Playing down/wishful thinking</td>
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<td>SESA</td>
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<td>108.74 (20.06)</td>
</tr>
<tr>
<td>FAL</td>
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<tr>
<td>Everyday life</td>
<td>32.18 (7.42)</td>
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<tr>
<td>Social life</td>
<td>31.26 (7.94)</td>
</tr>
<tr>
<td>Medical care</td>
<td>10.88 (3.05)</td>
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</table>

All course differences relate to the comparison with the baseline data (comparing first/second, first/third, and first/fourth measurement points). Significant changes: *p<0.05; **p<0.01; ***p<0.001.

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.

### Table 3 | Anonymised concluding evaluation of the intervention by the probands |
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<th></th>
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<tbody>
<tr>
<td><strong>Mean (SD), n=34</strong></td>
<td></td>
<td></td>
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<tr>
<td>Information on the illness</td>
<td>3.85 (0.93)</td>
<td></td>
<td></td>
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<tr>
<td>Help in coping with the illness</td>
<td>3.91 (0.75)</td>
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</tr>
<tr>
<td>Interchange with other patients</td>
<td>4.15 (0.82)</td>
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<td></td>
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<tr>
<td>Regular group sessions</td>
<td>4.12 (0.84)</td>
<td></td>
<td></td>
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<tr>
<td>Expert group leaders</td>
<td>4.68 (0.64)</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Disease specific topics</td>
<td>4.06 (0.81)</td>
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<tr>
<td>Feedback on test results</td>
<td>3.97 (0.72)</td>
<td></td>
<td></td>
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<tr>
<td>Own contribution to research</td>
<td>4.15 (1.16)</td>
<td></td>
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</table>

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 92, 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).
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.\textsuperscript{47} and Sohng.\textsuperscript{42} Six month follow up assessments within the framework of other studies\textsuperscript{44–46} 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 wellbeing were improved throughout the intervention and in part at the follow up measurement.

In comparison with existing offers of support for SLE patients,\textsuperscript{43–45} the present intervention is closest in its structure and objectives to the study design of Dobkin et al.\textsuperscript{47} 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\textsuperscript{23} 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.,\textsuperscript{47} which had originally been developed for cancer patients, failed fully to meet the specific problems of SLE patients.

However, with respect to a secondary objective of the same study—reduced illness intrusiveness—Edworthy et al.\textsuperscript{46} 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\textsuperscript{26}; 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.\textsuperscript{27} In view of the important role of social support,\textsuperscript{25–28} 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 fulfill 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 psycholog-ical 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.

ACKNOWLEDGEMENTS

We are indebted to Ms Borgi Winkler-Rohling, Chairwoman of the German Lupus Erythematosus Self Help Group, for several intensive discussions which had a crucial impact on the design of the group intervention. Sincere thanks are also due to Prof Dr Volker Tschuschke, Chair of Medical Psychology, University of Cologne, Germany, who provided valuable incentives for the evaluation of the study. We also thank Susan Griebach for help in the copy editing of the manuscript.

This study was funded by the Alfried Krupp Foundation.

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

Authors’ affiliations

S Millen, D Falagan, R Fischer-Betz, M Schneider, Department of Rheumatology, Heinrich-Heine-University, Düsseldorf, Germany

M Haupt, M Jänner, Outpatient Department of Psychiatry and Psychotherapy, Heinrich-Heine-University

*The first two authors contributed equally to this paper

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