

Group Psychotherapy Reduces Illness Intrusiveness in Systemic Lupus Erythematosus

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ABSTRACT. Objective. We investigated whether brief supportive-expressive group psychotherapy might reduce illness-induced interference with valued activities and interests (i.e., illness intrusiveness) among women with systemic lupus erythematosus (SLE) in relation to 3 life domains: (1) relationships and personal development (family relationships, other social relationships, self-expression), (2) intimacy (relationship with spouse, sex life), and/or (3) instrumental life (work, finances, active recreation).

Methods. Women with SLE recruited from 9 rheumatology centers were randomly assigned to receive either usual care (n = 66) or a 12 week brief supportive-expressive group psychotherapy followed by 3 monthly booster sessions (n = 58). Standard instruments assessed disease activity and damage, illness intrusiveness, and psychological distress at 4 measurement occasions: (1) pretreatment, (2) posttreatment, (3) 6 month followup, and (4) 12 month followup.

Results. Analysis of covariance, controlling for disease activity and household income, indicated that women who received brief supportive-expressive group psychotherapy experienced significant reductions in illness intrusiveness for 2 of 3 domains: (1) relationships and personal development and (2) intimacy. Benefits were evident at 6 and 12 month followups.

Conclusion. Brief supportive-expressive group psychotherapy facilitates adaptation to SLE by assisting women in reducing illness-induced disruptions into important domains of life experience. (J Rheumatol 2003;30:1011-6)

Key Indexing Terms:

QUALITY OF LIFE GROUP PSYCHOTHERAPY SYSTEMIC LUPUS ERYTHEMATOSUS
COPING PSYCHOSOCIAL ADAPTATION

Systemic lupus erythematosus (SLE) is stressful both psychologically and physiologically. For many people, the disease contributes to emotional distress in the form of anxiety, frustration, and depressed mood^{1,2}. A number of psychosocial stressors and adaptive challenges may underlie these difficulties.

Organ involvement is unpredictable in SLE because disease activity may affect one or more systems over time, including the kidney, lungs, joints, liver, and hematologic

and central nervous systems. The unpredictable nature of the disease and widespread potential for harm leads to anxiety. Shortened life expectancy raises concerns about mortality, and this in turn can compromise effective coping. Treatment may have severe repercussions at many different levels. Body image can be threatened, for example, by cushingoid facial changes resulting from prednisone therapy. Important life goals can be undermined when immunosuppression agents exert toxic effects on reproductive capacity.

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Economic resources can be strained when physicians prescribe medications that are not reimbursed by drug plans. Since SLE is a rare disease, with a prevalence of less than 1 per thousand in many population studies³⁻⁶, patients often feel isolated, unsupported, and misunderstood by their doctors, family members, and friends.

SLE affects women predominantly, often during the reproductive years when they are establishing families and careers^{7,8}. Family and social relationships are especially salient for women⁹. Because SLE affects them at a life stage when they would otherwise have expected to begin and/or raise a family, women may experience the condition as especially stressful. We introduced the concept of illness intrusiveness to summarize the extent to which chronic conditions, such as SLE, and their treatments interfere with psychologically meaningful activities. Many of the psychosocial challenges faced by women with SLE are subsumed by the concept of illness intrusiveness.

Illness intrusiveness¹⁰ involves illness-induced disruptions to lifestyles, activities, and interests and compromises quality of life in chronic disease. It intervenes between the objective circumstances of disease (e.g., pain, shortness of breath, weakness, memory loss) and treatment (e.g., negative side effects, costs of medications, time for provider visits) on the one hand, and subjective well-being and emotional distress on the other. Illness intrusiveness is a stressor that threatens quality of life. It is not a facet of quality of life, itself. Different variables correlate with illness intrusiveness as compared to emotional distress and subjective well-being¹⁰. Considerable evidence substantiates the illness intrusiveness theoretical framework across chronic conditions, including SLE^{11,12}. The Illness Intrusiveness Ratings Scale (IIRS) describes illness intrusiveness as it relates to 3 separate life domains: relationships and personal development, intimacy, and instrumental life domains¹³. Stress-process research shows that women are more sensitive than men when stressors arise in the context of interpersonal relationships¹⁴⁻¹⁷. In terms of the IIRS, such effects might be more evident when examining illness intrusiveness into intimacy or relationships and personal development as compared to instrumental life domains. Adjunctive psychosocial interventions, such as brief supportive-expressive group psychotherapy¹⁸, focus on minimizing illness-induced difficulties in relationships and intimacy. Their psychosocial benefits may, therefore, be evident in reduced illness intrusiveness into intimacy or relationships and personal development (i.e., compared to instrumental life domains, such as work and finances).

