

# Effect of Communicative and Critical Health Literacy on Trust in Physicians Among Patients With Systemic Lupus Erythematosus (SLE): The TRUMP2-SLE Project

Nao Oguro<sup>1</sup>, Nobuyuki Yajima<sup>2</sup>, Yoshia Miyawaki<sup>3</sup>, Ryusuke Yoshimi<sup>4</sup>, Yasuhiro Shimojima<sup>5</sup>, Ken-ei Sada<sup>6</sup>, Keigo Hayashi<sup>3</sup>, Kenta Shidahara<sup>3</sup>, Natsuki Sakurai<sup>4</sup>, Chiharu Hidekawa<sup>7</sup>, Dai Kishida<sup>5</sup>, Takanori Ichikawa<sup>5</sup>, Yuichi Ishikawa<sup>8</sup>, and Noriaki Kurita<sup>9</sup>

ABSTRACT. Objective. Patients who trust their physicians have been shown to demonstrate good medication adherence, self-management, and favorable disease outcomes. This study examines how trust in physicians is affected by functional health literacy (HL) and by broader concepts of HL, including communicative HL and critical HL, among patients with systemic lupus erythematosus (SLE).

*Methods.* This was a cross-sectional study using baseline data from the Trust Measurement for Physicians and Patients with SLE (TRUMP2-SLE) study, an ongoing multicenter cohort study conducted at 5 academic centers. The 14-item Functional, Communicative, and Critical Health Literacy Scale assessed the 3 dimensions of HL; each item of the scale was scored on a 4-point Likert scale, ranging from 1 to 4. Outcomes were trust in one's physician and trust in physicians in general using the 5-item Wake Forest Physician Trust Scale, which ranged from 0 to 100 points. General linear models were fit.

**Results.** A total of 362 patients with SLE were included. Trust in one's physician increased with higher functional and communicative HL (per 1-point increase: mean difference 3.39, 95% CI 0.39-6.39, and mean difference 5.88, 95% CI 2.04-9.71, respectively). Trust in physicians in general increased with higher communicative HL and decreased with higher critical HL (per 1-point increase: mean difference 7.09, 95% CI 2.34-11.83, and mean difference –6.88, 95% CI –11.72 to –2.04, respectively). Longer internet use was associated with both higher communicative and critical HL.

*Conclusion.* The findings suggest that rheumatologists need to improve their communication to match each patient's HL, which may foster trust and lead to improved self-management and outcomes in SLE. They also suggest that the formation of the rheumatologist-patient relationship may negate the effect of high critical HL in building trust.

Key Indexing Terms: communicative healthy literacy, critical health literacy, functional health literacy, physician trust, systemic lupus erythematosus

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<sup>1</sup>N. Oguro, MD, PhD, Division of Rheumatology, Department of Medicine, Showa University School of Medicine, Tokyo, and Department of Clinical Epidemiology, Graduate School of Medicine, Fukushima Medical University, Fukushima; <sup>2</sup>N. Yajima, MD, PhD, Division of Rheumatology, Department of Medicine, Showa University School of Medicine, Tokyo, Department of Healthcare Epidemiology, School of Public Health in the Graduate School of Medicine Kyoto University, Kyoto and Center for Innovative Research for Communities and Clinical Excellence, Fukushima Medical University, Fukushima; <sup>3</sup>Y. Miyawaki, MD, PhD, K. Hayashi, MD, PhD, K. Shidahara, MD, Department of Nephrology, Rheumatology, Endocrinology and Metabolism, Okayama University Graduate School of Medicine, Dentistry and Pharmaceutical Sciences, Okayama; <sup>4</sup>R. Yoshimi, MD, PhD, N. Sakurai, MD, Department of Stem Cell and Immune Regulation, Yokohama City University Graduate School of Medicine, Yokohama; 5Y. Shimojima, MD, PhD, D. Kishida, MD, PhD, T. Ichikawa, MD, PhD, Department of Medicine (Neurology and Rheumatology), Shinshu University School of Medicine, Matsumoto; 6K. Sada, MD, PhD, Department of Nephrology, Rheumatology, Endocrinology and

Metabolism, Okayama University Graduate School of Medicine, Dentistry and Pharmaceutical Sciences, Okayama, and Department of Clinical Epidemiology, Kochi Medical School, Kochi University, Nankoku; C. Hidekawa, MD, Center for Rheumatic Diseases, Yokohama City University Medical Center, Yokohama; Y. Ishikawa, MD, The First Department of Internal Medicine, School of Medicine, University of Occupational and Environmental Health, Kitakyushu; N. Kurita, MD, PhD, Department of Clinical Epidemiology, Graduate School of Medicine, Fukushima Medical University, and Department of Innovative Research and Education for Clinicians and Trainees (DiRECT), Fukushima Medical University Hospital, Fukishima, Japan.

