



Published in final edited form as:

Arthritis Care Res (Hoboken). 2019 March ; 71(3): 398–405. doi:10.1002/acr.23599.

Poverty, Neighborhoods, Persistent Stress, and SLE Outcomes: A Qualitative Study of the Patients' Perspective

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Abstract

Objective—To obtain the perspective of individuals with SLE about the role of poverty, neighborhood, and chronic stress in SLE outcomes.

Methods—723 persons with SLE were followed from 2003–2015 through annual structured interviews as part of the Lupus Outcomes Study to establish the effect of combinations of poverty, persistent poverty, living in an area of concentrated poverty, access to health care, and chronic stress on accumulated damage. We sampled 28 from the 723 on the basis of household income, geography, and outcomes in their last interview, and administered qualitative interviews to explore their perspectives on these factors on outcomes. The interviews were recorded and transcribed and analyzed using a grounded-theory approach.

Results—Persons in poverty frequently reported that poverty necessitated a choice to deal with food, medical care, and housing insecurity on a daily basis and to relegate dealing with SLE to a time of disease flares. They also reported that exposure to crime in their neighborhoods was a stress that triggered worsened disease activity. Affluent participants reported that neighborhood neither helped nor hindered dealing with SLE since they relied on networks not tied to neighborhoods to deal with SLE.

Conclusion—Mitigating poverty and reducing exposure to crime through moving to safer neighborhoods are factors identified by patients as potentially critical in outcomes for SLE.

The relationship between low income and poor outcomes of disease has been established in numerous studies of the general population^{1,2} and of those with specific clinical conditions, including systemic lupus erythematosus (SLE)^{3–7}. In a prior study⁸, we used a national longitudinal sample of persons with SLE to establish that current poverty and persistent poverty at one point predict extent of accumulated damage five years later, with the effect accentuated among the poor living in areas of concentrated poverty and the effect dampened

among those who permanently exit poverty. In the latter study, the extent of perceived stress over the last month⁹ accounted for a significant amount of the effect of poverty on damage.

However, there were several questions that emerged from the study, including what was it about poverty that resulted in higher levels of damage, including but not limited to the effects of differential access to the health care system; what were the kinds of stressors that were particularly salient in the lives of those with SLE; what were the phenomena that intensified or reduced the effects of stress for poor and non-poor alike or that had a greater effect on the poor; and what were the detrimental and beneficial aspects of the neighborhood in helping cope with SLE.

Because many of these questions had not previously been addressed systematically in the SLE literature, we embarked on an exploratory analysis using qualitative interviews with 28 persons with this condition systematically sampled from the larger study to provide insight into the specific processes that may result in higher levels of disease damage.

Methods

Overview

The prior study had identified broad themes relating poverty and living in an area of concentrated poverty to heightened damage, but not what the specific triggers were. In such a situation, qualitative interviews can be helpful in uncovering what individuals living with SLE perceive to be the reasons that low income or adverse neighborhood circumstances may lead to damage, along with the impacts of differential experience of the health care system. We developed a series of open-ended questions that delved into these issues and then used a grounded-theory approach to extract meaning from the interview data¹⁰.

Data Source

The data source for the research is the Lupus Outcomes Study (LOS)¹¹. The LOS began in 2003 by enrolling individuals with confirmed SLE diagnoses who had previously participated in genetics studies of lupus and had been recruited nationally from a combination of clinical and non-clinical sources.

The principal data collection for the LOS was an annual structured telephone interview covering the status of the SLE, enumeration of medications and health care, and standard demographic items. The content of the annual survey is more fully described in prior publications^{7,11,12}.

LOS participants reported on their household income in each annual survey, which, when combined with data on household size, enabled us to categorize each of them into those whose household income was at or below vs. above 125% of the Federal poverty level, the study definition of poverty⁷.

Extent of poverty in the participants' local neighborhoods was obtained by matching their geocoded addresses to information from the American Community Survey^{13,14} at the level of the Census block group, encompassing between 600 and 3,000 individuals in the

immediate neighborhood. We defined areas of concentrated poverty as those in which more than 30 percent of households were in poverty ¹⁵.

