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Understanding Systemic Lupus Erythematosus Patients' Desired Outcomes and Their Perceptions of the Risks and Benefits of Using Corticosteroids

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Introduction

Systemic Lupus Erythematosus (SLE) is a complex, multi-system autoimmune condition in which patients often experience periods of fluctuating disease activity. During periods of disease exacerbations, also known as flares, multiple organs, including the skin, joints, blood counts and kidneys can be affected.^{1, 2} Patients may experience other chronic issues as well, such as fatigue and cognitive impairment that are not associated with the flares.³ These symptoms and disease manifestations are often debilitating to the patients' physical and psychosocial well-being.^{2–6} Despite advancements in clinical management and improved survival,⁷ several aspects of SLE management remain challenging. For one, management of SLE flares often involves the use of potent medications like corticosteroids. Corticosteroids, the mainstay of SLE treatment, reduce disease symptoms and mitigate flares through suppressing the body's inflammatory and immune response.^{8, 9} However, corticosteroid use is a complex clinical dilemma because long-term use is associated with several adverse effects, such as a 50% increased risk for permanent organ damage and a 2.5-fold higher risk of a cardiovascular event.^{2, 10} Corticosteroids also are known to induce osteoporotic fractures, cataracts, glaucoma, and metabolic adverse events.^{11–15} Striking a balance between minimizing adverse effects and maximizing treatment outcomes necessitates careful consideration of the risk tolerances that SLE patients have towards the adverse effects of corticosteroids, as well as how SLE patients prioritize treatment outcomes.

The multi-systemic nature of SLE also presents a challenge for evaluating treatment outcomes. Outcomes assessment in SLE management is multidimensional and includes monitoring disease activity and the impact of the disease and treatment on organ damage and

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quality of life.^{16–18} While disease activity and organ damage are indicators of the patient's medical status, quality of life encapsulates the impact of the disease on a patient's overall well-being.³ Also, lupus activity does not necessarily correlate with quality of life.^{19, 20} Physicians and patients tend to disagree on their assessment of disease activity and share different perspectives on treatment outcomes.^{21–26} SLE patients tend to place more importance on self-perceived functional status and subjective symptoms while physicians place more importance on objective measures such as abnormal laboratory findings.²⁵ Therefore, knowledge of how SLE patients prioritize different outcomes is informative for clinicians in formulating and explaining treatment plans to SLE patients.

There are several studies examining the burden of corticosteroids use,^{2, 10, 27} but most do not examine the risks and benefits of corticosteroids use in SLE from the patients' perspective. This is an important area since treatment decisions on the use of corticosteroids in SLE management requires difficult trade-offs between efficacy and risk of toxicity, which inherently rely on the perceptions that patients have towards different treatment outcomes and risks. Therefore, this study utilizes a qualitative approach to examine SLE patients' most desired outcomes for the management of their illness and their concerns with corticosteroids.

Methods

This qualitative study proceeded in two phases. First, a series of five, individual in-depth interviews were conducted to explore SLE patients' experiences with disease control and concerns about corticosteroid use. In the second phase, focus groups were conducted to further explore the relevance and importance of themes that emerged from the in-depth interviews. This 2-phase process allowed us to capture the breadth and depth of individual experiences managing SLE treatment. The lead investigator (XN) conducted all of the in-depth individual interviews and moderated the focus groups with an assistant who helped with note taking. The study protocol was approved by the University of Maryland Institutional Review Board.

Participants and Recruitment Procedures

A convenience sample of participants was recruited between May 2015 and September 2015 from the community outpatient clinics of the Johns Hopkins Lupus Center and the University of Maryland Rheumatology clinic. Individuals were eligible for participation if they had a) a clinical diagnosis of SLE and b) either current or past experience with the use of corticosteroids. Exclusions were made if individuals had a cognitive disability that would prevent them from understanding what the study entailed and what they would have to do if they joined the study. Study flyers describing the study and the lead investigator's contact information were distributed to patients during their regularly scheduled clinical appointment. Interested individuals contacted the lead investigator (XN) who completed a brief telephone screen to determine eligibility. Face-to-face in-depth interviews were scheduled with eligible participants within one week after the telephone screen. Focus groups were convened when enough individuals were recruited to hold a group. During each interview or focus group, participants completed a brief questionnaire that captured basic sociodemographic characteristics and clinical management of SLE (i.e., duration of the

diagnosis). Written informed consent was obtained from all participants before any study assessments were administered or any interviews or focus group discussions were conducted. At the end of the interviews or focus groups, participants received a \$35 gift card as compensation for their time.

