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PAPER

Illness perceptions in patients with systemic lupus erythematosus and proliferative lupus nephritis

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This study investigated the illness perceptions of patients with systemic lupus erythematosus (SLE) and whether perceptions are influenced by type of treatment for proliferative lupus nephritis. In addition, the illness perceptions of SLE patients were compared with those of patients with other chronic illnesses. Thirty-two patients who had experienced at least one episode of proliferative lupus nephritis were included. Patients were treated with either a high or low-dose cyclophosphamide (CYC) regimen (National Institutes of Health [NIH] vs. Euro-Lupus protocol). Illness perceptions were measured with the Brief Illness Perception Questionnaire (B-IPQ) and a drawing assignment. The low-dose CYC group perceived their treatment as more helpful than the high-dose CYC group. In comparison with patients with asthma, SLE patients showed more negative illness perceptions on five of the eight illness perception domains. Drawings of the kidney provided additional information about perceptions of treatment effectiveness, kidney function and patients' understanding of their illness. Drawing characteristics showed associations with perceptions of consequences, identity, concern and personal control. These findings suggest that the type of treatment SLE patients with proliferative lupus nephritis receive may influence perceptions of treatment effectiveness. In addition, patients' drawings reveal perceptions of damage caused by lupus nephritis to the kidneys and the extent of relief provided by treatment. The finding that SLE is experienced as a more severe illness than other chronic illnesses supports the need to more frequently assess and aim to improve psychological functioning in SLE patients. *Lupus* (2011) **20**, 290–298.

Key words: drawing assignment; illness perceptions; proliferative lupus nephritis; systemic lupus erythematosus

Introduction

Systemic lupus erythematosus (SLE) is a severe chronic illness with major effects not only on patients' physical functioning but also on patients' psychological well-being. The importance of this latter effect is exemplified by the finding that health-related quality of life (HRQoL) tends to be lower in SLE patients than in patients with other chronic illnesses.¹ Despite the acknowledgement that SLE is a severe disease with substantial impact on the patients' life, few studies have assessed psychological functioning in SLE patients. The present study contributes to the need to map

out psychological functioning in SLE patients by assessing illness perceptions and their associations with socio-demographic and disease characteristics. In addition, the study investigated the effect of two different treatments for proliferative lupus nephritis on patients' illness perceptions.

Lupus nephritis is the most prevalent organ involvement in SLE. It affects up to 60% of patients² and results in a substantial increase in morbidity and mortality.³ Six different classes of lupus nephritis can be distinguished.⁴ Most importantly, a subdivision between proliferative and non-proliferative lupus nephritis can be made, which guides the choice of treatment regimen. At present, treatment for proliferative lupus nephritis in Leiden University Medical Center (LUMC) usually follows the Euro-Lupus protocol.⁵ Up to 2004, the older NIH regimen, which involved higher doses of cyclophosphamide (CYC), was the standard treatment.⁵ Because of the lower doses of CYC

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and substitution of a part of the CYC by mycophenolate mofetil (MMF), the Euro-Lupus protocol is thought to result in fewer toxic side effects.⁶ In addition, it would be expected that treatments with fewer side effects would form a lesser burden not only for physical health but also for psychological well-being.

There are many factors that influence the impact of illness on psychological and physical functioning, such as demographics, the condition itself, treatment and psychosocial factors.⁷ In the realm of psychosocial factors, illness perceptions play an important role. Leventhal's self-regulatory model proposes that patients are active problem-solvers who seek to make sense of illness and form mental representations that influence coping strategies.⁸ These mental representations of illness (or illness perceptions) are composed of cognitions about its identity (the name of the illness and its associated symptoms), its consequences, timeline, causes, personal control over the illness and the effectiveness of its treatment, as well as overall understanding. How individuals respond to illness is partly determined by these perceptions as well as their emotional responses.⁹