Sampling

Sampling for the qualitative interviews was based on a combination of specific criteria identified by the prior quantitative study, as outlined below, and purposive sampling based on an assessment by the study interviewers of which respondents to the structured annual survey would likely be informative respondents ¹⁶.

There were 723 respondents to the 2014–2015 LOS annual survey. From among the 723, we limited the universe of those targeted for qualitative interviews to those defined as poor (n=116) or who reported household incomes of \$100,000 or more (n=94) to highlight the impact of monetary resources on access to care and outcomes. From among those in poverty, we further stratified the latter into those who did (n=50) and did not (n=66) live in areas meeting the study definition of concentrated poverty. For both the poverty and affluent groups, we included those at or above vs. below the highest quartile of disease damage as measured by the Brief Index of Lupus Damage ^{17,18}. We also oversampled among respondents outside of California to ensure adequate geographic diversity. Finally, among those eligible on the basis of income, living in areas of concentrated poverty, degree of disease damage accumulated, and residence in- and outside of California, we set a higher priority on respondents designated by the interviewers as likely being informative.

Because of the long history of participation in the LOS annual quantitative interviews, all whom we asked to participate in the qualitative interviews agreed to participate; we did not have to go beyond those targeted as being potentially informative respondents. Qualitative interviews were completed with 28 individuals, 11 from the affluent group, and 17 in the poverty group, among whom 11 lived in areas of concentrated poverty. Twelve of the 28 individuals who completed qualitative interviews lived outside of California (5 and 7 from among the affluent and poverty groups, respectively).

Interviews were conducted by a single individual (JB), after obtaining verbal consent from each participant. Interviews were recorded and transcribed. The study was approved by the University of California, San Francisco Institutional Review Board.

Content and Conduct of Qualitative Interview

The content of the interviews was guided by a list of major themes to be covered to ensure that all respondents covered the same material; the themes were drawn from the findings of the quantitative study about the relationship among income, neighborhood poverty, stress, and accumulated damage. There were two overarching themes. The first concerned health care for SLE, including gaining access to SLE care, maintaining access, and maneuvering through the health care system. The second concerned the stressors that affect the status of their SLE. Also, we explicitly asked about the negative and positive aspects of their neighborhood in accessing SLE care or the status of their SLE.

We conducted a pretest of the interview protocol with study investigators and with several SLE clinic patients who were not LOS participants. Analysis of the pre-test interviews

resulted in the revised interview guide shown in Table 1. Interviews conducted with this guide took between 45 minutes and an hour to complete.

Analyses

The broad themes of the interviews derived from the prior quantitative study, but in the analysis, we used a grounded theory approach to capture and understand information on processes that differentiate the impact of low income, experience and meaning of stress, and beneficial and detrimental effects of neighborhood on SLE damage. To accomplish the goal of highlighting the processes that translate these characteristics into adverse disease outcomes, we systematically combed the interview content to make sure that we had captured the universe of responses about the processes, for example, that no other specific aspect of neighborhoods were being mentioned as having positive or negative effects. We then sought to see if the responses adhered to specific patterns, for example, that certain responses about specific phenomena were more common among the poor, which might suggest a potential explanation for why the poor experienced heightened levels of damage¹⁹.

To begin the process of combing the data, the interviewer summarized the responses of each respondent at the conclusion of the interview as they related to the study themes. One of us (EY) listened to the recordings, reviewed the transcripts, and then coded the responses for the health care theme (whether the individual was able to gain access to care and maintain it) and the stress theme. After review of the audio tapes and transcripts, respondents' comments about stressors were coded to those traditionally associated with the disease in qualitative studies such as the uncertainty of when flares will occur, dealing with the impacts of organ manifestations as well as generalized fatigue and pain, and the effect on functioning in and outside the home²⁰, what a respondent referred to as "daily hassles". However, given the study's focus on the impact of poverty, we also coded responses attributing SLE status to socioeconomic status and financial needs (such as worries about paying for food, rent, or medical care) and to adverse neighborhood conditions. As a check on the interpretation of the interview content and coding, the interviewer's contemporaneous summary of the interview was compared to the systematic review of the transcript and audiotape for the gist of the information derived from the interview and discrepancies resolved, if necessary.

