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A better self-efficacy is predictive of better health-related quality of life (HRQoL) in patients with systemic lupus erythematosus: data from the Almenara Lupus Cohort

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ABSTRACT

Objective To determine the possible predictive value of self-efficacy on health-related quality of life (HRQoL) in patients with SLE.

Methods Patients with SLE from the Almenara Lupus Cohort were included. Self-efficacy was ascertained with the six domains from the Patient-Reported Outcomes Measurement Information System (PROMIS) self-efficacy for managing chronic conditions. For PROMIS domains, a score of 50 is the average for a clinical population (people with a chronic condition), a higher score indicates that the respondent has greater self-efficacy. HRQoL was ascertained with the physical and mental component summary (PCS and MCS) measures of the Short-Form 36 (SF-36). Generalised estimating equations were performed, using as outcome the PCS or MCS in the subsequent visit, and the self-efficacy domain in the previous visit; multivariable models were adjusted for possible confounders. The confounders were measured in the same visit as the self-efficacy domain.

Results Two-hundred and nine patients for a total of 564 visits were included; 194 (92.8%) patients were women and mean age at diagnosis was 36.4 (14.0) years. In the multivariable models, a better PCS was predicted by a better self-efficacy for managing symptoms, managing medications and treatments and managing social interactions and general self-efficacy; a better MCS was predicted by a better self-efficacy for managing daily activities, managing symptoms, managing medications and treatments and managing social interactions.

Conclusion A better self-efficacy is predictive of subsequent better HRQoL, even after adjustment for possible confounders. These results should encourage clinicians to develop strategies to improve self-efficacy in patients with SLE.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Health-related quality of life (HRQoL) has been associated with several sociodemographic factors, but its association with disease activity and damage is still controversial.

⇒ Self-efficacy is the individual's confidence in the ability to perform specific tasks.

WHAT THIS STUDY ADDS

⇒ A better self-efficacy was associated with a subsequent better HRQoL.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ This study reinforces the need to develop effective strategies that improve self-efficacy.

INTRODUCTION

Self-efficacy is the belief that one can carry out a behaviour necessary to reach a desired goal.[1] Additionally, for patients with chronic conditions, self-efficacy for managing them is defined as an individual's confidence in his/her ability to successfully perform specific tasks or behaviours related to one's health in a variety of situations.[2]

The National Institutes of Health (NIH) Patient-Reported Outcomes Measurement Information System (PROMIS) was constituted to develop and evaluate a set of publicly available, efficient and flexible measurements of patient-reported outcomes (PROs).[3] The PROMIS self-efficacy for managing chronic conditions includes five domains: self-efficacy for managing daily activities, self-efficacy for managing symptoms, self-efficacy for managing medications and treatments, self-efficacy for managing emotions and self-efficacy for managing social interactions.[4] Additionally, the PROMIS general self-efficacy

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was developed to measure global self-efficacy.[5] All domain measures of the PROMIS self-efficacy for managing chronic conditions's instrument had a Cronbach's α ranging from 0.90 to 0.95. All short forms correlated highly with the full item bank (r>0.90). All measures have demonstrated good item-total correlations (r>0.55 for the eight-item short forms).[4] The general PROMIS self-efficacy had a Cronbach's α of 0.88.[5] PROMIS self-efficacy for managing chronic conditions correlated with other related measures as physical function, fatigue, depression, anxiety, global mental health, global physical health, disease severity and disability.[4] The general PROMIS self-efficacy correlated with life orientation test, generalised expectancy for success scale, NIH toolbox self-efficacy item bank and PROMIS global physical and mental health.[5]

Health-related quality of life (HRQoL) is affected in patients with SLE, and it is influenced by the patient's age, poverty, educational level, behavioural issues, some clinical manifestations and comorbidities.[6] However, the association between HRQoL and disease activity or damage has not been consistently reported, suggesting that factors related to the patient could be more relevant than those related to the disease itself. One of these factors is self-efficacy, as it measures the patients' ability to perform specific tasks. In older adults, self-efficacy has been shown to be a mediator between frailty and HRQoL, suggesting that improvements on one will result in improvements on the other.[7] In neurological disorders, it has been shown that self-efficacy for managing chronic conditions is a better predictor of better mental health, global health and lower disability rates than either disease severity or diagnosis.[8] However, the impact of self-efficacy on HRQoL has been scarcely evaluated in SLE.