Although the role of illness perceptions in the impact of illness is broadly recognized, only five studies have looked at illness perceptions in patients with SLE.¹⁰⁻¹⁴ In addition, comparison of these studies is limited because of the use of solely qualitative measures, such as interviews, to assess perceptions. Another important limitation is that no study included male patients. Three studies used semi-structured interviews based on Leventhal's self-regulatory model.¹⁰⁻¹² The first study could not support a relationship between illness perceptions and disease characteristics, such as disease activity and disease duration.¹¹ The most important finding of the second study was that every patient holds unique illness perceptions,¹² which is also reported by two other studies.^{11,13} However, such a result could be expected in studies with small sample sizes and uncontrolled measures, like interviews, where the findings depend on what comes to mind at the time of assessment. The third study found that the illness perceptions of SLE patients are consistent with the self-regulatory model and that patients' perceptions change over time.¹⁰ The fourth study is the only study that used a validated and reliable questionnaire, i.e., the Illness Perception Questionnaire Revised (IPQ-R), to investigate whether a cognitive behaviour therapy (CBT) intervention would influence patients' illness perceptions.¹⁴ The results showed that CBT had indeed influenced patients' perceptions of

treatment control and the effect of SLE on their emotions. The fifth study used a relatively new way to measure patients' illness perceptions by asking patients to draw their disease and to provide comments on their drawings.¹³ The author states that drawings may not only make the individual experience more tangible and comprehensible, but may also enhance patients' feelings of understanding. However, these results were based on the author's interpretation only, and drawings were not analysed to derive scores or other quantitative measures. A more extensive use of drawings to assess illness perceptions has been applied with patients with other chronic illnesses. In these studies, quantitative analysis of drawings has allowed measurement of underlying perceptions in patients with heart disease and headache.¹⁵⁻¹⁹

The present study aimed to assess illness perceptions in SLE patients and to examine their associations with socio-demographic and disease characteristics. It was hypothesized that type of treatment for lupus nephritis (i.e., NIH or Euro-Lupus) would influence patients' illness perceptions and that the perceptions of SLE patients would be different from those of patients with other chronic illnesses. Specifically, we expected to find a beneficial effect of the Euro-Lupus treatment on illness perceptions and that SLE patients would perceive their illness as more negative than patients with other chronic illnesses.

Method

Participants

Patients were selected from the electronic patient registration at Leiden University Medical Center (LUMC). This study was coupled with one investigating the effect of two different treatments for proliferative lupus nephritis on HRQoL. Therefore, inclusion criteria were a previous diagnosis of proliferative lupus nephritis and a received treatment according to one of two protocols (i.e., either the NIH or Euro-Lupus regimen). Patients were approached by telephone and received an information letter if they showed interest in the study. Ten days after sending the information letter, patients were contacted again by telephone to determine their willingness to participate in the study.

Thirty-seven patients fulfilled the criteria and were approached to participate in the study. One patient refused to join the study without knowing the objective, two patients could not be contacted and two patients decided not to participate on

personal grounds. Hence, the final participant group consisted of 32 patients (86.5% participation rate), with 16 patients in each treatment group. One patient was excluded from the analysis of the Brief Illness Perception Questionnaire (B-IPQ) because this patient developed a chemotherapy-induced SLE and proliferative lupus nephritis, which completely resolved after completion of the chemotherapeutic treatment.

Materials

The Brief-Illness Perception Questionnaire (B-IPQ)²⁰ and patients' drawings of their kidneys were used to assess illness perceptions. The B-IPQ contains eight items to score on a scale from 0 to 10 and one open-ended question where the participants have to state the three most important causes for their disease. A mean score is calculated for every scale and the reported causes can be grouped into categories on the basis of common themes. The B-IPQ has been shown to be a valid and reliable measure to assess illness perceptions in ill populations, including patients with renal disease,²⁰ but no validation for patients with SLE has been done. The Dutch version of the B-IPQ has been used in several studies with varying chronic patient populations.^{21–24}

In the drawing assignment, participants were asked to make two drawings: (1) a drawing of their kidneys at the time of the diagnosis of lupus nephritis and (2) a drawing of their kidneys after the treatment for lupus nephritis. It was stressed that the drawing should represent what they thought their kidneys looked like. Participants were ensured that the assignment had no purpose of judging their drawing abilities according to the drawing instructions protocol.¹⁸

Besides assessment of illness perceptions, parameters of kidney function were retrieved from the electronic patient registration at LUMC to assess the effect of both treatments on renal outcome. The following parameters were recorded: proteinuria, serum creatinine, serum albumin and haematuria. These parameters were registered at the start of treatment, at 6 months' follow-up, and at the time of assessment.

