


“...Not Having the Real Support That We Need”: Patients’ Experiences With Ambiguity of Systemic Lupus Erythematosus and Erosion of Social Support

Jerik Leung,¹ Jennifer Ra,¹ Elizabeth A. Baker,² and Alfred H. J. Kim¹ 

Objective. The patient-specific experience of living with systemic lupus erythematosus (SLE) is underreported, particularly when studying factors associated with health-related quality of life (HRQOL). Recent work has suggested that biomedical interventions are only partially predictive of HRQOL measures. A qualitative analysis of patient-specific experiences can uncover additional root causes of impaired HRQOL in populations with SLE beyond the scope of quantitative questionnaires.

Methods. Consented adult patients with SLE classified by the American College of Rheumatology or Systemic Lupus International Collaborating Clinics were recruited. Ten semistructured interviews were conducted across six participants. Interviews were audio recorded, transcribed, and analyzed using an iterative process. Findings were presented to an interactive public forum with patients with SLE, family members and friends of patients, and health care professionals to assess accuracy.

Results. Four themes emerged from the interviews: 1) ambiguity, inconsistency, and lack of symptom predictability due to SLE disease courses; 2) poor communication with family, friends, and/or partners and poor bidirectional communication between health care providers and patients (informational support); 3) lack of validation for patients’ experiences (appraisal support); and 4) problematic aspects of social support, including negative support and patients’ inability to reciprocate support because of role changes. Data also indicate a reciprocal association between appraisal and informational sources of support.

Conclusion. Findings indicate that inadequate appraisal and informational support from informal and formal sources are salient factors influencing HRQOL among patients with SLE. Findings also point to the necessity of integrating community organizations, physicians, and friends and family of patients with SLE into capacity-building interventions aimed at enhancing these sources of social support.

INTRODUCTION

Systemic lupus erythematosus (SLE) is a chronic autoimmune condition with a paroxysmal and unpredictable disease course (1). SLE manifests with a wide range of symptoms from joint pain, fatigue, and photosensitivity to irreversible organ damage leading to hospitalization or death (2). These symptoms

vary considerably across different individuals and over time within specific individuals, and furthermore, no current laboratory tests can definitively diagnose SLE. Thus, the diagnosis of SLE is challenging and often results in a 5-year delay from the onset of symptoms to diagnosis (3). Furthermore, SLE treatment options are not uniformly efficacious and may cause adverse effects that limit their use (2). As a result, patients experience uncertainty during

The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

Mr. Leung was supported by a Washington University Summer Undergraduate Research award. Ms. Ra was supported by a Gina M. Finzi Memorial Student Summer Fellowship Program award from the Lupus Foundation of America and a Washington University Summer Undergraduate Research award. Dr. Kim was supported by the NIH National Institute of Arthritis and Musculoskeletal and Skin Diseases under award R21-AR-069833, and an Alliance for Lupus Research Lupus Clinical Investigators Network Clinical Trial Network Infrastructure grant.

¹Jerik Leung, BA, Jennifer Ra, HS, Alfred H. J. Kim, MD, PhD: Washington University School of Medicine, St. Louis, Missouri; ²Elizabeth A. Baker, PhD,

MPH: College for Public Health and Social Justice, Saint Louis University, St. Louis, Missouri.

Dr. Kim participated in consulting, advisory boards, and speaker’s bureaus for Exagen Diagnostics, Inc. and advisory boards for GlaxoSmithKline. No other disclosures relevant to this article were reported.

Address correspondence to Elizabeth A. Baker, PhD, MPH, Department of Behavioral Science and Health Education, College for Public Health and Social Justice, Saint Louis University, 3545 Lafayette Avenue, Salus Center, St. Louis, MO 63103. E-mail: elizabeth.baker@slu.edu or to Alfred H. J. Kim, MD, PhD, Division of Rheumatology, Department of Medicine, Washington University School of Medicine, 660 South Euclid Avenue, Campus Box 8045, St. Louis, MO 63110. E-mail: akim@wustl.edu

SIGNIFICANCE & INNOVATIONS

- Patients living with systemic lupus erythematosus (SLE) desire to, but do not, receive appraisal and informational support from formal and informal network members. This makes it difficult for them to maintain social relationships.
- Communication challenges and the often ambiguous nature of SLE symptoms are primary contributors to the breakdown of sources of social support.
- Our findings suggest that appraisal and informational support have a reciprocal relationship.

the prediagnosis stage and during the trial of different treatment options postdiagnosis.

Uncertainty during these two critical phases (prediagnosis and postdiagnosis) of living with SLE contributes to the impairment of health-related quality of life (HRQOL) in patients with SLE (4,5). In comparison with other chronic diseases (such as hypertension, congestive heart failure, type 2 diabetes mellitus, myocardial infarction, and depression), HRQOL reported by patients with SLE was lower, as assessed by the Medical Outcomes Study Short Form-36 (SF-36) (6). In particular, the average social functioning and vitality domain scores in patients with SLE were equivalent to those in patients with depression and substantially lower than those in patients with other chronic diseases.

Previous research has identified social support as a persistent unmet need in patients with SLE (7,8). Additionally, among patients with SLE, there appears to be a positive association between HRQOL (encompassing all domains of SF-36) and amount of social support, measured using the Interpersonal Support Evaluation List (ISEL) (9). This is consistent with studies examining the roles of social support and relationships in other autoimmune diseases, such as rheumatoid arthritis (RA) (10,11) and systemic sclerosis (SSc) (12), which have shown that social support can reduce the impact of disease manifestations. However, although the association of social support with HRQOL appears to be clear, the precise types of social support needed and from whom, in addition to the effects of negative support (13), remain unclear (5).

