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## Relationship between Process of Care and Subsequent Increase in Damage in SLE

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### Abstract

**Objectives**—The present study evaluates whether low ratings of interactions with providers and health plans in 2013 were associated with increased SLE damage in 2015.

**Methods**—Data derive from the Lupus Outcomes Study (LOS) annual surveys and include items from the Consumer Assessment of Health Plans and Interpersonal Processes of Care Scale measuring dimensions of health care interactions. We use ordinary least squares regression to model the change in disease damage over a two-year period, 2013-2015, as a function of ratings of multiple dimensions of interactions with providers and health plans, with and without adjustment for demographic characteristics, socioeconomic status, and SLE and overall health status, and logistic regression to estimate the effect of the same matrix of variables on the probability of experiencing a minimal clinically important increase in damage.

**Results**—There were 566 LOS respondents who were followed from 2013-2015 and who rated their providers and health plans in 2013. After adjustment, persons with SLE rating their providers poorly in patient-provider communication experienced a significantly greater accrual of disease damage (0.23, 95% CI 0.09, 0.38) and were more likely to experience a minimal clinically important increase in damage (OR 2.35, 95%CI 1.25, 4.39). After adjustment, those rating their health plan poorly on care coordination experienced a significantly greater accrual of disease damage (0.19, 95%CI 0.03, 0.35) and were more likely to experience a minimal clinically important increase in damage (OR 2.20, 95%CI 1.12, 4.34).

**Conclusions**—Poor patient-provider communication and care coordination may result in increased disease damage.

Characteristics of the health care system and health coverage, for example having Medicaid coverage, being in managed care, or the specialty of the principal physician may affect access and outcomes among persons with SLE<sup>1-4</sup>. Two other sets of factors within health care may also affect health care and outcomes: the technical quality of SLE care and the nature of interactions between persons with SLE and providers and health plans. We previously established that consistently low ratings by patients in such interactions are related to the technical quality of the care received<sup>5</sup> and that technical quality of care may

affect the accrual of disease damage<sup>6</sup>. In the present study, we evaluate whether ratings of interactions between patients and providers and health plans at one point are related to the accrual of damage over the subsequent two years.

## Methods

### Data Source

Data derive from the UCSF Lupus Outcomes Study (LOS). The LOS was established in 2002 by re-enrolling persons with SLE who had previously participated in a study of genetic risk factors for SLE; SLE diagnosis, based on American College of Rheumatology criteria, was confirmed in all patients through medical chart review. LOS data are collected by an annual structured telephone interview conducted by experienced survey workers. The interview includes validated batteries covering sociodemographic characteristics, disease status, overall physical and mental health status, medications, health care utilization, and health insurance coverage. As part of the LOS, self-report measures of disease damage, the Brief Index of Lupus Damage, or BILD, and a set of quality indicators to measure the technical quality of care were developed and validated<sup>6,7</sup>. The LOS interview also includes a validated self-report measure of disease activity, the Systemic Lupus Activity Questionnaire, or SLAQ<sup>8</sup>.

### Measures of Interactions between Patients and Providers and Health Plans

Our prior article<sup>5</sup> includes a detailed listing of each item rating interactions with the provider and health plan and how the individual items map to the three major provider (patient-provider communication, shared decision-making, and trust in the provider) and three major health plan (care coordination, promptness/timeliness of care, and overall assessment of the health plan) domains. As detailed in the prior article, we transformed the original coding for the items to a 0 (worst) to -100 (best) scale using the method of Morales, et al.<sup>9</sup>. In the analysis, we dichotomized the scores for each domain into ratings at or below the worst quartile vs. above that.

### Analysis

In 2013, LOS interviews were completed with 810 persons. Of these, 644 had one or more physician visit and responded to all items rating their interactions with providers and health plans. In 2015, 566 of the 644 were re-interviewed and included in the analysis. Of the other 78, 18 died, 17 were lost-to-follow-up, and 43 declined further participation.