The aim of this study was to evaluate the impact of self-efficacy on HRQoL in our patients with SLE.

METHODS

The Almenara Lupus Cohort has been previously described.[9] In short, this cohort was started in 2012 at the Rheumatology Department of the Hospital Guillermo Almenara Irigoyen in Lima, Peru. Patients who signed the informed consent were recruited and followed every 6 months. Evaluations included an interview, medical records review, physical examination and laboratory tests. For these analyses, we have included those patients with at least two visits between October 2018 and February 2020.

SLE was defined using the 1997 revised American College of Rheumatology (ACR) criteria.[10] Demographic data included were gender, age at diagnosis, socioeconomic status according to the Graffar's method[11] and educational level, defined as years of formal education. Disease activity was ascertained using the Systemic Lupus Erythematosus Disease Activity Index 2000 (SLEDAI-2K).[11] Damage was ascertained with the Systemic Lupus International Collaborating Clinics/ACR Damage Index (SDI).[12] HRQoL was ascertained using the Short-Form 36 (SF-36).[13] The SF-36 includes two main components, physical and mental component summary (PCS and MCS) measures as well as the following eight domains (physical functioning, role physical, role emotional, fatigue, emotional health, social functioning, bodily pain and general health). Therapeutic variables included were current prednisone dose, antimalarials and immunosuppressive drugs use (including methotrexate, azathioprine, leflunomide, mycophenolate mofetil, calcineurin inhibitors, cyclophosphamide and rituximab); the later were recorded as current, past or never administered.

Self-efficacy was ascertained with the five domains of the PROMIS self-efficacy for managing chronic conditions: managing daily activities, managing symptoms, managing medications and treatments, managing emotions and managing social interactions[4] and the PROMIS general self-efficacy.[5] Self-efficacy for managing daily activities included the assessment of the subject's confidence in performing various activities of daily living without assistance; self-efficacy for managing symptoms included assessment of the subject's level of confidence to manage/control their symptoms, to manage their symptoms in different settings and to keep their symptoms from interfering with work, sleep, relationships or recreational activities; self-efficacy for managing medication and treatments included assessment of the subject's confidence in managing medication schedules of different complexity; self-efficacy for managing emotions included assessment of the subject's level of confidence to manage/control symptoms of anxiety, depression, helplessness, discouragement, frustration, disappointment and anger and self-efficacy for managing social interactions included assessment of the subject's confidence in participation in social activities and getting help when necessary.[4] Each of the five domains of the PROMIS self-efficacy for managing chronic conditions has eight items with raw scores ranging from 8 to 40 whereas PROMIS general self-efficacy has four items with a raw score ranging from 4 to 20. All raw scores are converted into T-scores metrics in which 50 is the average and 10 is the SD; for a clinical population (people with a chronic condition), a higher score indicates that the respondent has greater self-efficacy, for example, a score of 60 is 1 SD higher than the mean of the reference population.

The PROMIS self-efficacy measures were translated following the WHO Process of Translation and Adaptation of Instruments.[14] The forward translation was done by a bilingual rheumatologist, whose mother's tongue is Spanish. Then, these translations were evaluated by an expert panel including four bilingual rheumatologists to identify and resolve the translation's inadequate expressions/concepts. Then, the back-translation was done by a bilingual health professional whose mother's tongue is English and who had no prior knowledge of the questionnaire. Then, the draft was tested in 10 patients with SLE using face-to-face interviews to evaluate clarity and understanding.

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Cronbach's α for the PROMIS self-efficacy for managing chronic conditions were for managing daily activities 0.94, for managing symptoms 0.93, for managing medications and treatments 0.85, for managing emotions 0.95 and for managing social interactions 0.90 and for general PROMIS self-efficacy 0.94.