Few studies have utilized instruments that examine multiple types of social support (tangible, emotional, appraisal, and informational) (14,15), sources of social support (formal vs. informal) (16), or desires of individuals living with SLE. The four domains of social support (tangible, emotional, appraisal, and informational) that describe its functions are defined as follows: expressions of comfort and caring (emotional), advice and guidance (informational), material aid (tangible), and sense of belonging or affirmation (appraisal) (14). These functions of social support may be received or provided through either one's informal (including family, friends, and acquaintances) or formal networks (including health care providers, church groups, or the workplace) (17).

Generally, when using validated surveys (SF-36 and ISEL) to quantify the impact of general amounts of social support on HRQOL, the significance of patient experiences is not considered in the assessments (18). Qualitative methods, on the other hand, foreground patient experiences through either open-ended or semistructured interviews, which allow patients to add a richness and depth to the topic of discussion that would typically go undetected in quantitative questionnaires, thus facilitating enhanced understanding of more quantitative findings and generation of new hypotheses (19–23).

PATIENTS AND METHODS

Study design. Using a phenomenological approach, we conducted semistructured, qualitative interviews with patients with SLE to better understand their experiences of being diagnosed and living with SLE. (24). All interviews and recruiting were performed by a male undergraduate student conducting an independent research project (JL). JL has background in qualitative methods from anthropology coursework. JL had previously shadowed physicians in the Lupus Clinic at Washington University School of Medicine (St. Louis, MO) but had no formal involvement in other ongoing clinical research projects or with any potential respondents.

Interviews took place in a variety of locations determined by the participants that provided both privacy for conversation and convenience for the study participant, including medical procedure rooms, libraries, and individual homes. During some interviews, participants chose to bring a family member or supportive person. Two rounds of interviews were planned with study participants. An interview guide (available in the Supplemental Material) was constructed and consisted of questions and prompts to familiarize the researcher with the study participant, to gain a sense of the participant's path to diagnosis, and to discuss obstacles that the participant had associated with SLE. The second round of interviews further explored themes that emerged from the initial interviews. Interviews averaged 50–70 minutes.

Study participants and recruitment. Subjects with SLE classified by the American College of Rheumatology (25) or Systemic Lupus International Collaborating Clinics (26) classification criteria were recruited from the Lupus Clinic at Washington University from June 2016 to August 2016 (demographic and clinical details of recruited subjects are provided in Table 1). We used a convenience sample, speaking to patients who came in for regularly scheduled appointments during the recruitment time frame. No specific characteristics were sought. Of the 36 individuals to whom the project was introduced, 13 expressed interest in the project and consented to participate. All 13 of those individuals were contacted for first-round interviews, seven of which were successfully scheduled and completed. All 13 individuals were contacted twice to inquire about a first-round interview. Six of the seven

Table 1. Lupus clinic population characteristics^a

Demographics	Results
% female	88
% African American	57.7
% dsDNA-positive	67.8
% on prednisone	46.8
Prednisone dose, average \pm SD, mg	16.14 \pm 14.46
S2K RI-50 score, average \pm SD	5.14 \pm 5.74
Age, average \pm SD, y	41.7 \pm 13.3
Average blood iC3b level (range), μ g/mL	4.27 (0.7-21.0)
Average blood iC3b/C3 ratio (range), μ g/mg	4.49 (0.66-68.95)

Abbreviation: dsDNA, double-stranded DNA; S2K RI-50, systemic lupus erythematosus disease activity index 2000 responder index-50.

^a Data inclusive of 323 subjects with classified systemic lupus erythematosus.

study participants were contacted for follow-up interviews after transcription and analysis of the initial interviews (after reviewing first-round interviews, one individual's experience was an outlier, so this person was not asked to do a second interview, and their first-round interview was not included in the analysis). Four follow-up interviews were conducted. A total of 10 interviews were included in this analysis across six individuals. Reasons for noncompletion of interviews included unresponsiveness to interviewer's messages and difficulties with scheduling.

Ethics approval. This study was approved by the Washington University School of Medicine Institutional Review Board (protocol 201605104; initially approved June 1, 2016, and last approved August 20, 2018).

Data analysis. Interviews were audio recorded, transcribed verbatim, and reviewed for errors before beginning analysis. Qualitative analysis software was not used for transcription or generation of themes. Instead, open coding (27), whereby codes for recurring themes were generated as researchers read and reread through the transcripts, was utilized. As analyses progressed, codes were revised, and new codes were added as appropriate. Transcripts were coded by an initial coder (JL); once all transcription quotes were assigned to a code, they were printed and reviewed by two other members of the research team (EAB and AHJK). This approach enhanced credibility of our data because it challenged the initial coder's biases and enabled the coders to draw common conclusions supported by data. This step also allowed the researcher to determine whether quotes fit within a single code or were better suited to others. All coding decisions were documented to provide an audit trail of the data analysis process. Inductive analysis was then used to identify themes (28). During this step, codes were reviewed

to identify groupings or themes, and paragraphs were drafted to summarize these themes in ways that remained grounded in patients' words and experiences.

These themes were presented, in a process known as "member checking" (29), to an interactive public forum with patients with SLE (including some interview participants), family members and friends of patients with SLE, and health care professionals. The analysis and themes were presented to the audience, and participants were asked to reflect and comment on these from their perspective. They were asked broad questions such as the following:

- In what ways did the summary and themes represent their experiences?
- What would you add or take away from the themes as presented here?