Results

Table 2 describes the characteristics of the 28 study participants and shows their diversity in demographics and extent of SLE. On average, respondents were just under fifty years old and had had their SLE for more than two decades. Most were women. More than two-thirds were members of racial and ethnic minorities as a result of oversampling among the poor and those living in areas of concentrated poverty.

Table 3 summarizes the results of the qualitative interviews after coding. With respect to health care access, half of the 28 respondents reported obtaining a diagnosis of SLE and gaining access to SLE care within six months, and 20 reported maintenance of access and ability to maneuver through the health care system to get the care needed after ultimately gaining initial access (although as shown below, not without some challenges).

There were no appreciable differences by poverty status, those who do and do not live in areas of concentrated poverty, and those reporting high vs. low levels of damage in gaining access to SLE care within 6 months. However, it appears that those in poverty were slightly less likely than the affluent to maintain and successfully maneuver through the health system thereafter (10 of 17 of the poor vs. 10 of 11 of the affluent, respectively).

However, even though many gained access quickly and maintained it over time, initially accessing and then maintaining that access to health care presented challenges.

From a poor woman from an area with a high concentration of the poor in rural California:

I was seeing a specialist and then I went to not having insurance and not being able to go to the specialist. So, I started going to the community clinic, where it's income based....

From a poor woman living in a middle class area near a Central Valley city who lost her insurance before getting Medicaid:

When I was working at the hospital it was right before I was getting ready to be hired on full time. Then, they diagnosed me. Then, next thing I know I was put on SSI and I got Medi-Cal and food stamps for my children, then everything started going downhill and I started surgeries and getting sicker and sicker. In and out of the hospital. The kids thought I was going to die.

Finally, from an affluent woman in suburban Arizona:

And, not faulting the physicians, but that's the way our healthcare is structured right now. You can't describe your story, or even halfway give the details to put it all together to make some sense, or to start doing – for the doctors to take the time to think back to medical school, what they did and what they learned. Now, it's like, oh, okay, if I do this, we'll give you this and you're out the door. See you in two weeks.

Table 3 also includes information on the frequency with which respondents reported traditional stressors or specific socioeconomic stressors. The report of traditional stressors as triggers for SLE flares did not differ among the groups defined by poverty, residence in a high poverty area, or extent of damage; indeed, all 28 respondents were coded as indicating that both environmental triggers (such as sun exposure) or common daily hassles (such as family conflict, overwork, difficult commutes, etc.) affected their SLE.

However, only one of the affluent respondents reported socioeconomic stressors, in this case difficulty in paying for medical care, despite having insurance. In contrast, two-thirds of the poor mentioned such stressors. When further dividing the poor into those living in and out of areas of concentrated poverty, it did not appear that the poor outside of such areas were able to escape socioeconomic stressors. Further analysis of the two groups and comparison to those in the higher income category indicates why: although the poor inside areas of concentrated poverty lived in areas in which an average of 49 percent of the residents were poor, the poor outside those areas lived in areas in which an average of 18 percent were poor and certainly many lived adjacent to areas with higher concentrations of the poor. Thus, the

residential environments of the two groups of the poor were not as different as we had anticipated. In contrast, the affluent respondents lived in areas in which an average of only 8 percent of the residents were poor (data on concentrations of the poor not in tables).

Several respondents spoke to the inherent stress of facing monetary uncertainty while others spoke both of that and the impact of money concerns on bandwidth.

From the poor woman near a Central Valley city:

Money stresses make it [the SLE] worse. Definitely. Because I worry about money all the time and how my brother's paying my mortgage and how I wish it was me. How I wish I could be normal and work.

