

## Original article

# Prospective associations between illness perceptions and health outcomes in patients with systemic sclerosis and systemic lupus erythematosus: a cross-lagged analysis

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## Abstract

**Objective.** Perceptions of patients with SLE and SSc are strongly associated with physical and psychological outcomes. This interplay is not yet fully understood. Therefore, the aim of this study was to explore the prospective associations between illness perceptions and depressive symptoms, anxiety, perceived health status and disease activity in SLE and SSc patients.

**Methods.** Patients with SLE and SSc from a single-centre university hospital participated in a longitudinal study spanning 1 year. At both time points, participants completed the revised Illness Perception Questionnaire; Hospital Anxiety and Depression Scale for measuring depressive symptoms and anxiety; The EuroQol five-dimensions with 5 response levels for perceived health status; and disease activity was recorded. The directionality of the associations was investigated using cross-lagged path analysis.

**Results.** A total of 128 SLE and 113 SSc patients with a mean (s.d.) age of 46.28 (14.97) and 60.17 (10.82) years, respectively, and mean (s.d.) disease duration of 13.90 (9.31) and 8.48 (9.14) years, respectively, participated. In SLE, more depressive symptoms, more anxiety and worse perceived health status predicted a relative decrease in illness coherence 1 year later. More severe perceived consequences predicted a relative decrease in perceived health status. The perception of a more chronic time course predicted an increase in depressive symptoms. In SSc, reporting more depressive symptoms and more anxiety predicted a relative decrease in illness coherence. A good perceived health status and less reporting of depressive symptoms predicted a relative decrease in perceived consequences.

**Conclusion.** Evidence was obtained for reciprocal pathways between health outcomes and illness perceptions, although the predominant direction of effects was found to be from health outcomes to illness perceptions.

**Trial registration.** ClinicalTrials.gov, <http://clinicaltrials.gov>, NCT02655640.

**Key words:** illness perceptions, systemic lupus erythematosus, systemic sclerosis, cross-lagged analysis, health outcomes, longitudinal study

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### Key messages

- Health outcomes are determinants of illness perceptions in SLE and SSc.
- Perceived consequences and the perception of a long-lasting disease course in SLE predict depressive symptoms and perceived health status 1 year later.
- No prospective associations were found between disease activity and illness perceptions.

## Introduction

SLE and SSc are characterized by multiple organ involvement, a heterogeneous presentation and an unpredictable disease course, often leading to important morbidity and mortality [1, 2]. Both diseases affect more women than men, with a sex ratio for SLE of 9:1 and for SSc of 3:1. SSc is considered a rare disease (prevalence <1/5000) and has one of the highest mortality rates among all rheumatic diseases [3, 4]. Besides the organ involvement, SLE and SSc patients might experience difficulties with personal care, household chores, work and leisure activities owing to fatigue, dyspnoea and impairments in physical functioning [5–8]. In addition to physical impairments, patients might experience psychological consequences, such as depressive symptoms and anxiety. A recent meta-analysis stated that the prevalence estimate for SLE of major depression was 30%, and major anxiety occurred in 40% of the patients [9]. For SSc, this burden was also high, with 56% reporting major depression and 37% of SSc patients having anxiety disorders [10]. Physical and psychological impairment might influence patients' illness perceptions, which are the mental constructions patients develop about their illness.

Researchers found that illness perceptions in SLE and SSc are associated with physical and mental functioning and other health outcomes, such as sexual functioning, treatment adherence and depressive symptomatology [11–14], independently from disease-related characteristics or from the medical severity of the patients' condition. In the early 1980s, Leventhal and colleagues [15] conceptualized illness perceptions in the common sense model (CSM). The CSM shows that internal stimuli (e.g. symptom experience, such as pain) and external stimuli (e.g. disease-related information from family or health-care professionals) generate cognitive representations and emotional responses that guide the selection of coping procedures in order to eliminate and control potential or ongoing illness threats [16].