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Address correspondence to Dr. N. Kurita, Department of Clinical Epidemiology, Graduate School of Medicine, Fukushima Medical University, 1 Hikarigaoka, Fukushima City, Fukushima 960-1295, Japan. Email: kuritanoriaki@gmail.com.

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Trust in one's physician among patients with systemic lupus erythematosus (SLE) constitutes the central component of the physician-patient encounter.<sup>1,2</sup> Further, it is essential for ensuring honest communication and confidence in decision making for continuation or change of life-long medication regimens or life events, such as birth control. Its importance can be supported by the theoretical pathway linking communication to outcomes,3 and it is underscored by the findings of high trust in the attending physician, maintenance of medication adherence, and continuity of care as demonstrated in primary care and SLE practice.<sup>4-6</sup> Trust is not only based on competence but also on compassion for the patient and confidentiality.1 Therefore, it is the key for facilitating the disclosure of a patient's values and goals for care. Few studies have examined the factors affecting trust in one's physician for chronic diseases, including SLE. Patient factors, such as economic status and misdiagnosis experience,7 as well as relational factors, such as the duration of the physician-patient relationship,7 are reported to be related to trust in one's physician. However, whether or not disease-specific factors, such as disease activity, are reported to be associated with trust in physicians in general<sup>2</sup> and with trust in one's physician has not been studied. In addition, how external factors, such as exposure to information sources and health literacy (HL), affect trust in one's physician among patients with SLE has not been fully examined.

HL is narrowly viewed as the ability to sufficiently apply basic skills, such as reading and writing, to health-related information and is referred to as functional literacy.8 A survey of the general population showed that higher functional HL was associated with greater trust in physicians.9 However, trust in one's physician was not examined, and broader and more advanced skills of HL were not assessed. Much attention has also been paid to communicative literacy—the ability to extract information and meaning from several communications and to apply information to changing situations—and critical literacy—the ability to critically analyze information and use it to gain better control over life events and situations.8,10 Patients with SLE have frequent access to the internet and blogs, 11 and patients with rheumatoid arthritis who gather online information have lower trust in their physicians.<sup>12</sup> Given both of these findings, investigating how advanced HL and exposure to information resources among patients with SLE affect trust in their physicians is valuable in building trust and creating dialogue to effectively navigate patients in choosing and maintaining appropriate treatment regimens.

Therefore, this study aimed to examine how a variety of HL factors influence trust in one's physician and trust in physicians in general, using data from the Trust Measurement for Physicians and Patients with SLE (TRUMP2-SLE) study of Japanese patients with SLE, in which patients and physicians were racially concordant. Analyzing the correlation of HL factors and trust in one's physicians and trust in physician in general in a physician-patient racial concordant setting is important because of concerns regarding the potential negative effect of racial discordance on perceived health outcome, <sup>13</sup> satisfaction for care, <sup>14</sup> and trust. <sup>15</sup>

#### **METHODS**

Study design and setting. This was a cross-sectional study using baseline data from the TRUMP2-SLE study, an ongoing multicenter cohort study conducted at 5 academic medical centers: Showa University Hospital, Okayama University Hospital, Shinshu University Hospital, Yokohama City University Hospital, and Yokohama City University Medical Center. This study followed the Declaration of Helsinki and Good Clinical Practice guidelines and was approved by the Ethics Review Board of Showa University (approval number: 22-002-A).

The inclusion criteria were as follows: (1) patients with SLE according to the revised 1997 American College of Rheumatology classification criteria, (2) aged  $\geq 20$  years, (3) receiving rheumatology care at the participating center, and (4) with the ability to respond to the questionnaire survey. Patients with dementia or total blindness were excluded from the study. All the rheumatologists treating these patients were Japanese.

Exposures. HL skills were measured using the original Japanese version of the Functional, Communicative, and Critical Health Literacy Scale (FCCHL) by Ishikawa et al.¹0 The FCCHL assesses a multidimensional construct that includes 14 items scored on a 4-point Likert scale. It captures 3 domains: functional HL (5 items), the ability to read or understand the instructions or leaflets from healthcare providers, hospitals, and pharmacies; communicative HL (5 items), the ability to extract and communicate health information with doctors or the family; and critical HL (4 items), the ability to critically analyze health information and use it to make decisions (Supplementary Table S1, available with the online version of this article). Patients were asked to score each item on a scale of 1 (not at all) to 4 (often). A mean score was calculated for each domain, ranging from 1 (low HL) to 4 (high HL). The FCCHL was validated and demonstrated to have good reliability (coefficient α values of 0.84, 0.77, and 0.65 for functional, communicative, and critical HL, respectively) and construct validity.¹0