From a poor woman in rural Indiana who moved there from a more expensive city:

It's rough. I pay like \$50 a month-whenver I get my check-\$50 a month [for the motorized cart] is all I can afford to pay until it's paid. So, I'm going to go to a collection agency.

From a poor woman in a rural area of the Northwest when asked about medical expenses:

No. No, it was a nightmare. Especially when you're dealing, you know, with cardiologists and pulmonologists and nephrologists and every other -ologist. Now and then, it gets a little bumpy. ...There's not a really good path.

When asked about a better health care system she said:

Well, it certainly wouldn't cost as much. .. We ended up filing bankruptcy because of my medical bills.

A poor woman who had moved to rural Missouri from Chicago stated:

Well, I had to move in [with my family]- I had to leave my apartment, well, I lost everything.

The cost of medical care may also affect the more affluent. From an affluent woman living in an exurban part of the San Francisco Bay Area:

Well, right now I'm paying \$215 every month for a hospitalization I had last June, because ... I don't have \$5,000 sitting around.

The effect of monetary concerns forces many to delay dealing with anything other than with food, housing, and medical care insecurity.

From a poor woman living in an area of concentrated poverty in a Bay Area central city:

This was all in June. Oh, there was one more - I can't think of it now, but I know there were five things on my plate and it kind of hit me spiraling down. So, I had to deal with them as they came.

This respondent made the distinction between daily hassles and these more chronic financial concerns. She stated:

I think pretty much any stress that will keep me worried about it a week later [is the] kind of stress. So, the long-term stress. Not the oh my god am I going to make it to work on time kind of stress

The more affluent woman from an exurban Bay Area location suggested how financial concerns might translate into less than optimal monitoring of the SLE even for someone of her means. She envisioned a situation in which she didn't have to worry about bills:

It would be Dr. Moneybags, and he would pay my bills. And then I would go see my rheumatologist regularly. ... For them to check on my lupus and stuff, those special tests cost a fortune. And I have to pay 40 or 60%, or whatever my fricking percentage is. It's a lot.

The starkest distinction between affluent and poor study participants, regardless of whether or not they reside in an area of concentrated poverty, had to do with the role of neighborhood in their lives. For the affluent, neighborhood played no role in dealing with SLE. Indeed, most relied on extra-neighborhood sources such as relatives or professional connections to find and maintain health care or deal with their disease. An affluent New Englander stated:

Well, my wife's a nurse. So she knew that from her knowledge that Brigham and Women's Hospital in Boston had a lupus center...and my father is a doctor who recommended I get a second opinion there.

A woman from Arizona also cited using her professional connections and willingness to persevere:

Yes, I'm an advocate but I'm also a nurse and counselor. That's how I get to the care I need.

With respect to neighborhood, a woman from an affluent Boston suburb was typical in her response in indicating that she knew that living in a good neighborhood could be helpful but that it wasn't something she relied on.

Well, I guess I'd have to say, it's a very quiet neighborhood, so ... I don't think the neighborhood contributes to bringing on any kind of lupus symptom.

However, the poor repeatedly mention the experience of crime, the fear of crime, and being witness to illicit activities as primary factors affecting the status of their SLE. A poor woman living in an area of concentrated poverty in a large Midwestern city stated when asked about stresses that made her SLE worse:

You know, there's been [three] instances where they's try to break in my house and that just threw me for a loop. I was highly agitated by that. ... the latest one was the one where they knocked on the door – they knocked on the screen door.

A poor woman from an area of concentrated poverty in another Midwestern city recounted a similar experience:

Oh, God, the sirens - I hear one now. It's constant, now. ... I hear a lot of police. A lot of killings over here, robberies. So, when you do come in at night, it's the skids - like, "OK, can I make it in here safely, without being mugged or robbed?"

A woman from a Bay Area central city spoke more about her vision of a better neighborhood as a way of saying how difficult the experience of her current neighborhood is:

Helps reduce the stress or helps me deal [with the SLE]? Here you hear the hustle and bustle. Whereas when I go to a neighboring city it's more quiet. It's just - you don't feel like you're surrounded by all that chaos.