In-depth Interviews

Using a semi-structured guide (appendix), interviews comprised open-ended questions to stimulate a dialogue about patient experiences with SLE treatment, the outcomes that mattered to them and the concerns that they may have had with the use of corticosteroids. Specifically, participants were asked “Can you let me know what outcomes are important to you in your Lupus treatment?” and “Can you tell me about some of your concerns with using corticosteroids (e.g. prednisone)?”. Participants were also asked to describe their overall experiences with using corticosteroids. Probes were used, as appropriate, to encourage participants to share more details about a specific experience, thereby enabling a rich description of participants’ perceptions on desired outcomes and corticosteroid risks. The one-on-one interviews allowed for in-depth discussion of participants’ experiences and thoughts. Five individual interviews were conducted in total and each interview lasted for approximately one hour.

Focus Group Discussions

Focus groups were used to stimulate an interactive discussion about the thematic concepts that emerged from the in-depth individual interviews. Each focus group comprised of 3–5 participants. To facilitate the discussion, participants were provided with a list of the thematic concepts and asked to indicate any that were relevant to their own experience and note any that may have been missing from the list. Participants were encouraged to lead the discussion so as to stimulate interactions between them, to identify concepts that required further clarification, and to elaborate on the relevant concepts that they felt most salient. Feedback from each session was used to update the thematic concepts, which was presented to the subsequent groups. In this way, the process was iterative with each step building upon the previous step. Each focus group session lasted for approximately two hours and the sessions were conducted until thematic saturation i.e. no additional concepts emerged, and this was achieved by the fourth session.

Analysis

Descriptive statistics were used to characterize the self-reported sociodemographic and clinical management data. The data were summarized using STATA/SE® version 13.

All in-depth individual interviews and focus group discussions were audio-recorded with permission from the participants, and transcribed verbatim. The transcripts were analyzed using thematic analysis based on a grounded theory approach. We chose to adopt a grounded theory approach to the analysis as this approach encourages inductive development of a conceptual framework based on input from the participants rather than *a priori* theories or existing concepts.²⁸ Two coders conducted the thematic analysis by first reading the transcripts to get a general sense of the discussion and then independently sorted the textual passages into codes reflecting broad themes.²⁹ A codebook was developed based on the

themes identified. During regularly scheduled meetings, coding discrepancies were discussed until consensus was reached. This resulted in the refinement of the codes as the analysis proceeded. All qualitative analyses were conducted using NVivo® version 10.

Results

Description of the sample

Five SLE patients participated in the individual, in-depth interviews while 15 patients participated in the four focus groups. Of note, one of the participants who took part in the in-depth interview was feeling fatigue and had to leave at the end of the interview before filling out the sociodemographic questionnaire. Therefore, we only have sociodemographic information for four out of the five participants for the in-depth interviews. The four patients who provided sociodemographic information were women, African-Americans and between the ages of 31 to 57 years. Detailed characteristics of these 4 participants, together with the characteristics of the 15 participants in the focus groups are shown in Table 1. The majority of the 15 participants in the focus groups were women (80%), African American (60%) and were currently employed (60%). The median years diagnosed with SLE was 15.3 (range: 2 – 25) years and 53% were currently using corticosteroids to manage their SLE.