Statistical analyses

Categorical variables are reported as numbers and percentages, numerical variables as means and SD. The correlation between the self-efficacy's domains was evaluated using Spearman's rho. Due to the number of variables included in the multivariable model, at least 138 patients needed to be included for the analyses to be meaningful.[15]

Generalised estimating equations were performed, using as outcome the PCS or MCS in the subsequent visit to the one in which self-efficacy had been assessed; multivariable models were adjusted for possible confounders (age at diagnosis, gender, socioeconomic status, SLEDAI-2K, SDI, disease duration at baseline, prednisone daily dose, antimalarial and immunosuppressive drugs use and PCS or MCS in the previous visit). All the confounders were measured in the same visit than the self-efficacy domain.

As alternative analyses, each domain of the SF-36 was included as an outcome.

A $p<0.05$ was considered significant in all analyses. All analyses were performed using SPSS V.28.0 (IBM, Chicago, Illinois, USA).

RESULTS

Two-hundred and nine patients for a total of 564 visits were included, with a mean (SD) number of follow-up visits per patient of 1.7 (0.9); 194 (92.8%) patients were women, mean age at diagnosis was 36.4 (14.0) years and disease duration at baseline was 6.5 (6.0) years. Baseline characteristics are depicted in table 1. The correlations between self-efficacy's domains are shown in table 2.

In the multivariable models, a better self-efficacy for managing symptoms, for managing medication and treatment, for managing social interactions and general self-efficacy predicted a better PCS and self-efficacy for managing daily activities, for managing symptoms, for managing medications and treatment and for managing social interactions predicted a better MCS. These univariable and multivariable models are depicted in table 3.

In the alternative models, including each SF-36 domain as the outcome, bodily pain, role emotional and mental health were predicted by the five domains of self-efficacy for managing chronic conditions and the general self-efficacy; role physical was predicted by self-efficacy for managing daily activities, for managing symptoms, for managing medications and treatment, for managing social interactions and general self-efficacy; social functioning was predicted by self-efficacy for managing daily activities, for managing symptoms, for managing emotions, for managing social interactions and general

Table 1 Baseline characteristics of patients from the Almenara Lupus Cohort

Characteristics	N (%) or mean (SD)
Female gender	194 (92.8%)
Ethnicity	
Mestizo	204 (97.6%)
White	2 (1.0%)
Black	3 (1.4%)
Age at diagnosis, years	36.3 (14.0)
Disease duration, years	6.5 (6.0)
SLEDAI-2K	2.2 (3.2)
SDI	1.3 (1.5)
Prednisone daily dose, mg/day	3.2 (3.8)
Antimalarial use	
Never	11 (5.3%)
Past	48 (23.0%)
Current	150 (71.8%)
Immunosuppressive drug use	
Never	45 (21.5%)
Past	60 (28.7%)
Current	104 (49.8%)
SF-36	
PCS	52.0 (22.3)
MCS	53.9 (20.4)
Physical functioning	60.9 (26.4)
Role physical	42.6 (43.8)
Bodily pain	56.6 (25.4)
General health	47.0 (19.6)
Vitality	53.7 (18.1)
Social functioning	60.5 (24.1)
Role emotional	47.8 (42.7)
Mental health	60.7 (17.8)
PROMIS self-efficacy	
Self-efficacy for managing daily activities	45.5 (7.5)
Self-efficacy for managing symptoms	47.7 (8.2)
Self-efficacy for managing medications and treatments	43.9 (7.0)
Self-efficacy for managing emotions	44.6 (8.0)
Self-efficacy for managing social interactions	42.5 (7.9)
General self-efficacy	47.2 (10.4)

MCS, mental component summary; PCS, physical component summary; PROMIS, Patient-Reported Outcomes Measurement Information System; SDI, Systemic Lupus International Collaborating Clinics (SLICC)/American College of Rheumatology Damage Index; SF-36, Short-Form 36; SLEDAI-2K, Systemic Lupus Erythematosus Disease Activity Index 2K.