Member checking, when used in this way, allows for confirmation and/or disconfirmation of findings and therefore serves as validation of the analysis (29–31). It also provides a means for those interviewed and others to add additional information. This strengthens the validity of themes because it allows representatives of populations to directly evaluate the accuracy of themes. The feedback from this forum was recorded and integrated into the final analysis and themes. These themes are presented in this article with illustrative quotes.

RESULTS

All interview respondents identified as women, three individuals identified as African American, and three individuals identified as white (Table 2). Respondents were between the ages of 26 and 46 years and had been diagnosed with SLE at least two years prior to the interview. Demographics of the clinical cohort are described in Table 1.

Audience members for the interactive public forum included 34 individuals with SLE (along with their family members, partners, or friends) and eight health care professionals and/or members of patient advocacy organizations.

Thematic categories. From our interviews with SLE patients emerged four overarching and somewhat interrelated factors that influenced their HRQOL: 1) ambiguity, inconsistency, and lack of SLE symptom predictability; 2) communication challenges with family, friends, and/or partners and health care providers; 3) desire for validation from family, friends, and/or partners and health care providers; and 4) problematic aspects of social support.

Ambiguity, inconsistency, and lack of symptom predictability. The respondents noted that the ambiguous, inconsistent, and unpredictable aspects of SLE had negative

Table 2. Respondent characteristics

Respondent	Race/ Ethnicity	Age, y	Approximate Years Since Diagnosis	Interview Round	S2K RI- 50 Score (Closest Visit to Interview)	Medication (Closest Visit to Interview)	Fibromyalgia (Yes/No)
A	African American	26	2	1	N/A	None	No
	N/A	N/A	None	...
B	African American	46	20	1	N/A	BEL, HCQ	No
	2	N/A	BEL, HCQ	...
C	White	40	6	1	N/A	RTX, MMF, PDN	Yes
	N/A	N/A	N/A	...
D	African American	31	7	1	0	AZA, HCQ, PDN	No
	2	0	AZA, HCQ, PDN	...
E	White	42	2	1	6	HCQ	No
	2	5	HCQ, PDN	...
F	White	40	7	1	0	LEU, HCQ, PDN	No
	2	0	HCQ, PDN	...

Abbreviation: AZA, Azathioprine; BEL, Belimumab; HCQ, Hydroxychloroquine; LEU, Leflunomide; MMF, Mycophenylate mofetil; N/A, not applicable; PDN, Prednisone; RTX, Rituximab; S2K RI-50, systemic lupus erythematosus disease activity index 2000 responder index-50.

effects on their HRQOL both prediagnosis and postdiagnosis.

Prediagnosis. Respondents' illness experiences began with the recognition of symptoms never experienced before, such as constant fatigue, joint pain, rash, or photosensitivity. These symptoms had a paroxysmal course and, more importantly, went largely unexplained by multiple physicians from various subspecialties. In this prediagnosis stage, respondents related the wide variability of these initial symptoms, the, seemingly, unrelatedness to each other, and the lack of clear association to a single disease. This represented the first sign of ambiguity in respondents' SLE journey, unfortunately, at a critical time when respondents were searching for an explanation of their symptoms from physicians (Table 3, quote a).

Postdiagnosis. Subsequently, all interviewed respondents had been diagnosed with SLE, but this did not reduce the ambiguity associated with their symptoms, which were experienced in two ways. First, respondents noted within-patient variability; symptoms any one respondent experienced changed over the course of the disease, including flares in different organ systems at different times. Particularly, the variability of pain, fatigue, and other symptoms prevented respondents from planning or keeping social engagements (Table 3, quote b).

Secondly, the respondents noted inconsistency of symptoms between patients. Respondents observed that even when two people have a diagnosis of SLE, their individual symptoms

may vary markedly. This inconsistency of symptoms added to their sense of ambiguity because respondents could not find a common pattern of symptoms between themselves and others with SLE (Table 3, quote c).

Table 3. Illustrative quotes: ambiguity, inconsistency, and lack of symptom predictability

- "They [doctors] did check for lupus, numerous times, but my ANA wasn't off. Even [my rheumatologist] said that unless you do a specific type of test, it's not very reliable. I couldn't eat food that was prepared. I would react to stuff like an allergic reaction. I started to have a lot of pain in my body like fibromyalgia pain which I was diagnosed with after I [left my job]. Just extreme tiredness to the point where they [employer] put me on half-days [for work]. I was passing out [from fatigue] when I got home...They [physicians] had no idea what was wrong with me."
- "I might walk today but I may not be able to walk tomorrow. You just don't know. It's hit or miss. I don't know how I'll feel on any given day so it's hard to plan *anything*. Just because you feel fine [today], you don't [know] if you'll feel fine tomorrow. Your life is like...you don't know. Minute by minute."
- "Every patient is different. Just because I lose my hair... another patient with lupus may not lose their hair. I had trouble with my appetite [had trouble maintaining weight]. My friend's aunt [who has lupus], she's as big as this table."

Abbreviation: ANA, antinuclear antibodies.