We use ordinary least squares regression to model the change in the BILD damage scores between 2013 and 2015 as a function of the ratings of interactions between patients and providers and health plans, with and without adjustment for other characteristics that could affect the outcome measures. These include: demographic characteristics and socioeconomic status (age, gender, non-white race, education, marital status, poverty); SLE and overall health status (disease duration and the SLAQ activity measure); health behaviors (smoking history and body mass index); and health care characteristics (specialty mix, coverage in a health maintenance organization, and report of receiving 85% or more of SLE quality indicators for which each individual is eligible, the study definition of high quality of

care)<sup>10</sup>. We also use logistic regression to estimate the impact of the ratings of interactions with providers and health plans on the probability of experiencing a minimal clinically important increase in the damage score of two or more points as established in a prior study<sup>10</sup>, with and without adjustment for the same matrix of covariates. As sensitivity analyses, we estimate multivariate models that included baseline damage scores and change in activity over time. The results did not differ materially from those presented here. As another sensitivity analysis, we evaluated cut-points other than at the lowest quartile for each of the six domains of interactions with providers and health plans.

## Results

Table 1 shows the characteristics of the 566 LOS respondents who had one or more visits to their main SLE provider in 2013 and who were re-interviewed in 2015. The study participants were just over 50 years of age on average and had had their disease for close to two decades. A large proportion, 42.2%, was members of minority groups. Almost half had completed college and more than another third had attended some college. However, 15.9 percent met the study definition of living in poverty. Disease activity (SLAQ) levels changed little over the two years, declining by 0.41 points across an average of 11.07, while disease damage (BILD) increased substantially, by about half a point across an average of 2.83 in the initial year. Just under one in ten persons with SLE in the study experienced at least a two-point increase in their disease damage scores, the level we had previously adjudged to be a clinically important increase<sup>6</sup>.

Almost three-quarters reported physician visits to both rheumatologists and generalists in the year prior to the 2013 interview, about a sixth and a tenth saw only rheumatologists and generalists, respectively. Just under a third reported coverage in a HMO. Fewer than a quarter reported receiving 85 percent or more of the SLE quality indicators for which they were eligible, the study benchmark for high quality care. Of the six domains of interactions with providers and health plans, ratings were high for two of the three interactions with providers (patient-provider communication and trust in the provider), and were relatively high for all three interactions with health plans, ranging from about 73 to 81 on the 0-100 scale. However, ratings of shared decision-making with the provider were much lower, about 45 on the same scale.

In Table 2, we show the values for the extent of damage accrual between 2013 and 2015, with and without adjustment for covariates. Ratings in the lowest quartile in one provider domain in 2013, patient-provider communication, and in one health plan domain in the same year, care coordination, were associated with a significantly greater amount of damage accrual by 2015. After adjustment, those whose ratings of patient-provider communication were in the worst quartile experienced 0.23 points of greater damage (0.77 versus 0.54) by 2015, while those whose ratings of care coordination were in the lowest quartile reported 0.19 points of greater damage (0.75 vs. 0.56). Although ratings in the other domains of interaction with providers and health plans in 2013 were not significantly related to the accrual of damage by 2015, in every instance there was a trend for those with ratings in the worst quartile to experience a greater amount of damage accrual than those with ratings in the best three quartiles.

Table 3 shows the odds of experiencing at least a two-point increase in the BILD damage score between 2013 and 2015, the study definition of a minimal clinically important increase in damage. On both an adjusted and unadjusted basis, ratings of patient-provider communication in the lowest quartile were associated with a statistically significant increase in the odds of at least a two-point increase in the damage score (unadjusted OR 2.13, 95% CI 1.18, 3.82; adjusted OR 2.35, 95% CI 1.25, 4.39). With but not without adjustment, ratings of care coordination in the lowest quartile were also associated with a statistically significant increase in the odds of at least a two-point increase in the damage score (unadjusted OR 1.88, 95% CI 0.99, 3.57; adjusted OR 2.20, 95% CI 1.12, 4.34). Although ratings of no other domains of interactions with providers and health plans were associated with significantly increased odds of at least a two-point increase in damage scores, there were trends for low ratings in every domain to be associated with at least this level of damage accrual. In the sensitivity analysis in which we evaluated the impact of using cut-points on ratings other than at or below the worst quartile, results were similar to the primary results reported above. However, patients' ratings of trust in providers in the lowest decile were associated with an increased odds of at least a two-point increase in the damage score (adjusted OR 2.20, 95% CI 1.12, 4.34, data on sensitivity analysis not in tables),