Desired Outcomes

Six broad themes were initially identified from the five individual interviews. These included 1) reduction in flares, 2) reduction in physical symptoms, 3) maintenance of normal activities, 4) minimization of treatment side effects, 5) prevention of future organ damage, and 6) finding a cure. All six themes were endorsed by the focus group participants. One additional theme, reduction in hospitalizations, was identified in the focus groups. However, this was eventually categorized as a subtheme under “reduction in flares” because after further discussions with participants it was revealed that this concept was associated with flares that resulted in hospitalization. “Reduction in physical symptoms” was eventually categorized as a subtheme under “reduction in flares” and “maintenance of normal activities” as participants were describing physical symptoms as a sequela of a flare-up, and being limited by these symptoms in terms of their work or leisure activities. The final five central themes prioritized by SLE participants are described below. Exemplary quotes of each theme and subthemes are presented in Table 2.

Reduction in flares—Participants consistently wanted a reduction in flares, which was described along three dimensions. First, participants wanted a decrease in the frequency of flare episodes i.e. “*less flare-ups*”. Second, some of them were focused on the severity of their flares and wanted to reduce the number of times that they experience a flare serious enough that they have to be hospitalized. Third, participants also appeared to be primarily concerned with the physical symptoms that experience during a flare. They expressed a desire to reduce these symptoms, which included joint stiffness, pain, fatigue and rashes. Further, these participants also mentioned that the physical symptoms associated with their flares often affected their emotional well-being. One participant commented “*Butterfly rash and no hair I literally stayed in the house for a year. Literally. It was the worst.*”

Maintenance of normal activities—Maintaining their ability to go about their normal, day-to-day activities was important. Some of them have had the experience of canceling on social outings because of their SLE symptoms. Therefore, they really wanted to be able to go out on the weekends with their friends and loved ones, and not be restricted by their SLE symptoms. In addition, some of them who were employed had to modify their job responsibilities because of SLE. For example, one participant could not lift heavy objects; one participant could not stand for long periods of time, and some of them had to take some days off work whenever their symptoms worsened.

Minimization of treatment side effects—The majority of the participants wanted less treatment-emergent side effects. Some of these treatment side effects can be worse than the symptoms of SLE. In a patient's own words: *"I find that the medication side effects are worse than me getting over a flare at home."*

Prevention of future organ damage—Most participants expressed concerns with organ damage manifesting from both their SLE and SLE treatment. Some participants were aware that when they experienced a flare, their kidneys could be involved; and they were worried about further damage to them.

Finding a cure—Many of the participants are dissatisfied with the current treatment modalities available to them and wanted better options to keep their SLE under control. Almost all participants desired a cure over symptomatic management. This desired outcome might be related to participants' belief that the current existing treatments have *"all these horrific side effects"*.

Concerns with corticosteroids use

The majority of the participants (N=17) expressed concerns with the potential adverse effects of corticosteroids. The individuals expressed varying levels of concerns for different adverse effects. On one hand, some participants felt that keeping their SLE symptoms under control was more important than the adverse effects of corticosteroids. For example, participants were quoted as saying *"prednisone even with all of its bad side effects, makes you feel better"* and *"(When using prednisone) I'll be miserable because I'm fat but I would feel better. That's what it is, can't win."* Some participants also expressed dislike for corticosteroids and would like to avoid using the medication: *"I hate prednisone and faster I can get off and the faster, I want to be off of it"*. On the other hand, one participant was reluctant to taper corticosteroids as she believes that she needs the medication to keep her symptoms tolerable. She describes her experiences when her doctor tried to reduce her prednisone dose by adding a new medication: *"It didn't work and I felt the flare coming up so I stopped taking those (new medication), up my prednisone, minimize myself back to 5 and every now and again I try to go down to 4 but it doesn't work because even with the 5 I still have to take pain medications throughout the day."* A few participants (N=3) did not have concerns with corticosteroids because they did not personally experience any adverse effects and were not aware of the adverse effects that corticosteroids may cause. Other patients who expressed concerns with corticosteroids had experienced the adverse effects

themselves, had read about these adverse effects, or were informed about them through their provider.