Evidence involving other chronic diseases^{19,20} has shown that meaningful benefits can accrue when individuals take the opportunity, in a supportive group setting and with the guidance of a skilled facilitator, to reflect on the effects that disease imposes on one's life. Such benefits can take the

form of reduced emotional distress^{20,21}, increased pain control²², improved immune function²³, and extended survival^{18,24}. Patients with SLE who accept the opportunity to participate might, therefore, benefit from group psychotherapy.

We hypothesized that group psychotherapy designed to facilitate adaptation to SLE would reduce illness intrusiveness. We anticipated that these benefits would be more pronounced when we examined illness intrusiveness in the intimacy and relationships and personal development domains as compared to the instrumental life domain because of their relevance to women and the life stage at which SLE most commonly affects them. An opportunity arose to test these hypotheses in the context of a multicenter randomized clinical trial of group psychotherapy conducted by Dobkin, *et al*²⁵. In that study, the Symptom Checklist 90-Revised (SCL90-R)²⁶ was the primary outcome, as the focus was on overall emotional distress. The IIRS was included as a secondary outcome and this report focuses on this outcome.

The specificity of the illness intrusiveness concept led us to hypothesize that psychosocial benefits of brief supportive-expressive psychotherapy — an intervention that focuses specifically on interpersonal relationships and how to maximize them adaptively despite the constraints imposed by chronic disease — might be especially evident if investigated in terms of illness intrusiveness. The IIRS relates directly to illness-induced disruptions that interfere with psychologically meaningful endeavors in specific life domains salient to women. We hypothesized that after participating in brief supportive-expressive group psychotherapy, women with SLE might experience reduced illness intrusiveness in relation to (1) intimacy and (2) relationships and personal development.

MATERIALS AND METHODS

Subjects and procedures. Women with a diagnosis of SLE according to American College of Rheumatology (ACR) criteria^{27,28} were invited by their treating physician to participate in a randomized clinical trial. Only consenting volunteers participated. Subjects were enrolled from 9 rheumatology/immunology clinics across Canada. The final sample consisted of 124 women, with random allocation of 58 to the group psychotherapy sessions. The remaining 66 women were assigned to a usual-care control group. Twelve group sessions, conducted weekly, were provided to the intervention subjects. Three monthly "booster sessions" were offered following the termination of intensive treatment to reinforce changes and to encourage the transfer of new experiences into daily life. The primary outcome measure, the IIRS, was administered on 4 occasions: (1) prior to the intervention; (2) immediately post-intervention; (3) 6 months later; and (4) at a final 12 month followup occasion. Participants completed a battery of questionnaires that included measures of socioeconomic status (e.g., household income) and psychological distress (SCL90-R) at these measurement occasions [for details about the experimental procedures and for a detailed presentation of results involving the SCL90-R and other instruments, see reference 25]. Baseline and post-intervention measures of disease activity, using the Systemic Lupus Erythematosus Disease Activity Index (SLEDAI) and the Systemic Lupus Activity Measure (SLAM-R)²⁹, were completed by a physician. The Systemic Lupus International

Collaborating Clinics/ACR damage index (SLICC/ACR)³⁰ was completed at baseline only.

Measures. The IIRS³¹ asks respondents to rate the extent to which their "illness and/or its treatment interfere" with each of 13 life domains relevant to quality of life. Ratings are made along a 7-point Likert scale, ranging from 1 = "not very much/not applicable" to 7 = "very much." Total scores can range from 13 (minimum intrusiveness) to 91 (maximum intrusiveness). Three subscales are formed from the 13 items to measure interference with (1) relationships and personal development (family relations, other social relations, self-expression/self-improvement, religious expression, community and civic involvements, passive recreation); (2) intimacy (marital relationship and sex life); and (3) instrumental life domains (work, finances, health, and active recreation)^{13,31}. Subscales are scored by calculating the mean rating across items. Thus, they can range from 1.0 to 7.0, with increasing values indicating higher levels of illness intrusiveness into a given life domain.