In all adjusted models in Tables 2 and 3, having a household income at or below 125% of the Federal poverty level was associated with either the extent of damage accrual or the odds of experiencing at least a two-point increase in the damage score, respectively (data on the impact of poverty on damage accrual not in tables). However, having a household income at this level or below was only associated with low ratings on one interaction, the assessment of interactions with one's health plan, which was not itself associated with the extent of damage accrual or probability of a minimal clinically important increment in damage accrual. In the same models, neither education nor race/ethnicity was associated with damage accrual.

## Discussion

It stands to reason, but has not been proven, that good interactions with providers and health systems may prove beneficial in achieving good outcomes in a disease such as SLE. We do know that the specialty of the principal physician can matter and we know that providing care consistent with quality indicators may reduce long-term damage<sup>10</sup>. We also know from the prior study using the LOS that good interactions with providers and health systems is associated with higher technical quality of care<sup>5</sup>.

In the present study, we show that ratings of patient-provider communication and care coordination in the lowest quartile in 2013 were associated with a greater level of damage accrual by 2015. In addition, after adjustment, such ratings were associated with an increased odds of at least a two-point increase in the damage score over this time-period, the study definition of a clinically meaningful increase in damage. Consistent with these findings, albeit not at a level that was statistically significant, low ratings on all other domains of interactions with providers and health plans were also associated with reaching such a high level of damage accrual. In the sensitivity analyses, ratings of trust in the

provider in the lowest decile were associated with the odds of at least a two-point increase in the damage score.

The measures used in the present study were validated as tools with which to assess interactions with providers and health plans. Nevertheless, it is possible that persons with SLE with poor health status were more likely to give their providers and health plans lower ratings. However, this risk is minimized in the current study because the ratings of interactions were antecedent to the increase in disease damage and the study measured the increment in disease damage, not just the absolute level at the outset of the study. To test the hypothesis that those with high levels of damage may rate interactions with providers and health plans more poorly, we estimated models of communication with providers and care coordination which included damage as of 2013 and observed no substantial decrease in the effect compared to the results reported above which omitted the baseline damage score. Thus, there was little evidence that prior progression of damage eliminates the effect of poorly rated interactions with providers and health plans on subsequent accrual of damage. Other potential limitations in the analysis include the effect of using patient-reported measures of activity and damage which, although validated against physician-provided measures, may differ somewhat from the latter measures and the effect of the majority of the respondents having been sampled independently of clinical environments which may attenuate the range of severity of the SLE on the one hand while including many providers without a lot of experience in SLE care on the other. Finally, the six domains of interactions with providers and health plans were designed to be conceptually distinct, but relatively high correlations between the two that affected accrual of damage the most, communication with providers and care coordination (data on correlation between the two sets of interactions not reported here), indicate that it may be difficult to separate the domains sufficiently when trying to isolate aspects of care on which to intervene.

These limitations notwithstanding, strategies to improve interactions between patients and providers and health plans among persons with SLE include use of decision aids to reduce the complexity of choices in treatment<sup>11</sup> and to deal with often low levels of health literacy among SLE patients<sup>12</sup> and self-management training<sup>13</sup>, including components designed to increase self-efficacy and improve communication with providers<sup>14</sup> in order to get persons with SLE more actively engaged with their care since such patients may experience better outcomes<sup>15</sup>. In other diseases, use of patient navigators who can both act as intermediaries with providers when necessary and are practiced at helping patients organize the care across the specialties and facilities has been shown to improve outcomes<sup>16</sup>. Use of lists of indicators for quality of care could also guide providers in ensuring that what is known to improve outcomes is prescribed for patients with SLE.