Participants completed the B-IPQ and drawing assignment in a private room at LUMC in the presence of the principal investigator (GMND). Because this assessment was combined with another questionnaire-based study, time between completion of the first and second drawings could be extended to 20 to 30 minutes. So, patients started with the first drawing, continued with several questionnaires

including the B-IPQ, and finished with the second drawing. Prior to the assessment, participants provided informed consent. The study was approved by the Committee on Medical Ethics LUMC.

Design and Procedure

Data were analysed using SPSS Version 16.0 software. An alpha level of 0.05 was used for all statistical tests. Descriptive statistics and frequencies were obtained for the socio-demographic and disease characteristics and kidney function parameters. Independent *t*-tests were used to test differences in illness perceptions and measures of kidney function between the two treatment groups. Percent reductions in serum levels of proteinuria and creatinine and percent increases in serum albumin levels between the start of treatment and 6 months' follow-up were calculated and compared between the two groups with independent *t*-tests. One-sample *t*-tests were performed to compare the illness perceptions of patients with SLE with those of patients with asthma. Scores for the latter group were derived from the study of Broadbent *et al.* (2006).²⁰ Associations between illness perceptions and kidney function, and socio-demographic, disease and drawing characteristics, were examined with Pearson's *r* or Spearman's rho correlations.

The drawings were analysed by means of ImageJ software.²⁵ The drawings were analysed for the area of the kidneys, the way in which infection or damage was represented in the drawing, and the location in the kidney of the representation of infection or damage. Moreover, the drawings were rated for the patients' perceived efficacy of treatment and kidney function. Patients' perceived efficacy was assessed by comparing the drawing before treatment with the drawing after treatment. For instance, when the first drawing contained many dots to represent damage and the second drawing contained no dots, this was regarded as indicating a high perceived efficacy of treatment. Patients' perceived kidney function was assessed on the basis of the second drawing of the kidney after treatment. For instance, if the kidney in the second drawing contained no representations of damage, this was seen as demonstrating good perceived kidney function.

Results

Participants

The participant group consisted of 24 females and eight males. The majority of patients (62.5%) were

of Dutch origin. Patients in the NIH group began their treatment for proliferative lupus nephritis on average 8.6 (SD = 3.7) years ago, whereas the time since the start of treatment for patients in the Euro-Lupus group was on average 4.5 (SD = 0.82) years ago ($t = 4.30$, $df = 16.5$, $p = 0.001$). There were no other significant differences in socio-demographic or disease characteristics between the two treatment groups (see Table 1).

Table 2 shows kidney function parameters for the two treatment groups at the start of treatment, at 6 months' follow-up and at the time of assessment. At the start of treatment, patients from the NIH group showed higher levels of proteinuria ($t = 2.48$, $df = 21.4$, $p = 0.022$) and lower serum albumin levels ($t = -2.47$, $df = 25$, $p = 0.021$) than Euro-Lupus patients. Both groups showed good improvements at 6 months' follow-up and were comparable regarding all disease parameters. With regard to percent reductions or increases between start of treatment and 6 months' follow-up, only the percent increase in serum albumin was greater in the NIH group than in the Euro-Lupus group: 41.6% and 22.6%, respectively ($t = 2.07$, $df = 18$, $p = 0.053$). Patients in general showed stable disease at the time of assessment. Hence, even though patients from the NIH group showed

a worse protein loss at the start of treatment, renal outcome in general was comparable between both treatment groups.