The poor who lived in rural areas were not immune from the adverse effects of neighborhood on SLE. A woman from the rural Northwest said:

I live in a trailer park.... We would be considered to be living in the best of that part of town - for a town of 6,000 people, I mean. Yeah. And do [I] feel safe where [I] live? I have a loaded .357 on my nightstand. Yes, I do.

Although the actual experience or fear of crime was mentioned repeatedly, separating the impact of adverse neighborhoods from socioeconomic stressors is difficult. In an irony, one poor woman from an area of concentrated poverty in a Midwestern city quoted above, indicated that, at long last, her neighborhood was beginning to change for the better. However, she experienced the effects of gentrification as a mixed blessing, knowing that the experience of crime may be lessened, but also knowing that gentrification may not serve the current residents because she will have to leave the neighborhood for one that is more affordable. She stated:

Well, you know, from what I'm seeing, I see businesses moving back in. And, you know, I see a lot of things coming back in. But I don't think it's geared towards the population of the neighborhood.

Discussion

In the approach of behavioral science, asking people about their experiences may yield less insight than observing their behavior over time. That revealed preference of observing behavior may be more reliable than asking individuals about their behavior²¹ is based on the notion that individuals may not be able to understand why they do things or may say things to legitimate their behavior. The previous study of the authors was done with a behavioral science approach and yielded the finding that current poverty, duration of poverty, and exiting poverty could explain the extent of subsequent accumulated damage in SLE, that living in areas of concentrated poverty accentuated the effect of poverty on damage, and that higher levels of perceived stress accounted for much of the effect of poverty.

There were limits to the behavioral science approach, however. We knew from the quantitative study⁸ that poorer access to SLE care, lower quality of care, and poorer interactions with health care providers and health systems mattered in determining SLE health outcomes, but not all that much. We also knew that differences in health behaviors, such as smoking, between the poor and non-poor played a relatively small role. We knew that stress as measured by standardized measures had a substantial effect, but not whether those were actually the kinds of stresses that individuals experience as triggers for flares in

SLE. Finally, the literature on the health effects of neighborhoods posits that the presence of positive things like parks and accessible transportation and the absence of negative things like noise and crime may differentially affect the poor and non-poor, with the non-poor experiencing few of the deleterious impacts of neighborhoods and the poor experiencing few of the good ones²².

The results of the qualitative interviews reinforce the observation from the prior study about the role of health care. Participants who were affluent and poor reported similar experiences in getting to a steady state in SLE care, although the affluent were more likely to state that they were able to maintain that steady state and successfully maneuver through the system to obtain the care they needed. Both groups hold to similar views of the impact of traditional stressors for persons with SLE, including environmental challenges such as sun exposure and daily hassles like difficult commutes, overwork, and family strains. Although both groups cite these stressors, they state that this is as much because their providers or health education materials have told them to reduce such exposures as because they are central in their own perceptions of what matters in their SLE.

However, when asked about stresses that affect the status of their SLE, the poor were much more likely to report that socioeconomic stressors such as housing, food, and medical care insecurity affect them (the exception being one affluent woman with high out-of-pocket payments for medical care services). The respondents indicate how these concerns weigh on them: by forcing them to focus all attention on securing these basic necessities which, in turn, leads them to focus on SLE symptoms only when they must. Their insights are consistent with a burgeoning literature in health economics that focuses on the scarcity of time and energy in a manner analogous to the traditional focus of economics on the scarcity of financial wherewithal²³ and to the sociological literature which documents the stress associated with housing insecurity²⁴.