Outcomes. The main outcomes were "trust in one's own physician" and "trust in physicians in general," which were measured using the Japanese version of the 5-item Wake Forest Physician Trust Scale (ie, the Interpersonal Trust in Physician scale and the Trust in Doctors Generally scale, respectively). 16,17 Each scale was composed of 5 items that were rated using a 5-point Likert scale. Patients were asked to choose 1 response for each item, ranging from "strongly disagree" (1 point) to "strongly agree" (5 points). After inverting the score for a negatively worded item, the sum of the scores was converted into a score on a scale ranging from 0 to 100. To inquire about trust in their rheumatologist, the following instructive statement was presented: "Please answer these questions keeping in mind the physician who has been regularly treating you for SLE. We will refer to that physician as 'your doctor.' For the next questions, we are interested in your honest opinion about your doctor. For each of these questions, please state whether you strongly agree, agree, are neutral, disagree, or strongly disagree." The coefficient  $\alpha$  values for the Japanese version of the Interpersonal Trust in Physician scale and the Trust in Doctors Generally scale were 0.85 and 0.88, respectively, and the scales demonstrated construct validity.<sup>16</sup>

Measurement of covariates. Based on the evidence in the literature, confounding variables were those suspected to determine both HL and trust in physicians. The variables included were age, 7.18 sex, 18 highest academic level achieved, 16 household income, 7 disease activity, duration of illness, depression, 19 and time spent on the internet. 12 Disease activity was measured by the attending physician using the Systemic Lupus Erythematosus Disease Activity Index 2000 (SLEDAI-2K). Depression was measured by a single item in the Japanese version of the LupusPRO survey: "During the past 4 weeks, how often did you feel because of your lupus that you were depressed?" The presence of depression was defined when "None of the time" was not chosen. 20 Time spent on the internet was measured by asking "How much time do you spend on the internet and social network services in a day, not including time for work?" where respondents were asked to choose from 6 options, ranging from "never" to "more than 4 hours." In the analysis step, the responses were merged into the following categories based

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on the distribution of the responses: "not at all," "less than 1 hour," "1 hour to less than 2 hours," and "2 hours or more." The questionnaire was administered at each facility between June 2020 and August 2021. The patients could complete it either in the waiting room or at home. The questionnaire included assurances that the attending physician would not view the responses and that the responses would only be used at the central facility for aggregation.

Statistical analysis. All statistical analyses were performed using Stata/SE (version 16.1; StataCorp). Patient characteristics were described as frequencies and proportions for categorical variables and means and SDs for continuous variables.

The associations between the above-mentioned 8 patient characteristics and each of the 3 domains of the FCCHL were analyzed using general linear models

Next, the associations between the FCCHL and trust in one's physician and trust in physicians in general were analyzed using general linear models. The 8 patient characteristics described above were included in the multivariate analyses as covariates. Missing covariates were addressed using a multiple completion approach. A total of 20 imputations were performed by multiple imputations with chained equations, assuming that the analyzed data were missing at random. Statistical significance was set at P < 0.05.

Patient and public involvement. Neither the general public nor patients with SLE were involved in the planning, recruitment, or conduct of this study.

#### **RESULTS**

Study flow. Initially, 386 patients with SLE who met the inclusion criteria were identified. Of these, 24 patients without an FCCHL score, trust in one's physician score, or trust in physicians in general score were excluded. Overall, 362 patients were included in the analysis.

Patient characteristics. Patient characteristics in the primary analysis are presented in Table 1. The participants' mean age was 45.7 (SD 13.8) years, and 319 (88.1%) of them were women. The mean disease activity as determined by the SLEDAI-2K scale was 5.2 (SD 4.8) points. Among HL domains (exposures), functional HL scores tended to be higher (mean 3.5, SD 0.6), followed by communicative HL (mean 3.0, SD 0.7) and critical HL (mean 2.7, SD 0.6). The mean score of trust in one's physician (outcome; mean 78.9, SD 16.4) was higher than that of trust in physicians in general (outcome; mean 64.2, SD 20.3).

Patient characteristics associated with HL. Table 2 shows the association between each domain of the FCCHL and patient characteristics. Functional HL was inversely associated with older age (per 10-year increase: mean difference -0.08, 95% CI -0.14 to -0.03) and depressive symptoms (mean difference -0.28, 95% CI -0.46 to -0.1). Functional HL was positively associated with higher education levels (junior high school or lower and high school/college: mean difference 0.40, 95% CI 0.10-0.69; and university/graduate school: mean difference 0.45, 95% CI 0.14-0.76) and disease duration (< 5 yrs and  $\geq$  5 yrs but < 10 years: mean difference 0.22, 95% CI 0.02-041). Both communicative and critical HL were positively associated with longer internet usage (communicative HL vs none: < 1 hour, mean difference 0.37, 95% CI 0.13-0.61; 1 hour to < 2 hours: mean difference 0.56, 95% CI 0.3-0.82; ≥ 2 hours: mean difference 0.64, 95% CI 0.36-0.91; critical HL vs none: < 1 hour, mean difference 0.33, 95% CI 0.09-0.57; 1 hour to < 2 hours, mean difference 0.6, 95% CI 0.35-0.86; > 2 hours, mean difference 0.64, 95% CI 0.37-0.91).