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Table 2 Correlation between PROMIS self-efficacy's domains

	Self-efficacy for managing daily activities	Self-efficacy for managing symptoms	Self-efficacy for managing medications and treatments	Self-efficacy for managing emotions	Self-efficacy for managing social interactions	General self-efficacy
	Rho (p value)	Rho (p value)	Rho (p value)	Rho (p value)	Rho (p value)	Rho (p value)
Self-efficacy for managing daily activities	X					
Self-efficacy for managing symptoms	0.702 (<0.001)	X				
Self-efficacy for managing medications and treatments	0.439 (<0.001)	0.573 (<0.001)	X			
Self-efficacy for managing emotions	0.617 (<0.001)	0.645 (<0.001)	0.435 (<0.001)	X		
Self-efficacy for managing social interactions	0.453 (<0.001)	0.648 (<0.001)	0.487 (<0.001)	0.544 (<0.001)	X	
General self-efficacy	0.753 (<0.001)	0.706 (<0.001	0.507 (<0.001)	0.734 (<0.001	0.506 (<0.001)	X

PROMIS, Patient-Reported Outcomes Measurement Information System.

self-efficacy; general health was predicted by self-efficacy for managing daily activities, for managing symptoms, for managing social interactions and general self-efficacy; physical functioning was predicted by self-efficacy for managing daily activities and for managing social interactions; finally, vitality was not predicted by any of the self-efficacy domains; these data are depicted in tables 4 and 5.

DISCUSSION

In this primarily Mestizo prevalent lupus cohort, a better self-efficacy was associated with a better HRQoL, independently of the other well-known risk factors for it.

We have included the five domains of the PROMIS self-efficacy and the PROMIS general self-efficacy which correlated with each other; however, it is important to point out that these domains evaluate different aspects of self-efficacy, and that probably explains the differences on their impact on HRQoL. For example, those domains related to physical activities were more influenced by self-efficacy domains associated with activities (managing daily activities or managing social interactions) than those associated with emotions or treatment. And for the MCS, it was influenced by all the components of PROMIS self-efficacy except for self-efficacy for managing emotions, and general self-efficacy; role emotional and mental health were influenced by all the components of PROMIS self-efficacy and the PROMIS general self-efficacy, whereas social functioning was influenced by all the components of PROMIS self-efficacy and the PROMIS general self-efficacy except for self-efficacy for managing medications and treatment. The lack of association between vitality and self-efficacy suggests that other factors could be impacting on vitality, like anxiety or depression. These results are consistent with previous reports that found different predictors for those domains related to physical activities and mental health.[6 16–18]

In a cross-sectional analysis of the Georgia Lupus Registry, which included 699 patients, symptoms self-efficacy was associated with lower fatigue and pain interference, but treatment self-efficacy did not remain associated in the multivariable model.[19]

In a longitudinal Italian study, which included 162 patients with SLE, a better self-efficacy predicted a better HRQoL measured with the lupus PRO (LupusPRO).[20] However, these authors used the self-efficacy for managing chronic disease six-items which is a global scale while we have used six domains for self-efficacy; furthermore, they used the global score of the LupusPRO whereas we used the main components and all domains of the SF-36. Our approach has more granularity and considers more domains which can have different predictors. This is important, as we are showing in this study that the association between self-efficacy and HRQoL varies across the domains for both outcomes.

In 30 African-American patients with SLE from the Medical University of South Carolina, the intervention 'Better Choices, Better Health' Chronic Disease Self-Management Programme was performed. This programme covers techniques to deal with problems such as frustration, fatigue, pain and isolation, appropriate exercise for maintaining and improving strength, flexibility and endurance, appropriate use of medications, communicating effectively with family, friends and health professionals, nutrition and how to evaluate new treatments. This programme improved self-efficacy as well as improved fatigue, depression, social/role activities limitations and health distress, suggesting these outcomes are inter-related, and potentially modifiable.[21] Similar results

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Table 3 Predictive value of PROMIS self-efficacy on HRQoL in patients from the Almenara Lupus Cohort