Brief Illness Perception Questionnaire (B-IPQ)

Table 3 shows the mean scores on the eight B-IPQ items for the total patient group. Patients held the strongest perceptions about timeline and treatment control. Hence, they perceived their illness as chronic and experienced benefits from their treatment. The other illness perception scores clustered around the midrange of the items. Patients' perceptions about the most important cause for their SLE were grouped in five categories: stressful events (28.9%), no idea (20.0%), genetics (17.8%), immune system defaults (11.1%), environment (11.1%), and bad luck (11.1%).

The two treatment groups differed only in their perception of treatment control. Patients from the Euro-Lupus group thought that treatment had helped them more than patients from the NIH group ($t = -2.26$, $df = 29$, $p = 0.035$).

To investigate whether the illness perceptions of SLE patients differed from the perceptions of patients with another chronic illness, the scores of the total patient group were compared with scores

Table 1 Socio-demographic and disease characteristics for the NIH and Euro-Lupus group

	NIH ¹ (N = 16)	Euro-Lupus ² (N = 16)	Total (N = 32)
Percentage females	62.5%	87.5%	75.0%
Age, mean (SD)	36.8 (10.3)	33.8 (10.7)	35.3 (10.4)
Age at diagnosis of SLE, mean (SD)	25.2 (7.0)	25.3 (10.3)	25.3 (8.7)
Disease duration, mean (SD)	12.4 (4.9)	9.8 (4.8)	11.1 (5.0)
Years since start of treatment, mean (SD)	8.5 (3.7)	4.5 (0.82)**	6.5 (3.4)
Number of lupus nephritis episodes:			
First episode	11	9	20
Second or third episode	5	7	12
Ethnicity:			
Dutch	11 (34.4%)	10 (31.3%)	21 (65.6%)
Surinam	3 (9.4%)	4 (12.5%)	7 (21.9%)
Other	2 (6.3%)	2 (6.3%)	4 (12.5%)
Marital status:			
Living alone	7 (21.9%)	4 (12.5%)	11 (34.4%)
Married/cohabiting	9 (25.0%)	12 (34.4%)	21 (59.4%)
Higher education:			
Vocational	9 (28.1%)	10 (31.3%)	19 (59.4%)
University	3 (9.4%)	1 (3.1%)	4 (12.5%)
Work status:			
Student	1 (3.1%)	4 (12.5%)	5 (15.6%)
Employed	8 (25.0%)	7 (21.9%)	15 (46.8%)
Unemployed	7 (21.9%)	5 (15.6%)	12 (37.5%)

¹Treatment for proliferative lupus nephritis consisted of high-dose cyclophosphamide.

²Treatment for proliferative lupus nephritis consisted of low-dose cyclophosphamide and mycophenolate mofetil.

** $p < 0.01$.

Table 2 Kidney function parameters at the start of treatment, after 6 months, and at time of assessment

	NIH Mean (SD)	Euro-Lupus Mean (SD)	Reference ranges
Serum creatinine (µmol/l)			max. 106
Start of treatment (N = 32)	143.8 (97.5)	139.3 (133.0)	
After 6 months (N = 32)	117.1 (26.6)	97.9 (59.3)	
Assessment (N = 32)	108.4 (57.4)	85.6 (44.7)	
Proteinuria (g/24 h)			0–0.15
Start of treatment (N = 28)	4.7 (3.0)	2.6 (1.5)*	
After 6 months (N = 21)	1.1 (1.2)	1.0 (.91)	
Assessment (N = 17)	0.38 (0.50)	0.75 (1.4)	
Serum albumin (g/l)			40–50
Start of treatment (N = 28)	24.4 (6.3)	30.2 (6.5)*	
After 6 months (N = 24)	40.9 (6.1)	41.3 (3.8)	
Assessment (N = 16)	42.4 (7.1)	42.7 (3.7)	
Haematuria ^a			0
Start of treatment (N = 30)	4.0 (1.3)	3.6 (1.3)	
After 6 months (N = 22)	2.4 (2.0)	1.8 (1.4)	
Assessment (N = 27)	1.1 (1.6)	.79 (1.3)	

^aHaematuria was scored as follows: 1 = trace, 2 = few, 3 = several, 4 = many, 5 = full.