Table 1. Patient characteristics.

	Total, $N = 362$
Demographics	
Age, yrs, mean (SD)	45.7 (13.8)
Women	319 (88.1)
Education (n = 340)	
Junior high school or lower	17 (5)
High school/college	243 (71.5)
University/graduate school	80 (23.5)
Missing, n	22
Household income, ¥ (n = 298)	
< 1,000,000	27 (9.1)
1,000,000 to < 5,000,000	133 (44.6)
5,000,000 to < 10,000,000	118 (39.6)
≥ 10,000,000	20 (6.7)
Missing, n	64
Disease duration, yrs (n = 349)	
< 5	63 (18.1)
5 to < 10	74 (21.2)
10 to < 20	125 (35.8)
≥ 20	87 (24.9)
Missing, n	13
SLEDAI-2K, mean (SD)	5.2 (4.8)
Depression <sup>a</sup> (n = 293)	
Depressive symptoms	53 (18.1)
Missing, n	69
Duration of internet use, $h(n = 361)$	
0	49 (13.6)
< 1	124 (34.4)
1 to < 2	88 (24.4)
≥ 2	100 (27.7)
Missing, n	1
Health literacy <sup>b</sup> , mean (SD)	
Functional health literacy	3.5 (0.6)
Communicative health literacy	3.0 (0.7)
Critical health literacy	2.7 (0.6)
Trust in physician <sup>c</sup> , mean (SD)	
Trust in one's physician	78.9 (16.4)
Trust in physicians in general	64.2 (20.3)

Data are in n (%) unless otherwise indicated. <sup>a</sup> Depression was measured by a single item in the Japanese version of the LupusPRO survey. <sup>b</sup> Health literacy skills were measured using the original Japanese version of the Functional, Communicative, and Critical Health Literacy Scale; items are scored on a 4-point Likert scale, ranging from 1 ("not at all") to 4 ("often"). <sup>c</sup> Trust was measured using the 5-item Wake Forest Physician Trust Scale; items are scored on a 5-point Likert scale, ranging from "strongly disagree" (1 point) to "strongly agree" (5 points); total points ranged from 0 to 100. SLEDAI-2K: Systemic Lupus Erythematosus Disease Activity Index 2000.

Association between HL and trust in physicians. Table 3 shows the association between HL status and trust in the attending rheumatologist. Trust in one's physician increased with higher functional and communicative HL (per 1-point increase: mean difference 3.39, 95% CI 0.39-6.39, and mean difference 5.88, 95% CI 2.04-9.71, respectively). Disease activity, measured using the SLEDAI-2K, was also positively associated with higher trust in one's physician (per 1-point increase: mean difference 0.52, 95% CI 0.16-0.88). The association between internet use and trust in one's physician was not statistically significant.