Table 4. Illustrative quotes: communication challenges

- a. "I feel like I've been put into a dryer...there's no other way to say it...I feel like I've been put in the tumble cycle.... For me it's the achiness.... It feels like I fell down while running down the hill, like someone beat you up."
- b. "[My lupus] mostly affects my joints and major organs. The worse symptom that I have is my joint pain. Lupus swelling...my ankle, my leg. It can go off at any time."
- c. "It is good that people should know about this [lupus]. I lost some friends. Because they thought I was lying [about my symptoms]. I can't walk.... I may have felt like 90% better yesterday. But I have no energy today. [I tried to tell them] You think I'm blowing you off. But I'm not."
- d. "[Other] people don't believe that they're [people with lupus] sick. There becomes a trust issue in a relationship."
- e. "The biggest thing for me is the Raynaud's.... It's not like they [other family-event participants] thought I was weird, but they did ask, 'Are you ok? What's wrong with your feet?' So I had to explain it over and over. And that's just annoying..."
- f. "It's like when I'm in the clinic, I see posters everywhere. You know. Gosh. When I go down the street to the subway or something. I don't see flyers for it [lupus]. They [businesses] got a special sub [sandwich] or something for any fundraisers for other illness. Why can't we do the same thing for lupus? They're places that do that [fundraising for lupus]. I don't understand. That's why I think people think it's a joke."
- g. "I usually just say the whole 'my immune system is behaving badly' [when people ask]. That instead of a normal response to things, my body is attacking me instead...I'm honestly to the point where I'll briefly explain stuff [about lupus to other people] but I don't like that awkward crap that goes with it."
- h. "I just don't think they [people generally] care [about lupus]. They won't understand it [lupus] and I don't think they care. Why expose a part of my life when you [person with no knowledge of lupus] won't be around to pick me up when I fall. Not going to show that part of my life because you really don't care."
- i. "I don't think that lupus [has] really [been] defined to me. I know what happens but I don't think I really understand...I have joint pains, skin rashes. I just start breaking it down. But like I said, I don't even fully understand.... If I'm ok today, why am I not ok tomorrow?... That's the part I don't understand."
- j. "These are things that doctors [rheumatologists] know... that it's probably important for the patient to know, but they don't necessarily think about telling the patient that. [As a patient] you don't know how it's going to progress... They diagnose you with lupus. Well, what does that mean? Well it means you have joint issues. What does that mean?"
- k. "They [rheumatologists] say, 'Oh you have symptom A, symptom B, C.' I have symptom A plus this other thing. And they said, 'Well oh...you're supposed to have symptom A, B, C. That's [having symptom A, B, C] normal.' So I think it would just be better if they [rheumatologists] receive the information that they're getting [but] most of them throw at me what they read. Or what happens in another patient. With lupus, everyone is not the same."

Communication challenges. The second major theme from the data related to communication challenges with both respondents' family, friends, and partners (informal network) and

health care professionals (formal network). Some respondents described trying to explain SLE to family and friends through metaphor (Table 4, quote a), whereas others focused on specific symptoms (Table 4, quote b). In both cases, respondents indicated they felt that their communication was insufficient to inform others about SLE.

Family, friends, and partners. Respondents noted a number of challenges in communicating their experiences of living with SLE to family members, friends, or partners. Some tried to explain the gestalt of SLE through use of metaphors (Table 4, quote a).

Others were more direct in their descriptions and attempted to capture the key symptoms they experience as a result of living with SLE, primarily the intermittent and unpredictable bodily debilitations (Table 4, quote b).

Despite their attempts to clarify and describe their SLE, respondents indicated that they felt that their communication was insufficient to inform others about what SLE is and how it differs from other diseases. Importantly, they also highlighted that this inability to provide information to others about SLE led to interpersonal conflict (Table 4, quote c).

The unpredictability of SLE was particularly difficult to convey and contributed to miscommunications. Specifically, respondents felt that others did not listen to their words and wrongfully attributed negative intention to respondents' inability to meet social engagements. Miscommunication and misinterpretation of respondents' actions by others contributed to a breakdown of trust among individuals in their social worlds (Table 4, quote d).

In addition to this breakdown of trust, the constant battle to provide information about SLE to their family, friends, or partners elicited frustration, and respondents expressed annoyance that the burden of explanation typically fell on them; respondents felt that they had to continuously supply (and resupply) information about their disease to others but with little indication that these efforts were effective (Table 4, quote e).

Respondents partially attributed others' lack of information about SLE (and their challenges in conveying information) to insufficient public awareness campaigns regarding SLE. They felt that such efforts would lessen their personal burden of explanation and make it easier for people to believe their experiences (Table 4, quote f).

Ultimately, having to constantly explain their illness was taxing, and some respondents felt that the effort was not worth their time or energy (Table 4, quote g).

For some respondents, the cumulative effect of these continuous communication challenges was the decision to intentionally mask their symptoms. Although this allowed the respondents to avoid talking about their SLE symptoms, it also furthered misinterpretation by others (Table 4, quote h).

Health care providers. Poor communication was also prominent in respondents' interactions with their health care providers and manifested in two ways: 1) respondents wanted more information about SLE and 2) respondents struggled with health care providers' lack of knowledge about or misconceptions of SLE.

Respondents did not feel that they had the concrete information they needed about SLE. Sometimes, this was stated as a general confusion about some aspects of SLE (Table 4, quote i).

Other times, the desire for rheumatologists to fulfill this information-providing role was mentioned explicitly. Despite living with SLE, respondents expressed that they do not understand the disease in general and want additional information to help them better understand why they have certain symptoms at certain times and not at others. They found little meaning in knowing that they were diagnosed with SLE because they were missing a proper explanation, including information about their prognosis, from their rheumatologist (Table 4, quote j).

The desire for better communication was also expressed as a desire for the rheumatologist to do a better job of listening to patients. Respondents identified challenges in the exchange of information between themselves and their rheumatologists; they saw themselves as conveying information about their SLE symptomatology to their rheumatologist. However, respondents felt that their rheumatologists were often unable to accept the information they provided or shared information about SLE symptoms and the disease process on the basis of preconceived notions of the symptoms the patient was "supposed" to experience, which were based on medical texts they had read or on experiences with other patients (Table 4, quote k).