* $p < 0.05$.

of patients with asthma (scores were derived from Broadbent *et al.* (2006)).²⁰ This sample of asthma patients from the UK had a mean age of 39.8 (SD = 10.1) and 58.9% of patients were female. Table 3 shows that the illness perceptions of SLE patients were more negative on five of the eight items in comparison with asthma patients.

Associations between illness perceptions, kidney function and socio-demographic and disease characteristics

None of the kidney function parameters were associated with illness perceptions, but several socio-demographic and disease characteristics did show an association with illness perceptions. Patients' illness perceptions of emotion and identity showed a relationship with ethnicity and employment status, respectively. Emotional responses to SLE were higher for patients from Surinam than for patients of Dutch origin ($F = 4.40$, $df = 2$, $p = 0.021$). Patients who were unemployed or received sick benefit reported more symptoms than patients with a job or students ($t = 2.28$, $df = 24$, $p = 0.032$).

Two disease characteristics were associated with the illness perception concern. Patients with longer disease durations tended to be less concerned about their SLE ($r = -0.55$, $p = 0.001$). In addition, patients who had had two or more episodes of lupus nephritis were less concerned than patients with just one experienced episode ($t = 3.58$, $df = 29$, $p = 0.001$).

Table 3 Mean scores (SD) on the B-IPQ dimensions of SLE patients versus patients with asthma

Dimension	SLE (N = 31)	Asthma ¹ (N = 309)
Consequences ²	6.5 (2.3)	3.5 (2.3)***
Timeline	9.2 (1.8)	8.8 (2.2)
Personal control	5.6 (2.7)	6.7 (2.4)*
Treatment control	8.4 (1.6)	7.9 (2.0)
Identity ²	6.0 (2.6)	4.5 (2.3)**
Concern ²	5.8 (2.7)	4.6 (2.8)*
Understanding	6.8 (1.9)	6.5 (2.6)
Emotional response ²	5.8 (2.7)	3.3 (2.9)***

¹Values from Broadbent *et al.* (2006).

²Higher scores indicate more negative perceptions.

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

Drawing assignment

Thirty patients fulfilled the drawing assignment (see Figure 1 for examples of drawings from three patients). Twenty-one patients (70.0%) drew two kidneys and nine patients (30.0%) drew just one kidney. The area of the kidneys did not differ between the time of diagnosis and after treatment.

Twenty-two patients (73.3%) showed a clear difference between their drawings at diagnosis and after treatment. This difference could consist of 1) a change in the amount of damage that was drawn on the kidney, 2) a change in the distribution of this damage across the kidney, or 3) a change in the meaning of the drawn damage.

Amount of drawn damage

Sixteen patients (53.3%) used dots to represent damage to the kidney. The number of dots that were drawn at diagnosis was larger than the number drawn after treatment ($t = 3.66$, $df = 15$, $p = 0.002$). Six patients (20.0%) represented damage by colouring parts of the kidney. Of the second drawings of these patients, 83.3% showed less colouring. Seven patients (23.3%) left their kidneys blank both before and after treatment.

Distribution of damage

In some cases, another noticeable difference between two drawings was the position of the damage, which changed on seven occasions (31.8%). For instance, the first drawing showed dots globally distributed over the kidney and the second drawing located the dots in a circumscribed portion of the kidney (e.g., Figure 1B).