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	Functional HL		Communicative HL		Critical HL	
	Mean difference, point estimate (95% CI)	P	Mean difference, point estimate (95% CI)	P	Mean difference, point estimate (95% CI)	P
Age, per 10-yr increase	-0.08 (-0.14 to -0.03)	0.004	0.04 (-0.02 to 0.11)	0.17	0.02 (-0.05 to 0.08)	0.62
Women vs men	0.04 (-0.15 to 0.23)	0.67	0.1 (-0.11 to 0.31)	0.35	-0.03 (-0.24 to 0.18)	0.78
Education						
Junior high school or lower	Ref		Ref		Ref	
High school/college	0.40 (0.10 to 0.69)	0.008	-0.06 (-0.37 to 0.25)	0.72	0.03 (-0.28 to 0.33)	0.87
University/graduate school	0.45 (0.14 to 0.76)	0.005	-0.16 (-0.49 to 0.18)	0.36	-0.07 (-0.4 to 0.26)	0.68
Household income, ¥						
< 1,000,000	Ref		Ref		Ref	
1,000,000 to < 5,000,000	-0.02 (-0.25 to 0.21)	0.86	-0.1 (-0.37 to 0.17)	0.45	-0.05 (-0.33 to 0.23)	0.74
5,000,000 to < 10,000,000	0.04 (-0.20 to 0.28)	0.73	0.06 (-0.22 to 0.34)	0.66	0.01 (-0.27 to 0.29)	0.93
≥ 10,000,000	0.14 (-0.19 to 0.48)	0.40	0.06 (-0.34 to 0.45)	0.77	0.04 (-0.36 to 0.43)	0.85
Disease duration, yrs						
< 5	Ref		Ref		Ref	
5 to < 10	0.22 (0.02 to 0.41)	0.03	0.14 (-0.07 to 0.36)	0.20	0.12 (-0.09 to 0.33)	0.26
10 to < 20	0.15 (-0.03 to 0.33)	0.10	0.14 (-0.06 to 0.33)	0.18	0.16 (-0.03 to 0.35)	0.10
≥ 20	0.06 (-0.14 to 0.26)	0.54	0.03 (-0.19 to 0.25)	0.76	0.1 (-0.11 to 0.32)	0.34
SLEDAI-2K, per 1-point						
increase	-0.00 (-0.02  to  0.01)	0.47	0 (-0.01 to 0.01)	0.96	0 (-0.01  to  0.02)	0.70
Depressive symptoms	-0.28 (-0.46 to -0.10)	0.002	0.01 (-0.19 to 0.2)	0.95	0.06 (-0.15 to 0.26)	0.58
Duration of internet use, h						
0	Ref		Ref		Ref	
< 1	0.01 (-0.20 to 0.22)	0.94	0.37 (0.13 to 0.61)	0.002	0.33 (0.09 to 0.57)	0.006
1 to < 2	0.03 (-0.20 to 0.26)	0.83	0.56 (0.3 to 0.82)	< 0.001	0.6 (0.35 to 0.86)	< 0.001
≥ 2	0.02 (-0.23 to 0.26)	0.89	0.64 (0.36 to 0.91)	< 0.001	0.64 (0.37 to 0.91)	< 0.001

Values in bold are statistically significant. For each HL domain score, general linear models were fitted with the inclusion of all the variables listed above. HL: health literacy; SLEDAI-2K: Systemic Lupus Erythematosus Disease Activity Index 2000.

Table 4 shows the association between HL status and trust in physicians in general. Trust in physicians in general increased with higher communicative HL but decreased with higher critical HL (per 1-point increase: mean difference 7.09, 95% CI 2.34-11.83, and mean difference −6.88, 95% CI −11.72 to −2.04, respectively). We found that women had less trust in physicians in general than did men (mean difference −8.41, 95% CI −15.00 to −1.81). Further, longer internet use was associated with less trust in physicians in general (vs none; 1 to < 2 hours: mean difference −9.26, 95% CI −17.5 to −0.98, and ≥ 2 hours: mean difference −9.97, 95% CI −18.8 to −1.16).

### **DISCUSSION**

This study aimed to clarify the association between the broader concept of HL (ie, communicative and critical HL), which requires active attitudes to obtain, understand, analyze, and use health information, and trust in one's physicians and physicians in general among patients with SLE. Trust in one's own physician (ie, rheumatologist) was significantly associated with high functional and communicative HL. Trust in physicians in general was associated with higher communicative HL but was inversely associated with critical HL. Despite the recent increase in the importance of examining the effect of HL on the physician-patient relationship in patients with SLE, <sup>21</sup> this study was the first to analyze these associations in this specific population.

Notably, this study showed that functional HL was associated with trust in one's own rheumatologist. A previous study in Taiwan also found that functional HL was associated with trust in doctors.9 In that study, trust in one's physician was not examined; however, given that the study participants were from the general population, they did not necessarily have a disease and, therefore, did not have their own physician. Lack of functional HL in patients with SLE may lead to misunderstanding of health information and a loss of trust through conflicts between physicians' recommendations for appropriate treatment and management, and patients' unrealistic expectations of incorrect management practices.9 For example, before the summer, a patient may take a lower dose of steroids than that prescribed because they may be concerned about adverse effects, such as changes in appearance, which could affect their willingness to go to the beach.<sup>22,23</sup> Acting on this belief may cause the disease to flare up, which may compromise mutual trust if this patient's behavior is not confirmed at the earliest clinical encounter.

Further, we found that the association between higher communicative HL and higher trust in one's physician was independent of education level and functional HL. The present findings reinforce the importance of modes of patient-physician dialogue in fostering trust and, in particular, confirmed the theory by Street et al<sup>3</sup> that effective patient communication skills foster trust through the perception of the physician's viewpoint

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Table 3. Association of trust in patients' rheumatologists with health literacy and covariates (N = 362).