	PCS				MCS			
	Univariable model		Multivariable model		Univariable model		Multivariable model	
	B (SE)	P value	B (SE)	p value	B (SE)	P value	B (SE)	p value
Self-efficacy for managing daily activities	**1.59 (0.13)**	**<0.001**	0.22 (0.13)	0.091	**1.44 (0.13)**	**<0.001**	**0.39 (0.13)**	**0.002**
Self-efficacy for managing symptoms	**1.26 (0.14)**	**<0.001**	**0.25 (0.11)**	**0.021**	**1.19 (0.13)**	**<0.001**	**0.32 (0.12)**	**0.006**
Self-efficacy for managing medications and treatment*	**0.71 (0.17)**	**<0.001**	**0.20 (0.10)**	**0.046**	**0.65 (0.16)**	**<0.001**	**0.24 (0.10)**	**0.016**
Self-efficacy for managing emotions	**0.99 (0.16)**	**<0.001**	0.12 (0.11)	0.257	**1.05 (0.15)**	**<0.001**	0.17 (0.11)	0.161
Self-efficacy for managing social interactions	**0.77 (0.15)**	**<0.001**	**0.27 (0.09)**	**0.002**	**0.86 (0.14)**	**<0.001**	**0.37 (0.10)**	**<0.001**
General self-efficacy	**0.98 (0.11)**	**<0.001**	**0.18 (0.08)**	**0.037**	**0.92 (0.11)**	**<0.001**	0.20 (0.10)	0.051

Adjusted for age at diagnosis, gender, socioeconomic status, SLEDAI-2K, SLICC/American College of Rheumatology Damage Index, disease duration at baseline, prednisone daily dose, antimalarial and immunosuppressive drugs use and the PCS or MCS in the previous visit.
Values in bold are those that are statistically significant.
*One patient was excluded as she was not taking any medication during her follow-up.
HRQoL, health-related quality of life; MCS, mental component summary; PCS, physical component summary; PROMIS, Patient-Reported Outcomes Measurement Information System; SLEDAI-2K, Systemic Lupus Erythematosus Disease Activity Index 2K; SLICC, Systemic Lupus International Collaborating Clinics.

Table 4 Predictive value of PROMIS self-efficacy on HRQoL in patients from the Almenara Lupus Cohort

	Physical functioning		Role physical		Bodily pain		General health	
	B (SE)	p value	B (SE)	p value	B (SE)	p value	B (SE)	p value
Self-efficacy for managing daily activities	**0.34 (0.16)**	**0.036**	**0.84 (0.31)**	**0.007**	**0.51 (0.16)**	**0.001**	**0.47 (0.14)**	**0.001**
Self-efficacy for managing symptoms	0.26 (0.13)	0.053	**0.80 (0.27)**	**0.003**	**0.47 (0.14)**	**<0.001**	**0.32 (0.12)**	**0.006**
Self-efficacy for managing medications and treatment*	0.15 (0.14)	0.275	**0.71 (0.29)**	**0.015**	**0.28 (0.14)**	**0.045**	0.22 (0.12)	0.072
Self-efficacy for managing emotions	0.16 (0.11)	0.177	0.45 (0.28)	0.108	**0.38 (0.14)**	**0.008**	0.21 (0.11)	0.066
Self-efficacy for managing social interactions	**0.25 (0.11)**	**0.030**	**0.65 (0.26)**	**0.012**	**0.41 (0.14)**	**0.002**	**0.33 (0.10)**	**0.002**
General self-efficacy	0.18 (0.10)	0.081	**0.62 (0.21)**	**0.003**	**0.32 (0.11)**	**0.003**	**0.54 (0.06)**	**0.007**

Adjusted for age at diagnosis, gender, socioeconomic status, SLEDAI-2K, SLICC/American College of Rheumatology Damage Index, disease duration at baseline, prednisone daily dose, antimalarial and immunosuppressive drugs use and the same domain in the previous visit.
Values in bold are those that are statistically significant.
*One patient was excluded as she was not taking any medication during her follow-up.
HRQoL, health-related quality of life; PROMIS, Patient-Reported Outcomes Measurement Information System; SLEDAI-2K, Systemic Lupus Erythematosus Disease Activity Index 2K; SLICC, Systemic Lupus International Collaborating Clinics.