Meaning of the drawn damage

Fifteen patients (50.0%) wrote down the meaning of the depicted damage, which changed in four

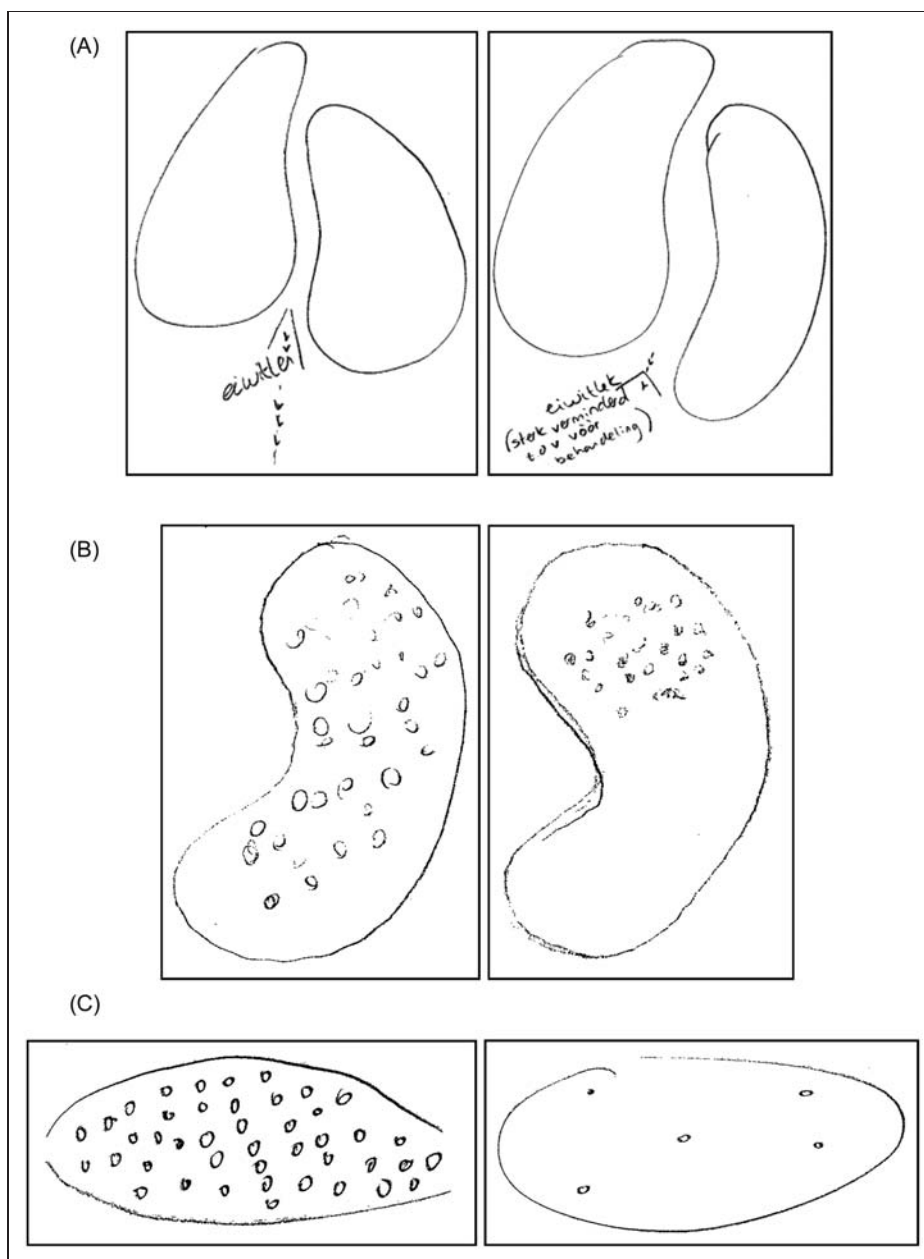


Figure 1 Drawings of three patients representing their kidneys at the start of treatment and after treatment. A. The word in the left drawing means ‘proteins’ and in the right drawing ‘proteins (highly decreased compared with before treatment)’.

instances (26.7%) in the second drawing. The most frequently mentioned representations were infection, protein leakage and holes.