Research based on the CSM is mostly focused on illness perceptions predicting health outcomes, but the relation is most probably dynamic, which means that outcomes can possibly predict perceptions of patients. Thus, some of these health outcomes, such as anxiety and depression, perceived health or even disease activity as a more objective outcome, can potentially influence illness perceptions, but this is not fully established or investigated [17]. Clarity regarding the direction of associations is needed when designing interventions to

alter illness perceptions, because clinicians need to know how and where to intervene [18]. The available studies on illness perceptions and anxiety, depression and perceived health status in patients with SLE and SSc are scarce, and most of them are cross-sectional, except for one study [19] that describes correlations of illness perceptions with changes in psychological outcomes without information on the directionality of the associations. We assume, based on the CSM [15], that the predominant direction of effects goes from the illness perception dimensions to subjective outcomes (i.e. depressive symptoms, anxiety, perceived health status) and disease activity as an objective outcome. This hypothesis is based on previous literature in diabetes patients [20], which shows that illness perceptions precede the formation of depressive symptoms and stress over time. The aim of the present study was to explore the directionality of effects linking illness perceptions and health outcomes in SLE and SSc patients.

## Methods

### Design

The present study is a longitudinal observational cohort study of patients with SLE and SSc, in which all variables of interest were measured at two time points with an interval of 12 months. The data for time 1 were collected between November 2015 and February 2016, and the data for time 2 were collected between November 2016 and February 2017. This study has been registered in [clinicaltrials.gov](https://clinicaltrials.gov), NCT02655640.

### Study population

Patients were eligible for inclusion if their medical and cognitive condition allowed them to complete questionnaires; if they did not have severe psychiatric problems; and if they were proficient in Dutch and were able to complete the questionnaires in Dutch. Overall, 284 patients with SLE and SSc who were in follow-up in our centre fulfilled the inclusion criteria and were therefore invited for participation.

### Procedure

At both time points, we sent a letter with information about the purpose of the study, a questionnaire pack and an informed consent form together with a pre-stamped envelope to all eligible patients. They were asked to complete the questionnaires and the informed

consent form and return it within 2 weeks. In the event of non-response, reminders were sent after 3, 5 and 7 weeks. After 9 weeks, patients were contacted by telephone if they were persistent non-responders. As an incentive, patients who completed the questionnaires at both time points received a voucher of €20.

### Clinical data

Both disease duration and disease activity were measured. In SLE patients, disease activity was evaluated using the SLEDAI score with the Safety of Oestrogens in Lupus Erythematosus National Assessment modification (i.e. Safety of Oestrogens in Lupus Erythematosus National Assessment-SLEDAI) [21]. The SLEDAI is a valid and reliable index that measures disease activity over the past 10 days [22]. It includes 24 weighted objective clinical and laboratory variables. The SLEDAI scores can range from 0 to 105 and allows patients to be categorized as follows: no activity, SLEDAI = 0; mild activity, SLEDAI = 1–5; moderate activity, SLEDAI = 6–10; high activity, SLEDAI = 11–19; or very high activity, SLEDAI  $\geq$  20 [23].

In SSc patients, disease activity was measured using the SSc disease activity index (2003) [24]. This index consists of both self-reported data and clinical and laboratory measures of disease activity. It consists of 10 weighted measures, and the scores can range from 0 to 10. An index score  $\geq$  3 reflects SSc that is active.

### Illness perceptions

Patients' perceptions about their illness were measured with the Dutch version [25] of the revised Illness Perception Questionnaire developed by Moss-Morris *et al.* [26]. The Illness Perception Questionnaire is a self-report instrument, which consists of nine dimensions or subscales: an illness identity dimension, seven illness perception subscales and a causal attributions dimension. It is a widely applied instrument across several disease groups and has demonstrated good reliability and validity [27]. The items for all subscales are rated by the patient on a five-point Likert scale from 'strongly disagree' (1) to strongly agree (5). Scores were calculated as the sum of the items per scale. For the present study, we focused on four illness perception dimensions: the degree to which an illness was viewed as acute or chronic (timeline acute/chronic); the perceived seriousness of the condition (consequences); the extent to which a patient feels his/her own actions can control the disease (personal control); and a patient's overall illness comprehension (illness coherence). The choice for these four dimensions was made because of reasons of parsimony regarding the applied statistical technique and also based on previous findings from the literature, describing cross-lagged analyses between illness perceptions and outcomes [20, 28] and correlational analyses.