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Table 5 The predictive value of PROMIS self-efficacy on HRQoL in patients from the Almenara Lupus Cohort

	Vitality		Social functioning		Role emotional		Mental health	
	B (SE)	p value	B (SE)	p value	B (SE)	p value	B (SE)	p value
Self-efficacy for managing daily activities	0.14 (0.11)	0.204	**0.71 (0.15)**	**<0.001**	**1.26 (0.32)**	**<0.001**	**0.35 (0.10)**	**<0.001**
Self-efficacy for managing symptoms	0.12 (0.11)	0.286	**0.55 (0.14)**	**<0.001**	**0.91 (0.27)**	**<0.001**	**0.40 (0.09)**	**<0.001**
Self-efficacy for managing medications and treatment*	0.04 (0.10)	0.684	0.19 (0.14)	0.162	**0.82 (0.30)**	**0.006**	**0.27 (0.10)**	**0.004**
Self-efficacy for managing emotions	0.13 (0.10)	0.199	**0.55 (0.16)**	**<0.001**	**0.60 (0.28)**	**0.032**	**0.25 (0.10)**	**0.015**
Self-efficacy for managing social interactions	0.20 (0.12)	0.086	**0.53 (0.14)**	**<0.001**	**0.88 (0.27)**	**0.001**	**0.40 (0.11)**	**<0.001**
General self-efficacy	0.08 (0.08)	0.371	**0.39 (0.12)**	**0.001**	**0.68 (0.23)**	**0.003**	**0.24 (0.09)**	**0.006**

Adjusted for age at diagnosis, gender, socioeconomic status, SLEDAI-2K, SLICC/American College of Rheumatology Damage Index, disease duration at baseline, prednisone daily dose, antimalarial and immunosuppressive drugs use and the same domain in the previous visit.
Values in bold are those that are statistically significant.
*Only patients taking at least one medication were included in these analyses.
HRQoL, health-related quality of life; PROMIS, Patient-Reported Outcomes Measurement Information System; SLEDAI-2K, Systemic Lupus Erythematosus Disease Activity Index 2K; SLICC, Systemic Lupus International Collaborating Clinics.

were found by the same group when peer mentoring was proposed to improve self-management of the disease.[22]

Similarly, 23 Irish women with SLE received an educational programme including fatigue management, pain management, exercise, joint protection, stress management and nutrition to facilitate the application of self-management skills to promote behavioural changes. This programme was associated with an improvement on depression, and some domains of the LupusQoL (physical health, burden to others and fatigue), but not with the other domains.[23]

In Canada, a web-based programme increased self-efficacy, but not in the activation (which measures the individual's level of confidence, beliefs, knowledge and skills for managing one's health) of the patients,[24] reinforcing the idea that self-efficacy can be improved by educational programmes. The impact of this self-management programme was higher in those with a low activation level at baseline; however, the uptake and retained engagement with the programme was suboptimal, suggesting that external support or longer periods are required to engage patients in a more sustained manner.[24]

In a systematic review which included 11 studies of patients with rheumatoid arthritis, a better self-efficacy was associated with a better HRQoL, goal achievement, physical activity participation, problem-solving coping, acceptance of illness but also with lower pain intensity depressive symptoms and anxiety.[25] Similarly, in non-autoimmune diseases, like chronic obstructive pulmonary disease[26] or diabetes,[27] a better self-efficacy has been found to be associated with a better HRQoL. Taking together the data from our study and those from the literature, reinforce the relevance of including self-efficacy as a potential modifiable factor in chronic diseases like SLE.

Our study has some limitations; first, as this is a prevalent cohort, we cannot exclude the impact of disease characteristics before the baseline visit. Second, we cannot exclude the impact of other characteristics that could affect self-efficacy and/or HRQoL like social/family support, personal belief, among others. The main strength of this study is sample size. This is the largest study that evaluates longitudinally the association between self-efficacy and HRQoL in patients with SLE.

In conclusion, a better self-efficacy is predictive of a subsequent better HRQoL, even after adjusting for possible confounders. These results should encourage clinicians to develop strategies to improve self-efficacy in patients with SLE.

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Contributors All authors were involved in drafting or revising this article critically for important intellectual content, and all authors approved the final version to be published. MFU-G has full access to all of the data from the study and takes responsibility for their integrity and the accuracy of the analyses performed. MFU-G is the guarantor of the study.

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