Perceived efficacy of treatment

The sets of drawings were categorized into three groups based on the patients’ perceived efficacy of treatment. Group 1 was defined as ‘no change to kidneys’, group 2 as ‘kidneys better’ and group 3 as ‘kidneys much better’. For instance, a patient’s drawings were put into group 3 when the first drawing contained many dots to represent damage and

the second drawing contained no dots. According to this classification, eight patients (26.7%) believed that their kidneys had not improved after treatment, eleven patients (36.7%) thought that their kidneys were better, and another eleven patients (36.7%) depicted their kidneys as much better after treatment.

Perceived current kidney function

The after-treatment drawings were assessed for the patient’s depiction of the kidneys’ current function. Three groups were distinguished: 1) poor function,

2) moderate function, and 3) good function. For instance, a second drawing with many dots or coloring was categorized as group 1. Two patients (6.7%) viewed their kidney function as poor, 14 patients (46.7%) as moderate, and 14 patients (46.7%) as good.

Associations between drawing characteristics, illness perceptions, kidney function and socio-demographic and disease characteristics

None of the socio-demographic characteristics and kidney function measures were related to the drawing characteristics, but several drawing characteristics did show associations with illness perceptions and disease characteristics.

The illness perception identity was associated with the number of kidneys that were drawn. Patients who drew two kidneys experienced more physical symptoms than patients who drew just one kidney ($t = -3.12$, $df = 27$, $p = 0.004$).

Reporting the meaning of the drawn damage on the kidneys was associated with the illness perceptions concern and personal control. Patients who stated the meaning of the dots or colouring in their drawings tended to be more concerned than patients who did not explain their drawing ($t = 2.11$, $df = 27$, $p = 0.044$). In addition, patients who wrote down the meaning also experienced less control over their illness than patients who did not write down the meaning ($t = -2.38$, $df = 27$, $p = 0.025$).

There was also a relationship between reporting the meaning of damage and the number of experienced episodes of lupus nephritis. Within the group of patients who had experienced one episode of lupus nephritis, the majority (80%) stated the meaning of their drawings, whereas in the group of patients who had experienced two or more episodes only a minority (20%) explained what they had drawn [$\chi^2(1, N = 30) = 5.0$, $p = 0.025$].

Perceived efficacy of treatment was associated with the illness perceptions identity and consequences. Patients who depicted their kidneys as much better after treatment experienced fewer physical symptoms and a smaller influence of SLE on their lives than patients who depicted their kidneys as unchanged after treatment ($F = 7.50$, $df = 2$, $p = 0.003$; $F = 6.45$, $df = 2$, $p = 0.005$).

Discussion

The present study assessed illness perceptions in SLE patients and its associations with socio-demographic and disease characteristics. In addition,

the study investigated the influence of two different treatments for proliferative lupus nephritis on illness perceptions and differences in illness perceptions between SLE patients and patients with another chronic illness. Patients who were treated with the less aggressive Euro-Lupus regimen rated their treatment as more helpful than patients who had received the heavier NIH treatment. SLE patients perceived their illness more negatively than patients with asthma on most illness perception dimensions. Patients with longer disease duration and those who had experienced more than one episode of lupus nephritis reported lower concern about their condition. Patients' drawings of their kidneys provided additional information on patients' perceptions of damage to their kidneys due to lupus nephritis and the extent of improvement due to treatment.

The finding that the two treatment groups differed in their perception of treatment effectiveness is consistent with self-regulation theory. Self-regulation theory states that patients are active problem-solvers who form mental models about their treatment based on their experiences.⁸ That patients see the Euro-Lupus treatment as more effective suggests that this regimen may have more positive effects for patients.

The more negative illness perceptions of SLE patients compared with patients with another chronic illness may indicate that SLE is a more severe illness, which has been suggested previously.¹ This higher impact of SLE stresses the necessity to investigate patients' psychological functioning more fully and to develop methods to improve it when desirable.

The notion that illness perceptions are susceptible to change was demonstrated by an effect of time and illness experience on the extent to which patients were concerned about their SLE. The longer patients had lived with SLE and the more episodes of lupus nephritis they had experienced, the less concern they expressed. One of the previous studies on illness perceptions in SLE patients also found beneficial changes in illness perceptions over time.¹⁰ However, these changes were self-reported and no associations with socio-demographic or disease characteristics were investigated.