	Cohen d <sup>b</sup>	Mean Difference, Point Estimate (95% CI)	P 0.03	
Functional HL, per 1-pt increase	0.21	3.39 (0.39 to 6.39)		
Communicative HL, per 1-pt increase	0.36	5.88 (2.04 to 9.71)	0.003	
Critical HL, per 1-pt increase	-0.09	-1.53 (-5.43 to 2.38)	0.44	
Age, per 10-yr increase	0.02	0.37 (-1.25 to 1.99)	0.65	
Women vs men	-0.30	-4.87 (-10.18  to  0.45)	0.07	
Education				
Junior high school or lower		Ref		
High school/college	-0.27	-4.44 (-12.50  to  3.67)	0.28	
University/graduate school	-0.14	-2.28 (-11.00 to 6.47)	0.61	
Household income, ¥				
< 1,000,000		Ref		
1,000,000 to < 5,000,000	-0.24	-3.96 (-10.70 to 2.77)	0.25	
5,000,000 to < 10,000,000	-0.22	-3.53 ( $-10.50$ to $3.44$ )	0.32	
≥ 10,000,000	-0.14	-2.36 (-11.80 to 7.04)	0.62	
Disease duration, yrs				
< 5		Ref		
5 to < 10	0.22	3.55 (-1.93 to 9.03)	0.20	
10 to < 20	0.08	1.30 (-3.68 to 6.29)	0.61	
≥ 20	-0.07	-1.22 (-6.80 to 4.38)	0.67	
SLEDAI-2K, per 1-pt increase	0.03	0.52 (0.16 to 0.88)	0.004	
Depressive symptoms	-0.05	-0.85 (-5.78 to 4.07)	0.73	
Duration of internet use, h				
0		Ref		
< 1	0.01	0.21 (-5.80 to 6.22)	0.95	
1 to < 2	-0.15	-2.38 (-9.06 to 4.30)	0.48	
≥ 2	-0.03	-0.56 (-7.66 to 6.54)	0.88	

Values in bold are statistically significant. The general linear model was fitted with the inclusion of all variables listed above. To calculate the corresponding standardized effect size (Cohen d), the point estimate was divided by the SD of scores for trust in interpersonal physicians. HL: health literacy; pt: point; SLEDAI-2K: Systemic Lupus Erythematosus Disease Activity Index 2000.

on the patient's condition, a mutual understanding of the clinical evidence, and the articulation of mutual values. Conversely, a previous finding that a physician's approach to patient-centered dialogue, such as considering the patient's interests, was associated with higher trust in physicians in general among patients with rheumatoid arthritis and SLE<sup>2</sup> may indicate that communicative HL is also elicited by physicians through patient-centered dialogue, which leads patients to be more willing to disclose their concerns. Combined with our finding that higher communicative HL was also associated with higher levels of trust in doctors in general, this may reflect a basic ability to establish a trusting relationship with any physician.

There are several explanations for the finding that higher critical HL was associated with lower trust in physicians in general but not with lower trust in one's own physician (ie, rheumatologist). First, the existence of a physician-patient relationship—and the opportunity to create one from early on—may increase patients' trust in their own physicians. This idea also supports the notion that physician-patient communication can promote patients' trust in their physician. Second, an alternative explanation could be that patients with SLE are perhaps more cautious with other physicians than with their rheumatologists.

Apart from these, there are also several explanations regarding the association between internet usage time and critical HL, and between internet usage time and trust in physicians. The positive correlation between internet usage time and critical HL may reflect the reality that patients are increasingly accessing online health information, acquiring more knowledge about a variety of medical care, and comparing it to the actual medical care provided to them. Rheumatologists need to be aware that their patients will seek information about their condition on the internet and discuss the distinction between high-quality and low-quality information available. Additionally, they also need to be able to guide their patients toward high-quality online information and have a list of recommended sites. Rheumatologists also need to be prepared to answer patients' queries that arise after consulting the internet, particularly if this information contradicts or differs from what they are saying because of the patient's specific circumstances.

This study has several clinical implications for rheumatologists and researchers. First, an additional method is needed to determine whether improved functional and communicative HL will enhance trust in physicians. For example, given the potential that communication can independently affect patients' trust in physicians, after taking into account a number of variables, such as education level, curriculum development for physician communication skills that enhance communicative HL would be a target. Physician attitudes, such as providing optimal information to patients; allowing patients to vent their worries; and being compassionate in order to develop a cooperative