Desire for validation. Respondents indicated that their experiences were not validated by either their family, friends, or partners (informal network) or their health care professionals (formal network). Respondents indicated that some of the lack of validation was due to the disease process itself. Respondents also attributed their lack of validation in part to their own behavior such that patients' lack of sharing their experiences made it difficult for people to validate that experience.

Family, friends, and partners. The breakdown in information exchange with others prevented respondents from receiving appraisal support from family, friends, or partners; in other words, they felt that they lacked a sense of validation, belonging, or understanding in part because they did not fully share their experience with others (Table 5, quote a).

In addition, respondents noted that specific aspects of SLE contributed to this process. In particular, the general public does not understand that SLE does not just involve having a symptom, but that it is a disease in which there is variability of symptom presentation. Respondents felt that this lack of awareness of the SLE disease process, coupled with the variety of symptoms with

Table 5. Illustrative quotes: desire for validation

-
- a. "They just don't understand. They don't have enough information.... I normally don't tell them. It's probably from past relationships. Because they [people who don't understand] fall back or they pity you. And I don't want that."
 - b. "Everybody doesn't have the rash. I think if everybody has the rashes, every lupus person, then they [others] would believe it. But everybody doesn't have them. It [lupus] attacks in different areas in different moments. Some people look at it, how is something making your head hurt and giving sores in your mouth? How is something making your body hurt? I don't really hang out with a lot of people. They just don't really believe it. And I don't like them anymore."
 - c. "Even when I'm healthy, I still need help. If you [I] try to do too much. Just because you feel good today, don't do everything. You could feel bad all week [if you try to do too much]. I'm trying to get him [my partner] to understand that. I think that the most important thing is that, no one in my family understands it. No one in my family. They don't ask me anything. They don't come see me. There is no help. There is nothing."
 - d. "I just break down sometime[s]. [The rheumatologist] asked me these asinine questions. But the answer I give is not good enough for [my rheumatologist]. It's not what [my rheumatologist] wants to hear. [My rheumatologist says to me] 'Oh no, you shouldn't have that [those symptoms].' *But I do.*"
 - e. "[My rheumatologist] always explains everything thoroughly. [My rheumatologist] actually looks like [he or she] cares. Which is a big problem [with doctors generally]. There are people that seem like they care. But if they would actually listen to you and listen to how your every day goes [things would be better]. [My rheumatologist] kept looking and researching. For me, this is the first medication that I've had that has actually helped me with lupus."
 - f. "I want to say thank you. It was also therapeutic. Because [the health care professional] listens. [They were] like a therapist. [They] let me voice all of my concerns. [They] actually listened. [They] also relayed them to the doctor. And my doctor's visits got easier.... It was really therapeutic. Thank you."
-

variable severity, made people in their social network not believe them and provide validation (Table 5, quote b).

Patients expressed a strong desire to feel validated in their experience but were denied this validation when other people did not understand their symptoms. This contributed to the sense that respondents could not rely on others for help when they needed it and represented a significant deterioration of their social network (Table 5, quote c).

Health care providers. Desire for validation was also evident in respondents' interactions with health care providers and was similar to their desire for rheumatologists to listen to them. As stated earlier, when speaking with their rheumatologists, respondents encountered established conceptions of SLE; physicians seemed focused on the "book" definition of SLE and what typical symptoms should be. In addition to

desiring informational exchanges that go beyond these book definitions, respondents also noted a strong desire to have their rheumatologists validate their individual experiences and symptoms (Table 5, quote d).

Additional evidence for this desire for validation was respondents' focus on physicians who appeared to genuinely care about their patients. When physicians not only listened but also acted in response to patient experiences, respondents associated these positive interactions with improvements in their condition (Table 5, quote e).

Respondents' desire for validation was affirmed at the member checking forum, during which the impact of health care professionals (both clinical and nonclinical) listening to respondents' words was powerful. Respondents' noted the importance of having not only their voices heard but also their experiences affirmed, as evidenced by the use of the word "therapeutic." In other words, respondents felt validated that health care professionals actually listened to their words (Table 5, quote f).

Problematic aspects of social support. Additional aspects of social support were present but did not fit into the categories presented. Examples in this section involve respondents' experiences with negative support (support that is received but not perceived as useful by the recipient) and changes in social roles that contributed to respondents' impaired ability to provide support to others and required them to change their self-identity.

Negative support. In addition to not receiving validating support from family, friends, or partners, respondents noted that such individuals provided negative support despite their good intentions. As one respondent noted, their friends and family believed they were aiding the respondent by advising against doing certain activities that might exacerbate their symptoms. However, respondents viewed this behavior as problematic. These negative interactions created another barrier to maintaining relationships with individuals in their social network (Table 6, quote a).

Changes in social roles. Respondents noted that changes in their ability to fulfill previous social roles was challenging. For example, respondents noted that they were no longer able to provide support to individuals in their social worlds (Table 6, quote b).

Others struggled with their changed role in society, which, in turn, challenged their self-identity (Table 6, quote c).