### Symptoms of anxiety and depression

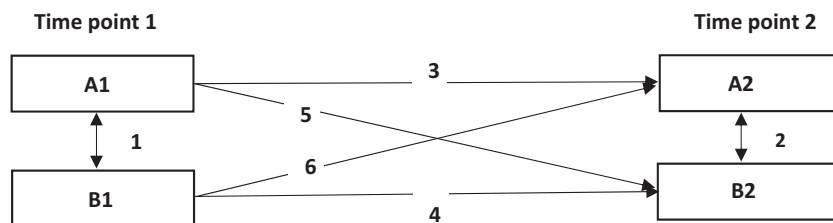
Anxiety and depression were assessed with the Hospital Anxiety and Depression Scale [29], a self-report questionnaire with seven items assessing anxiety and seven items assessing depressive symptomatology. The Hospital Anxiety and Depression Scale was chosen for use in this study because it is widely used, easily applied, avoids assessment of physical symptoms of depression, and has been validated in patients with rheumatic conditions and used in patients with SLE and SSc [9, 10, 30]. All items are scored on a four-point scale from 0 (not present) to 3 (considerable). The cut-off score for the diagnosis of probable depression/presence of depressive symptoms is a score of  $\geq$  8 on the depression subscale, and the cut-off score for the diagnosis of probable anxiety was also a score of  $\geq$  8 on the anxiety subscale. The higher the score, the greater the degree of depressive symptoms and anxiety.

### Perceived health status

Perceived health status was measured using the visual analog scale of the EuroQol five-dimensions with five response levels (EQ-5D-5L) [31–33]. This standardized, self-report questionnaire consists of two parts: a health profile based on a descriptive system that defines health in terms of five dimensions and self-rated health. For assessing perceived health status, we used the second part of the EQ-5D-5L, which measures the respondent's self-rated health on a visual analog scale (EQ-5D VAS), with a score ranging from 0 (worst imaginable health status) to 100 (best imaginable health state) on the day of completion.

### Statistical analysis

Cross-lagged analysis using structural equation modeling was conducted to examine prospective associations among illness perceptions and health outcomes (i.e. anxiety, depression, perceived health status and disease activity). A separate model was fitted for depressive symptoms, symptoms of anxiety, perceived health status and disease activity. In all four models, all within-time associations, stability paths and cross-lagged paths were estimated (except for the cross-lagged paths among the four illness perceptions). In addition, baseline age, gender and illness duration were controlled for by estimating paths to each construct in the model. Only the significant paths with these control variables were retained in order to make the estimated cross-lagged model more parsimonious. Cross-lagged paths are an indication of the predominant direction of effects over time but should not be interpreted as definite proof of causation. In Fig. 1, we describe a cross-lagged model in which variables A and B are measured at two time points, resulting in three types of relationships: within-time relationships (1 and 2); autoregressive or stability relationships (3 and 4); and cross-lagged relationships (5 and 6). The cross-lagged estimates can

**Fig. 1** Cross-lagged correlational model describing three types of relationships adapted from Anderson and Kida [34]

be interpreted as A1 predicting relative changes (i.e. relative increases or decreases) in B2 [34].

Maximum likelihood estimation with robust standard errors was used to take into account the non-normality of the data. To assess model fit, the following fit indices were used: the root mean square error of approximation (which should be  $<0.08$ ); the comparative fit index (which should be  $>0.90$ ); and the robust Satorra-Bentler scaled  $\chi^2$  statistic (which should be as small as possible) [35]. Data were analysed with Mplus version 7 (Muthén, L.K., Muthén, B.O., 2002. Mplus User's Guide, Los Angeles, CA). Missing data were dealt with using full information maximum likelihood.