The observation from our prior study of the accentuating effect of living in areas of concentrated poverty beyond the effect of personal poverty on damage accumulation led us to ask respondents about the salutary and adverse aspects of their neighborhoods. In contrast to what we expected to hear, the results of the qualitative interviews suggest that for the affluent neighborhoods mattered very little one way or another. Many had secured access to health providers through connections through work or family scattered across the country and none mentioned positive aspects of living in good neighborhoods as a relief from SLE symptoms or daily hassles. For the poor, none mentioned positive aspects of neighborhoods as a way of dealing with SLE care or stresses that affected their SLE status. But many cited the actual experience of crime or the fear of crime as an important stress affecting their well-being. Of course, in retrospect, the differences between the affluent and poor are consistent with the observation made repeatedly over the last century by sociologists that some of us live in networks not defined by space, but by social connections (what the classical sociologists referred to as “*gemeinschaft*”, or society and contemporary analysts refer to as “anywhere” people) while others do, for better or worse (what the traditional sociologists referred to as “*gesellschaft*”, or community and contemporary analysts call “somewhere” people)^{25–28}. However, the observation that the local community did not provide a haven in any way, shape, or form is consistent with contemporary understanding of the impact of

communities of concentrated poverty with respect to social phenomena in general ²⁹ and the health effects for persons with SLE in particular ^{7,8}.

The exposure to crime combined with the chronic stress of food, shelter, and medical care insecurity would appear to be the major factors differentiating the viewpoints of poor and affluent people about their SLE. These phenomena are fundamentally different than either the forms of stress psychologists catalog in the laboratory such as being asked to give a speech in public or daily hassles due to family conflicts, difficult commutes, or even periodic overwork. That they were mentioned in answer to the same series of questions asked of the affluent and poor indicates both that they were not mentioned as a result of “leading” the conversation and that they were truly salient to the poor.

There is increasing evidence in research not specifically focused on persons with SLE that providing the poor with the means of moving to areas with lower concentrations of the poor – to better neighborhoods -- redounds to them in turns of educational achievement and, down the road, higher earnings ³⁰. There are preliminary data indicating that there can be health benefits, too ^{31,32}. However, helping the poor to move to better neighborhoods through housing vouchers may have the paradoxical effect of rendering them more “house poor” unless the housing subsidies are sufficient to absorb the higher housing costs. If not, then reducing the stress associated with exposure to crime by providing housing vouchers may increase housing insecurity, another key source of stress ²⁴.

We began this inquiry with the supposition that the poor experienced a higher level of daily hassles, fewer of the beneficial aspects of neighborhoods, and more of the harmful ones. In response to the guided interviews for the present study, it is clear that the poor view chronic stress as manifest in food, housing, and medical care insecurity and exposure to crime as being crucial to their experience of SLE. Neither daily hassles of living with a chronic illness nor the absence of positive aspects of neighborhoods were identified in this way.

The voices of the persons with SLE with whom we conducted these extensive qualitative interviews also may help explain why medical care doesn't play a more central role in why the poor have more adverse outcomes – they report that they are largely able to initially access and then maintain that access to care -- and why the stresses associated with sustained financial insecurity and exposure to neighborhoods with high rates of crime do because they are not able to focus on the SLE until they cannot do otherwise.

Acknowledgments

Grant Support: Robert Wood Johnson Investigator in Health Policy Award, NIAMS P60 AR-053308, 2R01-AR-056476 (Yelin); NIAMS K23 AR-060259 (Yazdany)

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Significance and Innovations

- Prior studies established that personal poverty and living in areas of concentrated poverty were associated with increased levels of disease damage in SLE and that access to and quality of medical care were not the principal reasons for the increased damage.
- This study is the first to document that attention to securing adequate food, medical care, and housing relegates focusing on disease to a secondary concern, except at a time of disease flare.
- The study is also the first to document the extent to which the experience and/or fear of crime is a stress that affects persons in poverty who have SLE.