DISCUSSION

In our study, we aimed to enhance our understanding of patients' experiences with SLE, including their perceptions regarding factors that influenced their HRQOL. Four themes emerged from the data: 1) ambiguity, inconsistency, and lack of SLE symptom predictability; 2) communication challenges with family, friends, and/or partners and health care providers; 3) desire

Table 6. Illustrative quotes: problematic aspects of social support

- a. "Sometimes they [friends, family] limit stuff [that I want to do]. They tell me that I can't do stuff. They say don't do that. I know that it's out of care because they don't want me to be sick. [But] If I can do something, I like to do it when I can."
- b. "The mom you were before [lupus] is not the mom you are now. But going out and playing out in the yard, going camping and hiking. That doesn't happen. So is our family's social life.... You are someone that is taken care of now. Not someone who takes care of everybody."
- c. "Before I got sick I did not have any problems. I was extremely active. I always ate well...I can tell you that I was majorly depressed at first [after being forced to retire]...I struggle with how I fit [into my role] now. I've had to force myself to relax my standards on myself..."

for validation from family, friends, and/or partners and health care providers; and 4) problematic aspects of social support.

Our findings suggest a reciprocal relationship between informational and appraisal sources of support within patients' informal social networks. Although respondents tried to convey information to individuals in their informal network, their ideas and meanings were frequently misinterpreted by others, minimizing their ability to obtain validation from others in their social networks. Ultimately, these misinterpretations and feelings of invalidation contributed to erosion in respondents' informal relationships, demonstrated by the breakdown in trust in these relationships. Additionally, respondents themselves may have furthered this erosion of communication by masking their symptoms to avoid the frustration they associated with constantly needing to explain their condition.

As with their informal sources of support, respondents articulated a distinction between the importance of informational exchange (informational support) and of feeling valued (appraisal support) in their exchanges with health care providers (ie, formal networks). Respondents felt that increasing physician integration of information about SLE (from books and from listening to patients) and physician capacity to communicate to patients about SLE were essential for respondents feeling valued.

Our findings are consistent with studies aiming to elucidate patient experiences in other chronic rheumatic diseases, such as SSc (12), RA (32,33), and multiple sclerosis (MS) (34). Overlapping themes include dealing with uncertainty (SSc, RA, and MS), poor communication with physicians (MS), inadequate physician validation (SSc), role changes (SSc and RA), and poor availability of disease information (SSc). Additionally, our findings align with those from previous qualitative studies (35) that examined patients' experiences in SLE specifically, including a cycle of disabling and unpredictable pain, uncertainty associated with both gaining a diagnosis and subsequent prognosis, respondents' desire for more knowledge of SLE, and poor rapport with clinicians.

Mazzoni and Cicognani (13,36) have recently noted the impact of negative social support on SLE symptomatology. In a

qualitative study, they classified instances of social support that respondents found to be unhelpful into the following categories: oppressive support (ie, too focused on illness), support denying the illness, and support based on divergent illness representations (13). Our study affirms these findings, as evidenced by instances of respondents feeling limited by what others perceived as helpful support and persistent disconnect in understanding SLE symptoms.

Although others have noted the general importance of social support to HRQOL, our work contributes to the field by providing specific suggestions for interventions to improve particular aspects of social support. Our data demonstrate that communication challenges resulting from and about aspects of SLE are at the forefront of people's experiences. The capacity to communicate clear information about SLE appears to be important to the maintenance of both informal and formal networks. Respondents explicitly desired more information about SLE from their doctors. With this information, they will be better able to express their lived experiences and will potentially be better able to clinically manage their symptoms. Respondents also indicated that they would be better able to provide information to their informal networks (friends and family) if they received the informational support that they required from their formal networks (health care providers).

They also indicated that they wanted to see greater efforts to increase general knowledge of SLE through public awareness campaigns. Interventions designed to address informational and appraisal support may include specific activities to improve general communication skills (eg, interactive didactic sessions, role-playing, and video demonstrations), specific skills for interacting with health care providers (eg, asking questions and daily symptom journaling), or specific skills for talking about SLE (eg, useful phrases or terms). When designing interventions that incorporate these ideas, the integration of caregivers/supportive partners should be considered, a suggestion supported by previous work demonstrating the association of patient and caregiver HRQOL in SLE (37). Examples of this may be explicit encouragement/explanation of including a caregiver at not only appointments but also support group meetings and other educational activities. In addition to these interventions, our data also affirm the importance of using SLE-specific clinical metrics to assess patient satisfaction (38,39).

Our work is also unique because we began with patient experiences. This enabled us to elucidate the contribution of ambiguity to patient experiences as well as the importance of different types of support (appraisal and informational support) from different sources.

The small sample size (10 interviews across six individuals and 40 audience members during the interactive forum) limits the broad applicability of these findings to SLE at a population level, but within a phenomenological approach, it is considered appropriate to consider what some have called individual saturation or a full and complete accounting

of an individual's perspective (40). Thus, the goal within this approach is to ensure in-depth understanding and to have that understanding potentially lead to new lines of research. In addition, socioeconomic factors and race were not addressed explicitly during the data collection or analysis. The racial and sexual variability in our sample was limited (all women; only white or African American), partially because of the demographic characteristics of the available cohort (Table 1). Although there was not a male perspective of SLE in the interview portion of this qualitative work, we made efforts to include men and introduced the project to several male patients. The difficulty of recruiting male participants was compounded by their low representation in the available clinical cohort (Table 1). Future studies would need to better account for the demographic variations, particularly those examining larger populations, because these individuals with differing racial and sexual identities may offer additional perspectives/experiences of SLE.

There is also the potential concern of interpretation biases of researchers during interviews, but the member checking forum enhanced the credibility of initial findings. Thus, although associations drawn are not definitive, the themes presented here were the most salient and consistent across all respondents.