#### Ethical approval

All patients gave their consent for participation in the study, and the Institutional Review Board of the University Hospitals Leuven provided ethics approval for this study (approval no. B322201526067).

## Results

### Sample characteristics

Out of the 284 eligible patients, 241 participated (113 SSc patients and 128 SLE patients) at time 1 (response rate = 84.86%). These patients were asked to participate at time 2, of whom 221 agreed (response rate = 91.70%). There was a drop-out rate of 8.3% between times 1 and 2. Table 1 describes the demographic, clinical characteristics and health outcomes of the SLE and SSc patients at time 1.

### Cross-lagged analysis between illness representations of SLE patients and health outcomes

In Fig. 2, all significant stability coefficients and cross-lagged paths for SLE are presented. The first cross-lagged model linking the four illness perceptions to anxiety (Fig. 2A) shows that high levels of anxiety predicted a relative decrease in illness coherence 1 year later. In the second cross-lagged model, described in Fig. 2B, the presence of depressive symptoms predicted a relative decrease in illness coherence 1 year later. Furthermore, a chronic perception of the time course at time 1 predicted a relative increase in depressive symptoms at time 2. The third cross-lagged model (see

Fig. 2C) shows that high levels of perceived health status at time 1 predicted a relative increase in illness coherence at time 2 and that stronger perceptions of severe consequences predicted a relative decrease in perceived health status 1 year later. Finally, in the last model (see Fig. 2D) no cross-lagged paths were found linking illness perceptions to disease activity. As shown in Fig. 2, all models provided a good fit to the data.

### Cross-lagged analysis between illness representations of SSc patients and health outcomes

In Fig. 3, all significant stability coefficients and cross-lagged paths for SSc are presented. The first cross-lagged model, presented in Fig. 3A, shows that high levels of anxiety predicted a relative decrease in illness coherence 1 year later. The second cross-lagged model, in Fig. 3B, shows that high levels of depressive symptoms at time 1 predicted a relative decrease in illness coherence and personal control ( $P < 0.10$ ) and a relative increase in perceived consequences at time 2. Figure 3C shows that high levels of perceived health status at time 1 predicted a relative increase in personal control ( $P < 0.10$ ) and a relative decrease in perceived consequences 1 year later. Stronger perceived consequences predicted a relative increase in disease activity ( $P < 0.10$ ) at time 2 (see Fig. 3D). As shown in Fig. 3, all models provided a good fit to the data.

## Discussion

This study was the first to explore the prospective associations among illness perceptions and health outcomes in patients with SLE and SSc. For both diseases, we found that the predominant direction of effects goes, in most cases, from depressive feelings, anxiety and perceived health status to the illness perception dimensions.

For SLE patients, we found that high levels of anxiety, experiencing depressive feelings and a low perceived health status predicted relative decreases in illness coherence 1 year later. No other illness perception dimensions were predicted by these outcomes. Illness coherence is the degree to which a person holds a coherent understanding of the illness; it is a metacognition that taps whether the illness 'makes sense' to the patient [17]. Our results indicate that when patients report more depressive feelings or perceive their health