However, in the present study we observed an effect of patient-provider communication and care coordination even after taking the quality of care into account. This suggests that there can be no substitute for training providers to communicate more effectively with persons with SLE and in making the principal provider and health plan for SLE responsible for working with the patient to facilitate access to the wide range of health care services needed to care for this condition.

At any one point, the impact of best practices in care is limited by the available treatments. Thus, improving outcomes will largely be a matter of ensuring that best practices are adhered to and that there are no disparities in access to good quality of care by socioeconomic status or race/ethnicity. To the list of factors that can result in better or worse outcomes with respect to accrual of disease damage given currently available treatment options, we can now add patient-provider communication and care coordination, both of which may increase the odds of a clinically meaningful increase in disease damage by more than a factor of two. The next step in the research to tie patient interactions with providers and health plans to outcomes is to test specific mechanisms that could account for the relationship. Good candidates would include adherence to treatment as a result of poor patient-provider communication and lack of someone to aid in care coordination, whether a patient navigator or providers focused on performing the care coordination role.

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### **Significance and Innovations**

- First study to establish the impact of poor ratings of validated measures of interactions between patients and providers and health systems on SLE damage on a prospective basis.
- Poor communication between patients and providers and poor care coordination may result in a greater amount of damage accrual.
- Interventions to improve patient-provider and patient-health plan interactions may result in better SLE outcomes.

**Table 1**

Characteristics of Lupus Outcomes Study Participants in 2013 (n=566)

<b>Demographic Characteristics and Socioeconomic Status</b>	<b>% of participants, unless indicated</b>
Age *	51.40±12.92 (20 - 66)
Female	93.6
Nonwhite	42.2
Education	
High School or Less	18.4
Some College or Associate Degree	36.4
Bachelor's or Greater	45.2
Marital Status	
Never Married	19.6
Married or with Partner	18.6
Widowed, Separated, Divorced	61.8
Below 125% of Federal Poverty Level	15.9
<b>SLE and Overall Health Status</b>	
Disease Duration *	19.02±8.95 (1 - 50)
SLAQ Disease Activity - baseline *	11.07±7.34 (0 - 34)
Change in SLAQ- baseline to follow-up *	-0.41±5.00 (-24 - 21)
BILD Disease Damage - baseline *	2.83±2.69 (0 - 18)
Change in BILD - baseline to follow-up *	0.46±0.78 (0 - 5)
BILD increase of 2 points	9.4%
SF36 Physical Component Score (PCS)- baseline *	39.30±11.73 (12.61 - 64.71)
SF36 Mental Component Score (MCS) - baseline *	47.88±11.94 (7.07 - 68.49)
<b>Health Behaviors</b>	
Smoking Exposure	
Never smoked	64.0
Up to 10 pack-years	19.4
10 or More Pack-years	16.6
Body Mass Index *	27.12±7.08 (14.68 - 61.74)
<b>Health Care Characteristics</b>	
Specialty of Physicians Seen in Year Prior to Interview	
Rheumatologist and Generalist	72.4
Rheumatologist, but No Generalist	14.7
Generalist, but No Rheumatologist	11.0
Other Specialties Only	1.9
In HMO	31.1
Quality Indicator Pass Rate of 85 or Greater	24.2
<b>Rating of Interactions with Providers</b>	
Patient-Provider Communication *	90±12.84 (9-100)

<b><u>Demographic Characteristics and Socioeconomic Status</u></b>	<b>% of participants, unless indicated</b>
Shared Decision-making *	45.04±30.76 (0-100)
Trust *	89.12±17.23 (0-100)
<b>Rating of Interactions with Health Plans</b>	
Care Coordination *	77.89±29.53 (0-100)
Promptness/Timeliness of Care *	73.32±24.25 (0-100)
Assessment of Health Plan *	81.20±17.66 (0-100)