An important implication of these data is the need to identify whether inadequate social support directly contributes to impaired HRQOL in patients with SLE. Proper recognition of the deficiencies in social support is an unmet need in SLE (7,8). When appropriately addressed in other studies, improvements in HRQOL were observed (41–43). Efforts are underway to measure HRQOL, with either generic or SLE-specific patient-reported outcomes (PROs) as secondary outcomes in randomized controlled trials (39,44–47). It is not clear, however, whether these PROs can identify social support deficiencies as a root cause of impaired HRQOL. Furthermore, we suggest that future PROs may need to address the multiple etiologies that lead to erosions in social support.

In conclusion, our data point to the potential impact of informational and appraisal support from family, friends, and physicians, as well as to the impact of public awareness campaigns, on health outcomes and have implications with both intervention and research. In particular, interventions need to recognize the unique experiences of individuals with SLE, particularly regarding the ambiguity and uncertainty they experience. Within this context, interventions may need to consider developing the capacity of individuals with SLE to obtain informational and appraisal support within informal networks and enhancing physician skills in providing information and validation to individuals with SLE.

ACKNOWLEDGMENTS

All authors express their utmost gratitude to the individuals who participated in the study and provided their words, experi-

ences, and insights into living with systemic lupus erythematosus (SLE). The authors would also like to acknowledge Nancy Mathis and Lacey Feigl for administrative assistance and Vibeke Strand, Zahi Touma, Lisa Zickuhr, and Shivani Mitra for critical reading of the manuscript.

AUTHOR CONTRIBUTIONS

All authors were involved in drafting the article or revising it critically for important intellectual content, and all authors approved the final version to be published and take responsibility for the integrity of the data and the accuracy of the data analysis.

Study conception and design. Leung, Baker, Kim.

Acquisition of data. Leung, Ra.

Analysis and interpretation of data. Leung, Ra, Baker, Kim.

REFERENCES

- Petri M, Genovese M, Engle E, Hochberg M. Definition, incidence, and clinical description of flare in systemic lupus erythematosus. A prospective cohort study. *Arthritis Rheum* 1991;34:937–44.
- Kuhn A, Bonsmann G, Anders HJ, Herzer P, Tenbrock K, Schneider M. The diagnosis and treatment of systemic lupus erythematosus. *Dtsch Arztebl Int* 2015;112:423–32.
- Pistiner M, Wallace DJ, Nessim S, Metzger AL, Klinenberg JR. Lupus erythematosus in the 1980s: a survey of 570 patients. *Semin Arthritis Rheum* 1991;21:55–64.
- Stockl A. Complex syndromes, ambivalent diagnosis, and existential uncertainty: the case of systemic lupus erythematosus (SLE). *Soc Sci Med* 2007;65:1549–59.
- Mazzoni D, Cicognani E. Social support and health in patients with systemic lupus erythematosus: a literature review. *Lupus* 2011;20:1117–25.
- Jolly M. How does quality of life of patients with systemic lupus erythematosus compare with that of other common chronic illnesses? [review]. *J Rheumatol* 2005;32:1706–8.
- Danoff-Burg S, Friedberg F. Unmet needs of patients with systemic lupus erythematosus. *Behav Med* 2009;35:5–13.
- Moses N, Wiggers J, Nicholas C, Cockburn J. Prevalence and correlates of perceived unmet needs of people with systemic lupus erythematosus. *Patient Educ Couns* 2005;57:30–8.
- Sutcliffe N, Clarke AE, Levinton C, Frost C, Gordon C, Isenberg DA. Associates of health status in patients with systemic lupus erythematosus. *J Rheumatol* 1999;26:2352–6.
- Riemsma RP, Rasker JJ, Taal E, Griep EN, Wouters JM, Wiegman O. Fatigue in rheumatoid arthritis: the role of self-efficacy and problematic social support. *Br J Rheumatol* 1998;37:1042–6.
- Fitzpatrick R, Newman S, Lamb R, Shipley M. Social relationships and psychological well-being in rheumatoid arthritis. *Soc Sci Med* 1988;27:399–403.
- Sumpton D, Thakkar V, O'Neill S, Singh-Grewal D, Craig JC, Tong A. "It's not me, it's not really me." Insights from patients on living with systemic sclerosis: an interview study. *Arthritis Care Res (Hoboken)* 2017;69:1733–42.
- Mazzoni D, Cicognani E. Problematic social support from patients' perspective: the case of systemic lupus erythematosus. *Soc Work Health Care* 2014;53:435–45.
- Uchino BN. Social support and physical health: understanding the health consequences of relationships. New Haven (CT): Yale University Press; 2004.
- House JS. Work stress and social support. Reading (MA): Addison-Wesley; 1981.
- Israel BA, Rounds KA. Social networks and social support: a synthesis for health educators. In: Ward WB, Simonds SK, Mullen PD, Becker M, editors. *Advances in health education and promotion: a research annual*. Vol. 2. Greenwich (CT): Jai Press; 1987. p. 311–51.
- Guidry JJ, Aday LA, Zhang D, Winn RJ. The role of informal and formal social support networks for patients with cancer. *Cancer Pract* 1997;5:241–6.
- Carr AJ, Higginson IJ. Are quality of life measures patient centred? [research support]. *BMJ* 2001;322:1357–60.
- McElhone K, Castelino M, Abbott J, Bruce IN, Ahmad Y, Shelmerdine J, et al. The LupusQoL and associations with demographics and clinical measurements in patients with systemic lupus erythematosus. *J Rheumatol* 2010;37:2273–9.
- Miles A. Living with lupus: women and chronic illness in Ecuador. Austin (TX): University of Texas Press; 2013.
- Jolly M, Pickard AS, Sequeira W, Wallace DJ, Solem CT, Mikolaitis RA, et al. A brief assessment tool for body image in systemic lupus erythematosus. *Body Image* 2012;9:279–84.
- Hatfield-Timajchy K. Delayed diagnosis: the experience of women with systemic lupus erythematosus in Atlanta, Georgia. Atlanta: Emory University; 2007.
- Archenholtz B, Burckhardt CS, Segesten K. Quality of life of women with systemic lupus erythematosus or rheumatoid arthritis: domains of importance and dissatisfaction. *Qual Life Res* 1999;8:411–6.
- Creswell JW, Poth CN. *Qualitative inquiry and research design: choosing among five approaches*. 4th ed. Thousand Oaks (CA): SAGE Publications; 2018.
- Hochberg MC. Updating the American College of Rheumatology revised criteria for the classification of systemic lupus erythematosus. *Arthritis Rheum* 1997;40:1725.
- Petri M, Orbai AM, Alarcón GS, Gordon C, Merrill JT, Fortin PR, et al. Derivation and validation of the Systemic Lupus International Collaborating Clinics classification criteria for systemic lupus erythematosus. *Arthritis Rheum* 2012;64:2677–86.
- Strauss A, Corbin J. *Basics of qualitative research: techniques and procedures for developing grounded theory*. 2nd ed. Thousand Oaks (CA): SAGE Publications; 1998.
- Patton MQ. *Qualitative research & evaluation methods: integrating theory and practice*. 4th ed. Thousand Oaks (CA): SAGE Publications; 2015.
- Lincoln YS, Guba EG. *Naturalistic inquiry*. Newbury Park (CA): SAGE Publications; 1985.
- Charmaz K. *Grounded theory*. In: Smith JA, editor. *Qualitative psychology: a practical guide to research methods*. 2nd ed. London: SAGE Publications; 2008. p. 81–110.
- Guba EG, Lincoln YS. *Fourth generation evaluation*. Newbury Park (CA): SAGE Publications; 1989.
- Flurey CA, Morris M, Richards P, Hughes R, Hewlett S. It's like a juggling act: rheumatoid arthritis patient perspectives on daily life and flare while on current treatment regimes. *Rheumatology (Oxford)*. 2014;53:696–703.
- Kvrgic Z, Asiedu GB, Crowson CS, Ridgeway JL, Davis JM III. "Like no one is listening to me": a qualitative study of patient-provider discordance between global assessments of disease activity in rheumatoid arthritis. *Arthritis Care Res (Hoboken)* 2018;70:1439–47.
- Dennison L, McCloy Smith E, Bradbury K, Galea I. How do people with multiple sclerosis experience prognostic uncertainty and prognosis communication? A qualitative study. *PLoS One* 2016;11:e0158982.
- Sutanto B, Singh-Grewal D, McNeil HP, O'Neill S, Craig JC, Jones J, et al. Experiences and perspectives of adults living with