Disease activity was measured using the SLAM-R²⁹ and the SLEDAI^{29,32,33}. The SLAM-R is based on a physician's report of the patient's subjective symptoms and examination and laboratory assessment that includes a complete blood cell count, erythrocyte sedimentation rate, creatinine, and urinalysis. Scores may range from 0 (no disease activity) to 84 (maximum disease activity). The SLEDAI is also based on physician examination and laboratory assessment but uses a weighted index score, with each item marked as present or absent, and then multiplied by a factor representing the seriousness of the disease activity. Scores can range from 0 (no disease activity) to 105 (maximum disease activity).

SLE disease damage was measured using the SLICC/ACR damage index³⁰. The SLICC/ACR is a physician-rated index that assesses cumulative organ damage due to disease, complications of therapy, or intercurrent illness such as cancer. Total scores range from 0 (no damage) to 46 (maximum damage).

The SCL90-R is a 90-item self-report questionnaire that reflects psychological symptom patterns of psychiatric and medical patients experienced in the past week²⁶. It consists of 9 primary dimensions that can be combined to generate a global index of distress. The global severity index (GSI) reflects both the number and intensity of symptoms and is considered to be the best single indicator of psychological distress. Higher scores indicate greater psychological distress.

Data analyses. All statistical analyses were undertaken using Statistical Package for the Social Sciences (SPSS), version 10.0.7. Descriptive statistics including means, medians, and standard deviations were calculated for all variables collected during each assessment period. A Pearson correlation matrix was computed to examine bivariate correlations between the outcome variable (IIRS) and its subscales and each potential covariate (we examined education, age, marital status, household income, and disease activity as potential covariates). Household income and disease activity correlated significantly with illness intrusiveness and so they were retained as covariates.

A mixed analysis of covariance (ANCOVA) controlling for disease activity and household income was used to test our hypotheses about the differential benefit of group psychotherapy across life domains and over time. Group (Group Psychotherapy vs Control) was the between-groups factor. There were 2 within-groups factors: IIRS Life Domain (Relationships and Personal Development, Intimacy, and Instrumental) and Measurement Occasion (pretest, posttest, 6 month followup, and 12 month followup). Statistically significant interaction effects were plotted to facilitate interpretation. Because our hypotheses were specific and directional, we employed 1-tailed a priori planned contrasts to maximize statistical power.

Because disease activity was assessed by both the SLAM-R and SLEDAI, all analyses involving disease activity were repeated using each of these instruments. In all cases, the patterns of findings were identical in terms of direction and statistical significance. Although we report results using the SLAM-R, the same findings were evident when the SLEDAI was employed as the covariate.

RESULTS

Subjects. Subjects, all women, were predominantly middle class and Caucasian (84.2%), with an average age of 42.5 years (SD 10.83). At baseline, the mean time since diagnosis was 10.83 years (SD 8.67); the mean SLAM-R score was 7.4 (SD 3.38), indicating moderate disease activity³⁴; the mean SLICC/ACR score was 1.46 (SD 1.73). There were no significant differences between the group psychotherapy subjects and the controls. Table 1 provides descriptive statistics for the 2 experimental groups.

Illness intrusiveness in SLE. The fundamental premise of the illness intrusiveness theoretical framework was tested by examining 2 sets of correlations between measures taken at baseline: (1) those between disease characteristics (SLAM-R and SLEDAI) and illness intrusiveness, and (2) those between illness intrusiveness and emotional distress (SCL90-R GSI). Results were consistent with the framework. Increased illness intrusiveness (both total scores and individual subscales) correlated significantly with higher levels of disease activity as represented by both measures. When we controlled for disease activity, increased illness intrusiveness correlated significantly and uniquely with emotional distress. Table 2 presents these results.

Does group psychotherapy reduce illness intrusiveness? Statistically significant 3-way Group \times IIRS Life Domain \times Measurement Occasion interactions supported our hypothesis that group psychotherapy would reduce illness intrusiveness differentially across life domains. Group means are plotted in Figures 1 and 2, which illustrate the effects of the intervention, up to 12 months post-treatment, on the relationships and personal development (Figure 1) and intimacy (Figure 2) IIRS subscales. Subjects who received brief supportive-expressive group psychotherapy experienced significantly greater reductions in illness intrusiveness, overall ($F = 5.282$; $p = 0.012$), and this was accounted for primarily by the IIRS Intimacy ($F = 5.057$; $p = 0.013$) and Relationships and Personal Development subscales ($F = 2.34$; $p = 0.065$). Instrumental activities related to health, work, and finances were not significantly affected by the intervention.