\* Mean ± standard deviation and range

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**Table 2**  
Impact of Ratings of Interactions with Providers and Health Plans in Worst vs. Better Quartiles on Change in Disease Damage, with and without Adjustment for Demographic Characteristics, Socioeconomic Status, SLE and Overall Health Status, Health Behaviors, and Health Care Characteristics

Measure of Interactions	Unadjusted			Adjusted		
	Worst Quartile <sup>1</sup>	Better Three Quartiles	Change in Damage Scores (95% CI)	Worst Quartile	Better Three Quartiles	Change in Damage Scores (95% CI)
<b>Individual Provider Domains</b>						
Patient-Provider Communication	0.63 (0.51, 0.76)	0.41 (0.33, 0.48)	0.22 (0.13, 0.31) *	0.77 (0.62, 0.92)	0.54 (0.43, 0.64)	0.22 (0.13, 0.31) *
Shared Decision-making	0.54 (0.41, 0.67)	0.44 (0.37, 0.51)	0.10 (0.02, 0.18)	0.67 (0.52, 0.82)	0.57 (0.46, 0.68)	0.10 (0.02, 0.18)
Trust	0.55 (0.41, 0.69)	0.44 (0.37, 0.51)	0.11 (0.03, 0.19)	0.67 (0.52, 0.83)	0.57 (0.46, 0.68)	0.11 (0.03, 0.19)
<b>Individual Health Plan Domains</b>						
Care Coordination	0.62 (0.47, 0.77)	0.43 (0.36, 0.50)	0.19 (0.10, 0.28) *	0.75 (0.58, 0.92)	0.56 (0.46, 0.67)	0.19 (0.10, 0.28) *
Promptness/Timeliness of Care	0.47 (0.35, 0.60)	0.46 (0.38, 0.53)	0.01 (0.00, 0.02)	0.62 (0.47, 0.77)	0.58 (0.48, 0.69)	0.01 (0.00, 0.02)
Assessment of Health Plan	0.54 (0.41, 0.66)	0.44 (0.36, 0.51)	0.10 (0.02, 0.18)	0.66 (0.51, 0.80)	0.56 (0.45, 0.68)	0.10 (0.02, 0.18)

<sup>1</sup> Scores to Define Worst Quartile in Ratings:

- Patient-Provider Communication: less than 86.8
- Shared Decision making: less than 16.7
- Trust: less than 83.3
- Care Coordination: 67.0
- Promptness/Timeliness of Care: less than 58.5
- Assessment of Health Plan: less than 72.5

\* p<0.05 for difference between worst and better three quartiles.

**Table 3**  
 Impact of Ratings of Interactions with Providers and Health Plans in Worst vs. Better Quartiles on Probability of Clinically Important Increase in Disease Damage, with and without Adjustment for Demographic Characteristics and Socioeconomic Status, SLE and Overall Health Status, Health Behaviors, and Health Care Characteristics

Measures of Interactions	Unadjusted	Adjusted
<b>Individual Health Plan Domains</b>		
Patient-Provider Communication	2.13 (1.18, 3.82)	2.35 (1.25, 4.39) *
Shared Decision-making	1.25 (0.67, 2.35)	1.27 (0.65, 2.49)
Trust	1.64 (0.88, 3.06)	1.63 (0.85, 3.14)
<b>Individual Health Plan Domains</b>		
Care Coordination	1.88 (0.99, 3.57)	2.20 (1.12, 4.34) *
Promptness/Timeliness of Care	1.08 (0.58, 2.03)	1.33 (0.68, 2.60)
Assessment of Health Plan	1.24 (0.67, 2.29)	1.25 (0.65, 2.41)

**Scores to Define Worst Quartile in Ratings:**

- Patient-Provider Communication: less than 86.8
- Shared Decision making: less than 16.7
- Trust: less than 83.3
- Care Coordination: 67.0
- Promptness/Timeliness of Care: less than 58.5
- Assessment of Health Plan: less than 72.5

\* p<0.05 for difference between worst and better three quartiles.