**TABLE 1** Overview of patient characteristics at time point 1

Characteristic	SSc (n = 113)	SLE (n = 128)
Gender		
Women, n (%)	76 (67.3%)	123 (96.1%)
Age, mean (s.d.), years	60.17 (10.82)	46.28 (14.97)
Social status, n (%)		
Married	83 (73.5)	78 (60.9)
Cohabitation	3 (2.7)	23 (18.0)
Single	8 (7.1)	11 (8.6)
Divorced	12 (10.6)	9 (7.0)
Widow	7 (6.2)	5 (3.9)
Other	–	2 (1.6)
Living situation, n (%)		
Living alone	20 (17.7)	16 (12.5)
Cohabitation with partner and children	24 (21.2)	46 (35.9)
Cohabitation with partner	59 (52.2)	53 (41.4)
Cohabitation with children	4 (3.5)	6 (4.7)
Cohabitation with friends	3 (2.7)	7 (5.5)
Other	2 (1.8)	–
Education, n (%)		
Primary school	21 (18.6)	10 (7.8)
Secondary school	68 (60.2)	58 (45.3)
Bachelor's degree	17 (15.0)	41 (32.0)
Master's degree	7 (6.2)	18 (14.1)
Work status, n (%)		
Full time	14 (12.4)	33 (25.8)
Part time (because of illness)	7 (6.2)	13 (10.2)
Part time (personal choice)	3 (2.7)	16 (12.5)
Retired	49 (43.4)	20 (15.6)
Student	–	6 (4.7)
Unemployed	2 (1.8)	4 (3.1)
Disability benefit	18 (15.9)	24 (18.8)
Sickness benefit	8 (7.1)	2 (1.6)
Other	12 (10.6)	10 (7.8)
Disease duration, mean (s.d.), years	8.48 (9.14)	13.90 (9.31)
Disease activity, mean (s.d.)	1.51 (1.49)	3.40 (3.27)
Anxiety, mean (s.d.)	6.77 (3.54)	7.39 (4.07)
Depression, mean (s.d.)	5.59 (3.71)	4.89 (4.25)
Perceived health status, mean (s.d.)	63.63 (16.79)	68.32 (15.64)

status as worse, this may lead to a less coherent understanding of the disease. Broadbent and co-workers [36] mention that illness coherence can be seen as a summary of how the other perceptions fit together to provide a coherent model rather than being an independent illness perception *per se*. Thus, experiencing depressive symptoms may activate beliefs about the disease in general, which implies that patients can become insecure about their condition. A closer look at the illness perception dimensions shows that perceiving the illness as more chronic predicts depressive symptomatology and that more perceived consequences predicted a poorer perceived health status in the case of SLE. Cross-sectional literature about illness perceptions in SLE and depression also found that the more chronic

the perception of the disease, the more depressive symptoms. The finding that more severe consequences predicted worse perceived health status is in line with literature concerning other conditions [37] and in line with literature stating that the consequences dimension is often a major factor in explaining or predicting outcomes [18]. Patients also report this in daily practice. Patients who experience consequences at a social or financial level, for instance SSc patients who have lost work because of their condition or SLE patients who experience fatigue, have a more negative view of their condition [19, 37].

For SSc patients, significant and marginally significant associations were found between health outcomes and illness perceptions. Moreover, we found that high levels of anxiety and depressive symptomatology predicted relative decreases in illness coherence and increases in perceived consequences and personal control (marginally significant association), in the case of depressive symptomatology, 1 year later. A positively perceived health status also predicted less perceived consequences attributable to the disease. In SLE patients, we found that less perceived consequences predicted a better perceived health status.