Table 1

Interview Guide

1) Health Care theme: Gaining and maintaining access to health care in general and principal provider specifically for SLE

- a. How long between first symptoms and diagnosis?
- b. How long between diagnosis and reaching steady state of a treatment plan with health care providers?
 - i. Regular source of care
 - ii. Principal provider of care
- c. How did you get to the regular source of care and a principal provider of care?
 - i. What were fits and starts?
 - ii. How much was done yourself and how much by involving others?
 1. Others who knew people who had SLE or other serious conditions?
 2. Others who provided tangible and intangible support?
- d. Once in system, what has worked about the regular source of care and principal provider and what not?
 - i. Insurance issues
 - ii. Accessibility of care
 - iii. Communication/coordination
 1. Falling between cracks
 - iv. Shared decision-making
- e. What about SLE makes it difficult to get the right doctor and stay with him or her?

2) Living with SLE theme: Description for someone newly diagnosed with SLE what makes this illness difficult for you?

- a. In your mind, what triggers a flare in your lupus?
 - i. What are the stresses that you know will make your lupus worse?
 - ii. What helps to keep it in check?
- b. How do you get help from your family and friends to deal with these issues of having SLE?
 - i. What do they do to help?
 - ii. What do you wish they could do for you but don't?
- c. Moving beyond your immediate family and friends, what in your neighborhood helps you deal with lupus and what gets in the way?
 - i. Are there a lot of people with whom you can talk about your lupus?
 - ii. Do these people help you deal with your lupus by doing things for you or talking things through with you?
 - iii. What in the neighborhood got in the way of getting connected to the regular source of care and main lupus doctor?
 - iv. What in the neighborhood helps you deal with your lupus day by day and what is a source of stress?
 1. What in this neighborhood helps reduce the stress of having lupus or at least helps you deal with your lupus?
 2. What role if any does your neighborhood play in triggering lupus flares?

3) Open-ended closing to see if there are any issues not covered by the health care and living with SLE themes.

- a. What would be the ideal physician to help you manage your lupus? What would that physician do for you?
- b. What do you need to help you deal with your lupus?
- c. What would you say to people who ask what they or your friends and family can do to help you deal with your lupus?
- d. What would you say to people who ask what would be a good neighborhood for someone with lupus to live in?

Table 2

Characteristics of Study Respondents (n=28)

Characteristic	N	Mean	Std. Dev.	Range
Age		49.1	12.1	22–70
Duration of Disease		20.5	7.6	5–23
Female	25			
Race/Ethnicity				
White, not of Hispanic Background	8			
Hispanic of Any Race	4			
African American	10			
Asian American	4			
Other Races/Ethnicities	2			
Disease Activity ¹ in Worst Quartile	8			
Disease Damage ² in Worst Quartile	14			
High Level of Depressive Symptoms ³	8			

¹Systemic Lupus Activity Questionnaire (SLAQ)^{33,34} score of 15 or higher

²Brief Index of Lupus Damage (BILD)^{17,18} score of 5 or higher

³CESD scores of 24 or higher^{35,36}

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Experiences of Persons with SLE in Gaining and Maintaining Access to Health Care and Dealing with Personal- and Neighborhood-Level Stressors that Affect SLE Status, by High Income vs. Poverty, Living in Neighborhood of Concentrated Poverty vs. Not, and Being in Worst Quartile of Disease Damage in 2015

Table 3

Group	Health Care Issues			
	N	Gained Access to SLE Care in < 6 months	Maintained Access/Maneuvered through System	
Income				
High Income (household income \$100,000)	11	6	10	
In Poverty	17	8	10	
Residence (among those in Poverty)				
Living in Areas of Concentrated Poverty	11	6	5	
Not Living in Areas of Concentrated Poverty	6	2	5	
Disease Status				
Highest Quartile of Damage	14	6	10	
Lowest Three Quartiles of Damage	14	8	10	
Group				
	N	Traditional Stressors	Stressors Mentioned Socioeconomic Stressors	Adverse Neighborhood Effects
Income				
High Income (household income \$100,000)	11	11	1	0
In Poverty	17	17	11	13
Residence (among those in Poverty)				
Living in Areas of Concentrated Poverty	11	11	6	8
Not Living in Areas of Concentrated Poverty	6	6	5	5
Disease Status				
Highest Quartile of Damage	14	14	3	3
Lowest Three Quartiles of Damage	14	14	7	10