- systemic lupus erythematosus: thematic synthesis of qualitative studies. *Arthritis Care Res (Hoboken)* 2013;65:1752–65.
36. Mazzoni D, Cicognani E. The problematic support scale: a validation among patients with systemic lupus erythematosus. *J Health Psychol* 2016;21:1711–7.
37. Jolly M, Thakkar A, Mikolaitis RA, Block JA. Caregiving, dyadic quality of life and dyadic relationships in lupus. *Lupus* 2015;24:918–26.
38. Jolly M, Kosinski M, Garris CP, Oglesby AK. Prospective validation of the Lupus Impact Tracker: a patient-completed tool for clinical practice to evaluate the impact of systemic lupus erythematosus. *Arthritis Rheumatol* 2016;68:1422–31.
39. Jolly M, Pickard AS, Block JA, Kumar RB, Mikolaitis RA, Wilke CT, et al. Disease-specific patient reported outcome tools for systemic lupus erythematosus. *Semin Arthritis Rheum* 2012;42:56–65.
40. Saunders B, Sim J, Kingstone T, Baker S, Waterfield J, Bartlam B, et al. Saturation in qualitative research: exploring its conceptualization and operationalization. *Qual Quant* 2018;52:1893–907.
41. Kozora E, Ellison MC, Waxmonsky JA, Wamboldt FS, Patterson TL. Major life stress, coping styles, and social support in relation to psychological distress in patients with systemic lupus erythematosus. *Lupus* 2005;14:363–72.
42. Dobkin PL, Fortin PR, Joseph L, Esdaile JM, Danoff DS, Clarke AE. Psychosocial contributors to mental and physical health in patients with systemic lupus erythematosus. *Arthritis Care Res* 1998;11:23–31.
43. Zheng Y, Ye DQ, Pan HF, Li WX, Li LH, Li J, et al. Influence of social support on health-related quality of life in patients with systemic lupus erythematosus. *Clin Rheumatol* 2009;28:265–9.
44. Strand V, Chu AD. Generic versus disease-specific measures of health-related quality of life in systemic lupus erythematosus. *J Rheumatol* 2011;38:1821–3.
45. McElhone K, Abbott J, Shelmerdine J, Bruce IN, Ahmad Y, Gordon C, et al. Development and validation of a disease-specific health-related quality of life measure, the LupusQoL, for adults with systemic lupus erythematosus. *Arthritis Rheum* 2007;57:972–9.
46. Doward LC, McKenna SP, Whalley D, Tennant A, Griffiths B, Emery P, et al. The development of the L-QoL: a quality-of-life instrument specific to systemic lupus erythematosus. *Ann Rheum Dis* 2009;68:196–200.
47. Annapureddy N, Devilliers H, Jolly M. Patient-reported outcomes in lupus clinical trials with biologics. *Lupus* 2016;25:1111–21.