DISCUSSION

Chronic disease introduces numerous stressors, adaptive challenges, and coping demands. Many people respond effectively and experience a high quality of life. In a number of cases, however, people experience difficulties and can suffer significant emotional distress. Illness intrusiveness represents one such stressor that threatens quality of life. In this study, illness intrusiveness was associated with increased disease activity and with elevated emotional distress, replicating previous observations in this population^{11,12}, and supporting the applicability of the theoretical framework for women with SLE.

In many cases, effective coping involves distracting

Table 1. Sample characteristics: demographics and disease at baseline.

Variable	Group Psychotherapy, n = 58	Control Group, n = 66
Age, yrs, mean (SD)	42.0 (11.2)	43.0 (10.4)
Education, yrs, mean (SD)	14.2 (2.6)	13.6 (3.1)
Income*	4.0 (2.0)	3.8 (1.8)
Caucasian, %	87.7	80.3
Married, %	35.1	48.5
SLAM-R, mean (SD)	7.4 (3.6)	7.3 (3.4)
SLEDAI, mean (SD)	7.4 (6.6)	6.3 (5.6)
SLICC/ACR/DI, mean (SD)	1.5 (1.6)	1.5 (1.8)
Disease duration, yrs, mean (SD)	11.4 (8.6)	10.5 (8.8)
Baseline prednisone,** mg	1270.7 (2347.2)	1630.5 (2312.4)

* Combined household income scale ranged from 1 to 6 (e.g., 3 = \$21,000–30,000; 4 = \$31,000–40,000).

** Baseline prednisone dose refers to cumulative dosage (mg) over preceding 6 months as reported by the patient.

Table 2. Correlations between illness intrusiveness and hypothesized correlates.

Variable	SLAM-R	SLEDAI	SCL90-R GSI†
IIRS total score	0.38***	0.30***	0.48*** (0.52***)
Subscales			
Relationships and personal development	0.32***	0.23**	0.52*** (0.55***)
Intimacy	0.23**	0.20*	0.27** (0.29***)
Instrumental	0.42***	0.33***	0.34*** (0.39***)

† Partial correlation coefficient controlling for SLAM-R (SLEDAI). * $p < 0.025$, ** $p < 0.01$, *** $p < 0.001$.

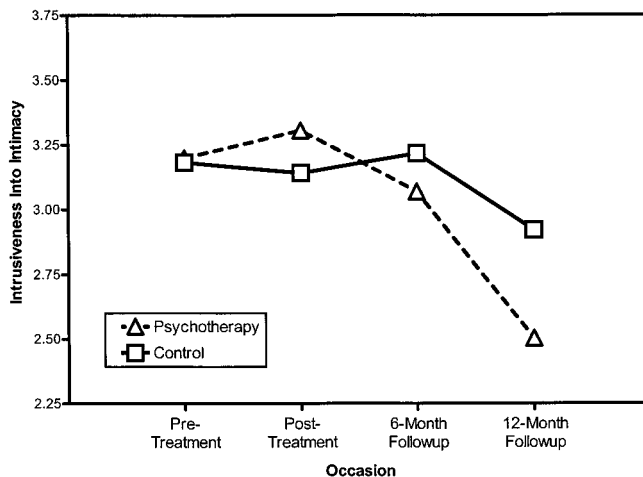


Figure 1. Group \times Illness Intrusiveness (Intimacy subscale) interaction effect. Illness intrusiveness into intimacy (marital relationship, sex life) decreased among women with SLE who received brief supportive-expressive group psychotherapy, but not among women with SLE who were randomly assigned to the control condition. Illness intrusiveness did not begin to diverge until 6 months after the conclusion of the therapeutic intervention.