Participants raised several concerns about corticosteroid-associated weight gain, organ damage, bone fracture, and sleep disturbances. These perceptions were further articulated endorsed by the focus groups participants, who also identified other concerns that include eye issues (cataracts), bone necrosis, dental issues, unusual mood swings/irritability, and sleep disturbances. Eventually, the codes for bone fractures, bone necrosis, and eyes issues were collapsed under the broad theme of organ damage. The final themes and subthemes related to SLE patients' concerns about corticosteroids use are outlined below. Exemplary quotes for each theme are presented in Table 3.

Weight gain—Weight gain was the most common concern and the average amount of weight that patients stated that they gained while using corticosteroids ranged from less than 10 pounds to almost 30 pounds. Participants frequently reported a noticeable increase in appetite when they were taking corticosteroids, and this led to weight gain. Participants were also distressed at the rapidity of the weight gain and some of them experienced low self-esteem as a result. For example, one of them stated “*I probably didn’t even bother to look in the mirror for maybe 8 to 9 months just because I felt so horrible.*” However, not all participants who experienced weight gain were affected negatively. Some who gained weight from the corticosteroids shrugged it off as part of the treatment process.

Organ damage—SLE patients expressed concerns with organ damage that may arise from corticosteroid use. Some were worried about organ damage in general while others expressed concerns with specific organs. Bone-related damage, such as bone fractures and bone necrosis, was the most common concern. For example, one participant from the focus groups recalled getting knee replacement surgeries because of corticosteroid-induced bone damage. Another participant mentioned having to deal with cataracts because of corticosteroids.

Mood swings/irritability—Mood swings/irritability were experienced by several participants. These individuals experienced extreme and unpredictable mood swings, which were debilitating and interfered with family relations and social activities. Specifically, one of them gave an example of a time when she had to leave the room of a party that she was hosting because of she was feeling uncharacteristically irritable.

Sleep disturbances—A few participants reported problems with sleeping when they were using corticosteroids. One participant described staying past her normal bedtime as the medicine kept her up at night. Those who experienced sleep disturbances found it distressing as it affected their daily routines.

Dental issues—A couple of participants said that they experienced problems with their teeth and they attributed it to the corticosteroids. In their opinion, the corticosteroids caused their teeth to become brittle. This was a problem for them as it affected their ability to chew and one of them mentioned having to get dentures as a result of this.

Discussion

Using an iterative, qualitative approach that leverages the depth of information from individual interviews and the interactive nature of focus groups, this study identified outcomes that are most important to SLE patients, and elicited patients' concerns regarding use of corticosteroids. We focused on corticosteroids use in SLE treatment given that corticosteroid tapering remains an important, but often clinically challenging, goal in SLE management.

The patients in our study sample wanted their SLE treatment to reduce flares, allow them to maintain their normal activities, have minimal side effects, prevent future organ damage, and cure their disease. Our study findings are corroborated by other health-related quality of life studies, which observed that concepts, such as side effects of treatment, ability to carry out regular work and social activities, physical symptoms of the disease, self-image and emotional well-being, were important to patients living with SLE.^{3, 30, 31} Reduction in flares, reduction in physical symptoms, and ability to carry out regular activities are common themes that appears across studies, including ours. Further, SLE symptoms often have a negative impact on patients' social, family, and work activities.^{5, 32, 33} In our study, difficulties in keeping up work and social activities also affected participants' emotional well-being. In the clinical setting, patients are evaluated based on disease activity. However, patients and physicians often display discrepancies in their assessment of disease activity.^{22–25, 34} Physicians typically place more emphasis on objective manifestations such as abnormal laboratory findings, whereas patients are more influenced by the subjective manifestations such as their self-perceived physical and psychological functioning.^{24, 25} For example, it has been demonstrated that SLE patients associated improvement in pain and fatigue with overall improvement in health status.³⁵ Clinician-perceived improvements in disease activity may not necessarily translate to meaningful improvements in how the patients perceive their health.³⁵ Therefore, while evaluating treatment outcomes, it is important for clinicians to consider patients' assessments as they offer a unique perspective on how the treatment is affecting their health status. One way to do so is to incorporate the use of SLE-specific patient-reported outcomes (PROs) instruments in the clinical setting.³⁶