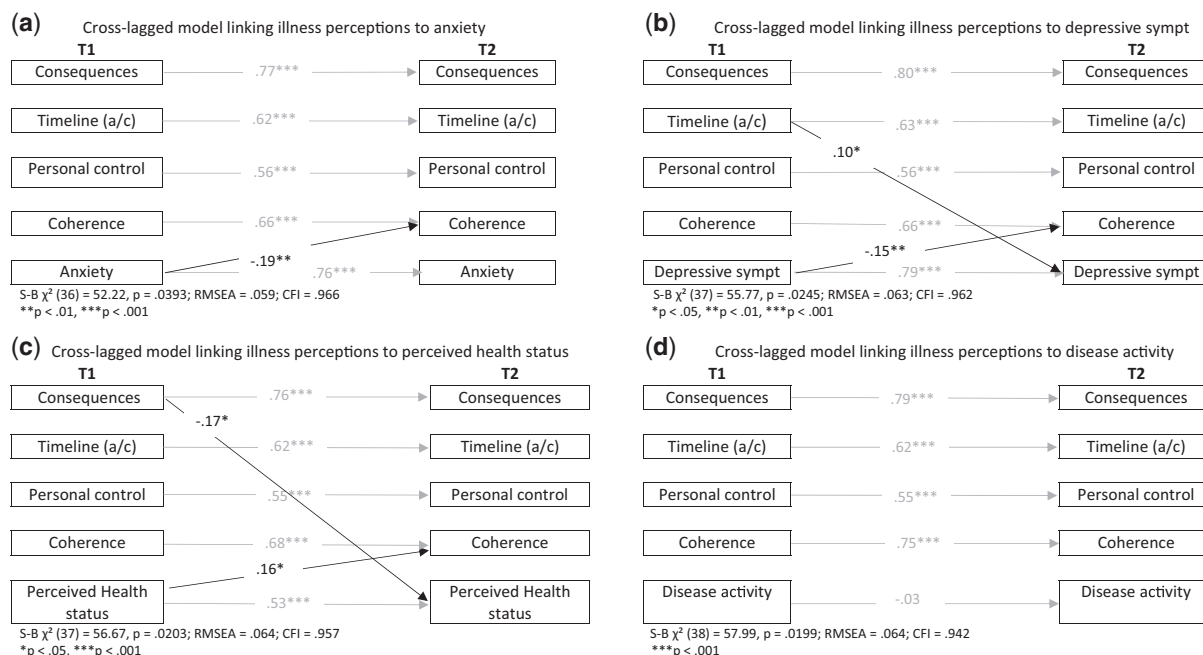
Probably, the explanation for this is that in SSc the skin involvement and damage is more visible and debilitating, which might explain why in SSc perceived health status precedes the formation of the consequences dimension [38].

A closer look at disease activity shows that in the SLE group disease activity levels were low and that no cross-lagged associations were found linking illness perceptions with disease activity. This is in line with an SLE study [19], published 20 years ago, and also with Hagger and Orbell [39], who state that illness perceptions are unrelated or weakly related to disease state. A possible reason is that disease activity is measured by the SLEDAI, an index which is based solely on more objective biochemical and clinical characteristics and no subjective patient reported characteristics or measurements. In SSc, the perceived consequences of the disease predicted the disease activity at a marginally significant level.

We found in SLE that outcomes predominantly predicted illness perceptions and that a relative decrease in perceived consequences predicted a relative increase in perceived health status and that a relative increase in timeline acute/chronic predicted a relative increase in depressive symptomatology. Our findings stress the importance of holistic care and imply that health-care professionals need to pay attention to their patients' perceptions, psychological well-being and perceived health status. Inaccurate perceptions can be tackled with specific counselling techniques, such as cognitive behavioural therapy. Before drawing up further practical implications, further research in this area is needed.

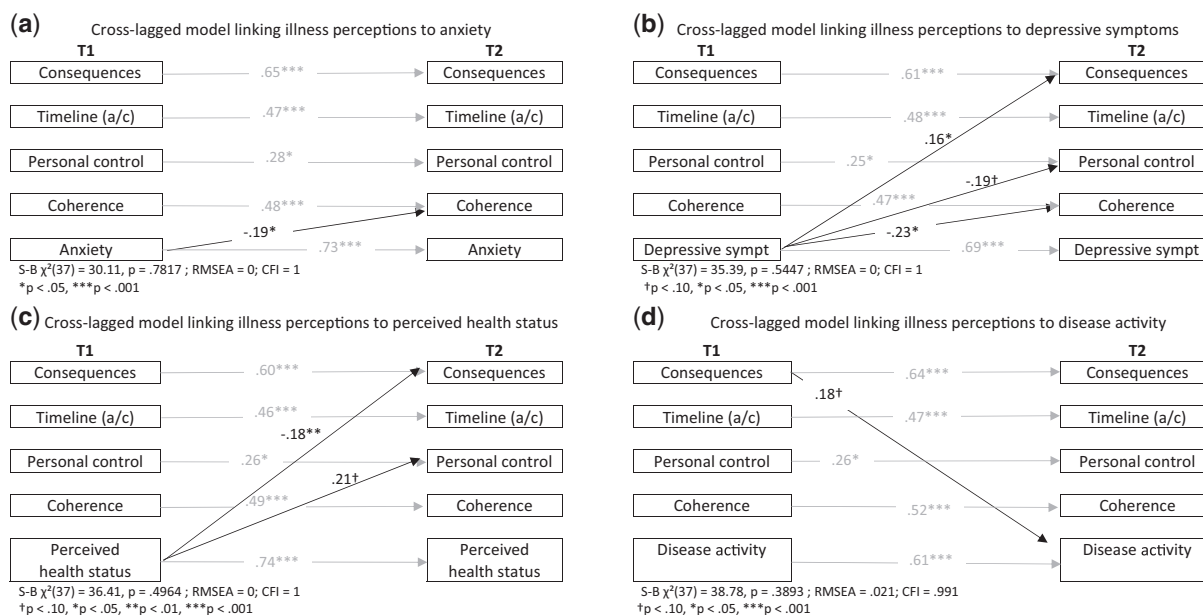
Some limitations need to be taken into account when interpreting the study results. Kline [35] described that for structural equation modelling a sample of 5–10 respondents per variable is needed, which was not feasible in the present study. We need to emphasize the