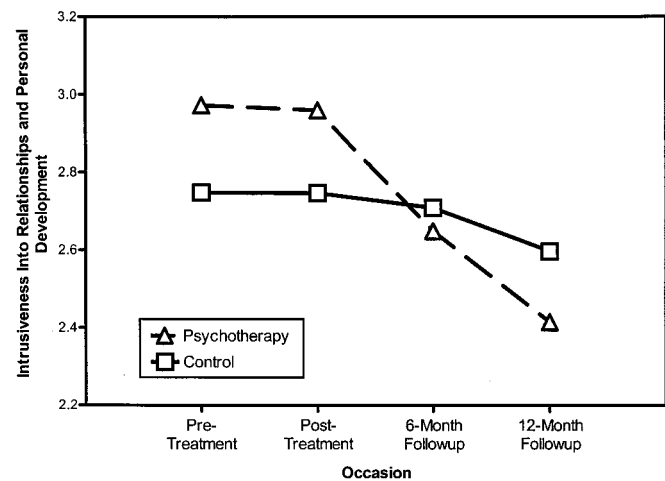


Figure 2. Group \times Illness Intrusiveness (Relationships and Personal Development subscale) interaction effect. Illness intrusiveness into relationships and personal development (family and other social relations, self-expression/self-improvement, religious expression, community and civic involvements, passive recreation) decreased from pretreatment to 12 month followup among women with SLE who participated in brief supportive-expressive group psychotherapy, compared to women randomly assigned to the control condition (who experienced no change in this variable throughout the study period).

oneself from psychosocial threats or other stressors in order to carry on with life. This can be adaptive when the problems cannot be controlled, corrected, or eliminated so that the most effective response is to focus on day-to-day challenges³⁶. Many people are able to do this for many years. Issues that were associated with significant psychological pain at an earlier point in the disease experience may thus decrease in salience. Although people may stop attending to these issues, their destructive effect may quickly be reactivated (e.g., when in good health, many people are insensitive to others affected by chronic disease but feel guilty when reminded of this after the onset of SLE). Such unresolved conflicts and concerns may threaten psychological well-being repeatedly over the years, especially when the person lacks the ability or resources to resolve them. Group psychotherapy may be especially helpful in relation to such stressors because it assists people in recognizing the issues and in resolving them effectively. Given that people may have learned to ignore or suppress formerly threatening thoughts and feelings, however, participation in group psychotherapy may initially be unpleasant if the process temporarily increases awareness of such issues rather than producing an immediately soothing effect³⁷.

Our findings were consistent with this understanding of the group psychotherapy process for women living with SLE. As observed in other chronic and life-threatening conditions^{38,39}, group psychotherapy benefits in the form of reduced illness intrusiveness did not begin to emerge until well after the termination of therapy and were not evident until the 6 month followup. Evidence that the observed benefits are valid can be taken from our observations that (1) the reductions were statistically significant by the 6 month followup, and (2) they continued to intensify, increasing in magnitude by the 12 month measurement occasion.

Consistent with our hypotheses, anchored in the stress-process literature, women with lupus who received brief supportive-expressive group psychotherapy experienced reduced illness intrusiveness in 2 particular domains — relationships and personal development and intimacy — but not in the instrumental life domain. This corroborates the position that women are especially responsive to stressors that arise in domains of life that involve relationships with others as compared to instrumental domains, such as work and finances^{16,40}. The key to effective psychological interventions, therefore, may depend on a careful matching of therapeutic targets (or processes) with the particular vulnerabilities among those affected by chronic disease⁴¹. Demonstration of effectiveness so achieved also depends upon the selection of measurement instruments that are sufficiently focused and sensitive as to record these directly and specifically⁴².

Some cautions are necessary in interpreting these findings. First, the magnitude of the results was not over-

whelming. This may be attributable to insufficient statistical power and/or to comparatively small effect sizes. It is important to remember that SLE is usually a progressive disease and that the ability of group psychotherapy to facilitate adaptation must be predicated on an effective medical regimen to control the disease process as much as possible. Although illness intrusiveness decreased following brief supportive-expressive group psychotherapy, these benefits did not extend to more global improvements in emotional distress²⁵. This issue merits further consideration. It may be that a longer incubation period is required before reductions in illness intrusiveness can produce subsequent reductions in emotional distress. Alternatively, the magnitude of improvements in illness intrusiveness may simply have been insufficient to produce corresponding improvements in emotional states. It is also possible that other stressors (e.g., uncertainty about the course of illness, stigma, others' lack of understanding about the disease and its disabling effects) exert a more powerful psychosocial influence than illness intrusiveness among women with SLE. Inasmuch as IIRS scores correlated significantly and uniquely with global distress and, in some cases, these were moderate in magnitude, further research is required to resolve this apparent contradiction. Finally, although a number of methodological strengths enhance our confidence in the validity of the results, it will be important to replicate them before one can be confident in their validity and generalizability. Given that clinical research cannot rule out all credible alternative hypotheses (e.g., it is not possible to randomly assign disease status), it remains for independent investigators to reproduce our findings.

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