Another key finding of our study is the primary concerns that SLE patients have with corticosteroid use. Many of the study participants were concerned with weight gain, unusual mood swings, and sleep disturbances. Although these issues may be of less clinical importance compared to organ damage, patients in our study explained that both weight gain and unusual mood swings were distressing as these adverse effects directly affect their self-image, emotional well-being and ability to plan or partake in social activities. While there are many studies demonstrating the association between corticosteroids and organ damage,^{2, 10, 14, 15} less attention is given to issues such as weight gain³⁷, mood swings and sleep disturbances, which can be debilitating to the patients' lives. Although participants appeared to be concerned with general organ damage, those who expressed specific concerns were mostly about bone-related damage such as fractures. Surprisingly, patients did not particularly express concerns with other serious forms of organ damage such as cardiovascular damage, or metabolic adverse effects. This may suggest that SLE patients are more concerned with adverse effects that immediately affected their day-to-day lives. For

example, bone-related damage often affected these patients' mobility and physical functioning, which may have restricted their daily activities. In contrast, cardiovascular issues like atherosclerosis, and metabolic risks might arise later and early on might be asymptomatic, and thus, less likely to affect the daily living of patients.

From our study, we also observed that patients were more likely to be concerned about adverse effects that their physicians have informed them about, or that they had personally experienced. Not all patients were aware of the adverse effects that were associated with corticosteroids use and this could explain why our study participants reflected varying levels of concerns with corticosteroids. Further, as aforementioned, participants in our study did not express specific concerns with the serious cardiovascular or metabolic risks of corticosteroids. We cannot exclude the possibility that the participants were unaware of these adverse effects, and therefore, did not reflect substantial concerns about them. It is important for SLE patients to be cognizant of the cardiovascular and metabolic risks of corticosteroids as these adverse effects may result in irreversible damage and death if left unmanaged. Taken together, this highlights the need for educating SLE patients about both the short-term and long-term adverse effects that are associated with corticosteroids so that they will be more willing to work closely with their physicians to adjust their corticosteroids use.

The study findings should be interpreted in light of several limitations. Our study sample was recruited from two clinical sites in one geographic locale and thus, may not be representative of all SLE patients. We cannot exclude the possibility that other themes may have emerged had we recruited a larger sample from multiple sites. However, our study sample appeared to be evenly distributed across socioeconomic characteristics such as income and education level. Further, although SLE predominantly affects women, we were still able to include the male perspective in our study with three male participants. Our study sample also included a large proportion of African-Americans, who are disproportionately affected by SLE.³⁸ Therefore, given our diverse study sample, we hope that the possibility of omitting salient themes is minimal. However, we also acknowledge that our study did not include any Asian participants, who are also known to be disproportionately affected by SLE. In addition, we expect our study sample to comprise of patients who are at the lower spectrum of disease severity, as it is unlikely that patients who were severely ill were present at the outpatient clinics during the time of recruitment. People who were severely ill may have different perceptions of desired outcomes and treatment concerns, which would not have been captured in our study.

In summary, this study identified the outcomes that SLE patients most desired and the primary concerns that they have regarding corticosteroid use. SLE patients often want their treatment to improve the subjective manifestations of their disease such as the physical symptoms and impact of SLE on their normal activities. Besides organ damage, SLE patients are also concerned with adverse effects like weight gain, mood swings/irritability and sleep disturbances, which can affect their social and emotional well-being.

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Appendix – Semi-structured Interview Field Guide

[Greetings and Introduction]

Thank you for taking the time to speak with me about your experiences with Lupus. I am talking with you today to listen and learn about your journey with Lupus. It can be hard to struggle with keeping the condition under control and to deal with the side effects of treatments like corticosteroids. Through this interview, I hope that you can help me understand what it was like for you.

I want you to know that you can speak freely with me; there are no wrong answers today. You are the expert and so your voice is very important. Our goal is to learn from you so that other people, just like you, can make the most helpful treatment decisions for themselves.

Please let me know if a question I have asked is not clear or if you are uncomfortable answering. I will gladly repeat or rephrase the question, or skip any questions that make you uncomfortable.