In addition to these naturally occurring changes, previous work has shown positive changes in the perceptions of identity, treatment control, and emotional representations after a single CBT intervention of 2 h.¹⁴ The study does show some important limitations (small sample size ($N = 22$), self-selection of treatment condition, and participant differences across conditions), which may

explain why the effects were rather small. However, the positive results suggest that it would be worthwhile to perform randomized controlled studies with larger samples and varying types of interventions.

Two previous semi-structured interview studies found that patients' illness perceptions often conflicted with medical information and recommendations.^{11,12} A comparable finding in the present study is that few patients named auto-immunity as an important causal mechanism of their SLE symptoms. Instead, the most frequently stated causal factors were related to experiencing stress. In addition, a considerable percentage of patients had no idea what played a role in the origin of their SLE symptoms. This finding does not really support the presence of perceptions that conflict with medical information, but rather a lack of adequate medical knowledge. Improving patients' understanding of the mechanisms of SLE may contribute to a better adjustment to living with their illness.

Few studies have used drawings as a research method for assessing illness perceptions.^{13,15-18} Among these studies is one that asked 38 SLE patients to draw their disease and comment on what they had drawn.¹³ The author recommends the use of drawings in clinical practice to improve clinicians' understanding of patients' psychological status. However, information from the drawings could not be extended beyond the individual patient and there were no attempts to investigate associations with other measures of illness perceptions or disease parameters. Previous work with cardiac patients has shown that drawing characteristics are associated with outcome measures.^{15,16,18} For instance, myocardial infarction patients who drew a larger amount of damage at discharge¹⁸ and a bigger heart at 3 months' follow-up¹⁵ showed a slower recovery and more heart-focused anxiety.

In the present study, all patients were surprised by the drawing assignment, and many patients showed some initial reluctance. Many patients reported that they had never thought about what their kidneys looked like and that they had never seen their kidneys. However, after a moment of reflection almost every patient successfully completed both drawings. Several patients who gave explanations for their drawings named protein leakage or some kind of filters that were leaking. Thus, some patients were aware of at least one of the most important clinical manifestations of lupus nephritis and could represent it in a drawing. The observation that the majority of patients (70%) drew less damage in their second drawing seems

to indicate that patients perceived an improvement in their kidney function because of treatment, but recovery was not complete or without damage. More detailed drawings and the inclusion of comments were associated with poorer perceptions, and these drawing features may indicate greater cognitive focus on the illness. Patients' drawings added important information to the questionnaire assessment, showing details about how patients understood the illness, their perceptions of its effects on the kidneys, and the effects of treatment, as well as their perception of how well their kidneys were currently functioning.

Although the influence of type of treatment on patients' illness perceptions was small, the possible effects on perceptions of treatment effectiveness may have important implications. For instance, patients are more likely to adhere to treatment that is perceived as effective. In addition, when aggressive treatments are necessary, any adjustment that can reduce the burden of treatment is worth considering.

The more positive illness perceptions reported by patients with longer disease duration and those who had experienced more episodes of lupus nephritis suggests that patients in the early phases of their SLE may especially benefit from interventions aimed at modifying patients' illness perceptions. A combination of questionnaire and visual-based assessment is likely to capture the broadest range of patients' perceptions.

Some limitations of the present study include the small sample size, the non-random allocation of patients to treatment groups, and the lack of ethnic diversity in the sample, which limits its power and generalizability. In addition, the study was cross-sectional, which limits its ability to draw conclusions about changes in perceptions over time. Finally, it should be mentioned that the sample of SLE patients was not matched for age and sex with the referent sample of asthma patients.

In conclusion, SLE may have a higher impact on patients' life than other chronic illnesses, and the level of impact may be influenced by type of treatment. Patients' drawings provide additional information on the physical and psychological burden of SLE.

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Conflict of interest

The authors have no conflict of interest.

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