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	Cohen d	Mean Difference, Point Estimate (95% CI)	P
Functional HL, per 1-pt increase	0.09	1.81 (-1.92 to 5.53)	0.34
Communicative HL, per 1-pt increase	0.35	7.09 (2.34 to 11.83)	0.004
Critical HL, per 1-pt increase	-0.34	-6.88 (-11.72 to -2.04)	0.005
Age, per 10-yr increase	0.04	0.72 (-1.29 to 2.73)	0.48
Women vs men	-0.41	-8.41 (-15.00 to -1.81)	0.01
Education			
Junior high school or lower		Ref	
High school/college	-0.14	-2.85 (-13.0 to 7.31)	0.58
University/graduate school	-0.39	-7.88 (-18.7 to 2.92)	0.15
Household income, ¥			
< 1,000,000		Ref	
1,000,000 to < 5,000,000	-0.25	-5.14 (-13.1 to 2.84)	0.21
5,000,000 to < 10,000,000	-0.27	-5.40 (-13.5 to 2.75)	0.19
≥ 10,000,000	-0.14	-2.92 (-14.4 to 8.51)	0.62
Disease duration, yrs			
< 5		Ref	
5 to < 10	-0.12	-2.51 (-9.42 to 4.40)	0.48
10 to < 20	-0.16	-3.27 (-9.52 to 2.98)	0.30
≥ 20	-0.21	-4.26 (-11.2 to 2.69)	0.23
SLEDAI-2K, per 1-pt increase	0.02	0.36 (-0.09 to 0.8)	0.12
Depressive symptoms	-0.01	-0.26 (-6.28 to 5.76)	0.93
Duration of internet use, h			
0		Ref	
< 1	-0.30	-6.13 (-13.60 to 1.34)	0.11
1 to < 2	-0.46	-9.26 (-17.50 to -0.98)	0.03
≥ 2	-0.49	-9.97 (-18.80 to -1.16)	0.03

Values in bold are statistically significant. The general linear model was fitted with the inclusion of all variables listed above. To calculate the corresponding standardized effect size (Cohen d), the point estimate was divided by the SD of scores for trust in general physicians. HL: health literacy; pt: point; SLEDAI-2K: Systemic Lupus Erythematosus Disease Activity Index 2000.

relationship with patients<sup>3</sup> may facilitate patients' willingness to communicate and enhance communicative HL. Second, given that HL is correlated with internet use, rheumatologists may need to prepare for a structured dialogue when patients find information on the internet, especially when such information contradicts the rheumatologist's recommendations. Patients with SLE have been reported to seek information about their condition and treatment options on the internet and to build their own knowledge base for inquiring with their healthcare providers. 11 Patients with rheumatic diseases who discuss their internet findings with their physicians have been reported to be more satisfied with their medical encounter.<sup>24</sup> The first step toward a structured dialogue would be to ask if patients seek information on the internet<sup>24</sup> and to accept queries formulated through information on the internet. Next, it may be beneficial to incorporate certain topics into the dialogue, such as the trustworthiness of information on the internet based on scientific findings, whether a treatment found on the internet is safe in light of the patient's medical condition, and whether the treatment found is effective on the outcomes that the patient and physician are targeting compared to current treatments.

The study has several strengths. First, this is the first study to reveal an association between trust in one's own physician and HL among patients with SLE. In addition, we were able to expand the correlates of HL by measuring broader concepts of

HL dimensions, such as communicative and critical HL. It is also worth mentioning that we were able to show the association between HL and trust in one's physician by studying a single race, eliminating racial differences, and adjusting for educational and economic status. Second, the multicenter design ensured the external validity of our findings.

Although this study demonstrated vital insights, it has several limitations. First, HL was not measured using an objective test, although a self-report instrument with well-validated reliability and validity was used. Even though the literacy rate for the Japanese people has not been studied since the 1960s and is, therefore, substituted by the primary school enrollment rate, the figure is above 99% and, thus, the effect of not using an objective test would be minimal.25 Second, the duration of internet use was not limited to the search for health information. However, the duration of internet use may reflect the ability to access online health information. Third, because of the cross-sectional nature of this study, attention should be paid to reverse causality. An alternative explanation could be that the loss of trust in physicians increases the motivation to acquire health information on one's own or generates a belief in interpreting health information carefully. Fourth, since depression used as a covariate was measured based solely on depression related to lupus, depression for many other reasons may not have been captured. Thus, a residual confounding of

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depression on the relationship between HL and trust in physicians is still possible.

In conclusion, the findings suggest a correlation between communicative HL and trust in physicians—both their own physician (ie, rheumatologist) and physicians in general—among patients with SLE. This suggests that patients' ability to communicate about their own health condition is associated with forming trusting relationships with their own physician and physicians in general. Higher critical HL was not correlated with relationships with patients' own physicians but was correlated with lower trust in physicians in general. This implies that higher critical HL could lead to less trusting relationships, but that perhaps there is something modifying this relationship between the patient with SLE and their rheumatologist.

### DATA AVAILABILITY

The datasets generated and/or analyzed during the study are available from the corresponding author upon reasonable request.

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## **ONLINE SUPPLEMENT**

Supplementary material accompanies the online version of this article.