**Fig. 2** Overview of the cross-lagged path estimations between illness perceptions and health outcomes in SLE



**(A)** Cross-lagged model linking illness perceptions to anxiety. **(B)** Cross-lagged model linking illness perceptions to depressive symptoms. **(C)** Cross-lagged model linking illness perceptions to perceived health status. **(D)** Cross-lagged model linking illness perceptions to disease activity. Note that within-time correlations and paths of the control variables (age, sex and disease duration) are not presented for reasons of clarity. All path coefficients are standardized. Only significant stability and cross-lagged paths are demonstrated.

**Fig. 3** Overview of the cross-lagged path estimations between illness perceptions and health outcomes in SSC



**(A)** Cross-lagged model linking illness perceptions to anxiety. **(B)** Cross-lagged model linking illness perceptions to depressive symptoms. **(C)** Cross-lagged model linking illness perceptions to perceived health status. **(D)** Cross-lagged model linking illness perceptions to disease activity. Note that within-time correlations and paths of the control variables (age, sex and disease duration) are not presented for reasons of clarity. All path coefficients are standardized. Only significant stability and marginally significant cross-lagged paths are demonstrated.

relative rarity of these complex diseases and the exploratory nature of this study. Another limitation is the single-centre setting, which can reduce the generalizability of the findings to other settings.

This means that further research needs to be organized in a much larger sample size than in the present study. Given that SLE and SSc are rather less prevalent and rare diseases, we would recommend the organization and coordination of a multicentre study. Also, a cross-lagged analysis in an inception cohort or in patients with early SSc and SLE would give us more information about the evolution of illness perceptions and health outcomes over time. Cross-lagged designs in close proximity to first diagnosis would capture better the dynamic effects proposed in its original operationalization [40]. Further research also needs to include and assess coping procedures because, according to Hagger and Orbell [39], coping mediates the link between illness perceptions and outcomes. Further research needs to illuminate this, because maybe we can understand the results of the present study better when we understand the coping mechanisms within this relationship.

Despite these limitations and suggestions for future research, the present study has several strengths. Although this is a single-centre study, the number of patients per disease group is appropriate, because SSc and SLE have a rather low prevalence rate in Belgium and Europe compared with the USA and South Australia. Furthermore, these two diseases are examples of complex chronic diseases with an unpredictable course, which makes extrapolation to other chronic inflammatory conditions of autoimmune origin (such as SS, PM, etc.) possible. Another strength is that we had a very good response rate at both time points. At time point 2, only 8.3% of eligible patients did not participate. A possible reason for the high response rate was the incentives and personal reminders in order to reduce non-response.

In conclusion, we can state that for SLE and SSc, anxiety, depressive feelings and perceived health status predict illness perceptions. Also for SLE, perceived consequences and the perception of a chronic disease course predicted perceived health status and depression, respectively. The finding that health outcomes precede illness perceptions shows that self-regulation is dynamic, as described in the CSM.

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