### REFERENCES

- Pearson SD, Raeke LH. Patients' trust in physicians: many theories, few measures, and little data. J Gen Intern Med 2000;15:509-13.
- Berrios-Rivera JP, Street Jr RL, Garcia Popa-Lisseanu MG, et al. Trust in physicians and elements of the medical interaction in patients with rheumatoid arthritis and systemic lupus erythematosus. Arthritis Rheum 2006;55:385-93.
- Street Jr RL, Makoul G, Arora NK, Epstein RM. How does communication heal? Pathways linking clinician-patient communication to health outcomes. Patient Educ Couns 2009;74:295-301.
- Thom DH, Ribisl KM, Stewart AL, Luke DA. Further validation and reliability testing of the Trust in Physician scale. The Stanford Trust Study Physicians. Med Care 1999;37:510-7.
- Georgopoulou S, Nel L, Sangle SR, D'Cruz DP. Physician-patient interaction and medication adherence in lupus nephritis. Lupus 2020;29:1168-78.
- Mosley-Williams A, Lumley MA, Gillis M, Leisen J, Guice D. Barriers to treatment adherence among African American and white women with systemic lupus erythematosus. Arthritis Rheum 2002;47:630-8.
- Suzuki R, Yajima N, Sakurai K, et al. Association of patients' past misdiagnosis experiences with trust in their current physician among Japanese adults. J Gen Intern Med 2022;37:1115-21.
- Nutbeam D. Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21st century. Health Promot Int 2000;15:259-67.

- 9. Tsai T-I, Yu W-R, Lee S-YD. Is health literacy associated with greater medical care trust? Int J Qual Health Care 2018;30:514-9.
- Ishikawa H, Takeuchi T, Yano E. Measuring functional, communicative, and critical health literacy among diabetic patients. Diabetes Care 2008;31:874-9.
- 11. Meunier B, Jourde-Chiche N, Mancini J, Chekroun M, Retornaz F, Chiche L. Characteristics and information searched for by French patients with systemic lupus erythematosus: a web-community data-driven online survey. Lupus 2016;25:370-5.
- Salt E, Rayens MK, Kerr AM, Alikhan M, Crofford LJ. Examining rheumatoid arthritis patients' trust in their provider over time: the effects of demographic factors and accessing sources of information. Orthop Nurs 2015;34:159-65.
- Kumar D, Schlundt DG, Wallston KA. Patient-physician race concordance and its relationship to perceived health outcomes. Ethn Dis 2009;19:345-51.
- Takeshita J, Wang S, Loren AW, et al. Association of racial/ethnic and gender concordance between patients and physicians with patient experience ratings. JAMA Netw Open 2020;3:e2024583.
- Street Jr RL, O'Malley KJ, Cooper LA, Haidet P. Understanding concordance in patient-physician relationships: personal and ethnic dimensions of shared identity. Ann Fam Med 2008;6:198-205.
- Oguro N, Suzuki R, Yajima N, et al. The impact that family members' health care experiences have on patients' trust in physicians. BMC Health Serv Res 2021;21:1122.
- Dugan E, Trachtenberg F, Hall MA. Development of abbreviated measures to assess patient trust in a physician, a health insurer, and the medical profession. BMC Health Serv Res 2005;5:64.
- Croker JE, Swancutt DR, Roberts MJ, Abel GA, Roland M, Campbell JL. Factors affecting patients' trust and confidence in GPs: evidence from the English national GP patient survey. BMJ Open 2013;3:e002762.
- Dong X, Bergren S, Simon MA. Cross-sectional and longitudinal association between trust in physician and depressive symptoms among U.S. community-dwelling Chinese older adults. J Gerontol A Biol Sci Med Sci 2017;72:S125-30.
- Inoue M, Shiozawa K, Yoshihara R, et al. The Japanese LupusPRO: a cross-cultural validation of an outcome measure for lupus. Lupus 2017;26:849-56.
- Maheswaranathan M, Cantrell S, Eudy AM, et al. Investigating health literacy in systemic lupus erythematosus: a descriptive review. Curr Allergy Asthma Rep 2020;20:79.
- Farinha F, Freitas F, Águeda A, Cunha I, Barcelos A. Concerns of patients with systemic lupus erythematosus and adherence to therapy - a qualitative study. Patient Prefer Adherence 2017;11:1213-9.
- Chambers SA, Raine R, Rahman A, Isenberg D. Why do patients with systemic lupus erythematosus take or fail to take their prescribed medications? A qualitative study in a UK cohort. Rheumatology 2009;48:266-71.
- Hay MC, Cadigan RJ, Khanna D, et al. Prepared patients: internet information seeking by new rheumatology patients. Arthritis Rheum 2008;59:575-82.
- Ministry of Education, Culture, Sports, Science and Technology. Statistical Abstract of Education, Culture, Sports, Science and Technology (2021 edition). [Internet. Accessed December 13, 2022.] Available from: https://www.mext.go.jp/b\_menu/ toukei/002/002b/1417059\_00006.htm

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