Our conversation today is confidential, and at this time do you give me permission to record the interview?

We'll be speaking for about two hours, and at any time please feel free to ask me to stop the recording. Do you have any questions for me before we begin?

[PATIENTS STRUGGLES WITH LUPUS]

I am interested in listening and learning from your general experiences with Lupus and how it has affected your daily life.

Can you please describe how Lupus has affected you in your daily lives?

Probe

- Can you give examples of how Lupus has prevented you from doing things that you used to do?
- In what ways have Lupus prevented you from doing your daily activities?

[PATIENTS DESIRED OUTCOMES]

Can you please let me know what outcomes are important to you in your Lupus treatment?

Probe

- What do you hope to achieve with your Lupus treatment?
- What are the immediate improvements that you would want to see with your Lupus treatment?

- What are the long-term improvements that you would want to see with your Lupus treatment in the future?

[PATIENTS CONCERNS/EXPERIENCES WITH CORTICOSTEROID]

I also hope to learn more about your experience with using corticosteroids as part of your Lupus treatment.

Can you tell me about some of your concerns with using corticosteroids?

Probe

- What are the side effects that you have experienced with corticosteroids?
- Which side effects of corticosteroids are you most concerned with?
- Are there any risks of corticosteroids that you are concerned with?

Can you describe what it was like for you from the time you first started corticosteroids until now?

Probes

- What were some of the most important choices that you had to make about using corticosteroids?
- Did the use of corticosteroids require you to make any major changes in your life, and how did those changes make you feel?
- Can you explain the ways in which corticosteroids have helped improve your Lupus?
- What are some of the struggles or challenges that you face with using corticosteroids to manage your Lupus?
- Is there anything more that you would like to tell me about your experience with using corticosteroids?

[Thank the Participants]

Table 1

Self-reported Sociodemographic and Clinical Characteristics of Study Participants of the Interviews (N=5)^{*} and Focus Groups (N=15)

Characteristic	Interviews [*] N (%)	Focus Groups (N) (%)
Age (median, range)	45.5 (31 – 57)	45 (21 – 66)
Gender		
Female	4 (100.0)	12 (80.0)
Male	0 (0.0)	3 (20.0)
Race/Ethnicity[^]		
Black or African American	4 (100.0)	9 (60.0)
Hispanic	0 (0.0)	3 (20.0)
White	0 (0.0)	4 (26.7)
Marital status		
Single	3 (75.0)	5 (33.3)
Married	1 (25.0)	4 (26.7)
Divorced/Separated	0 (0.0)	6 (40.0)
Education		
High school or less	1 (25.0)	7 (46.7)
College	3 (75.0)	2 (13.3)
Postgraduate	0 (0.0)	6 (40.0)
Employment status		
Working	3 (75.0)	9 (60.0)
Not working	1 (25.0)	5 (33.3)
Retired	0 (0.0)	1 (6.7)
Annual household income		
\$25, 000	0 (0.0)	5 (33.3)
\$25,001 – \$50, 000	0 (0.0)	2 (13.3)
\$50, 001 – \$75, 000	2 (50.0)	1 (6.7)
>\$75, 000	1 (25.0)	5 (33.3)
Don't know	1 (25.0)	2 (13.3)
Insurance type		
None	1 (25.0)	0 (0.0)
Public	1 (25.0)	2 (13.3)
Private	2 (50.0)	11 (73.3)
Both	0 (0.0)	2 (13.3)
Years diagnosed with SLE (median, range)	9.5 (3 – 25)	15.3 (2 – 25)
User of Corticosteroids		
Current users	2 (50.0)	8 (53.3)
Past users	2 (50.0)	7 (46.7)

^{*} One participant in the in-depth interviews was feeling fatigue at the end of the interview and did not get to fill out the sociodemographic questionnaire.

[^] One participant in the focus groups reported both White and Hispanic.

Table 2

Themes, Subthemes and Exemplary Quotes Describing SLE Patients' Desired Outcomes

Themes and Subthemes	Exemplary Quotes
Reduction in flares <ul style="list-style-type: none"> Reduction in physical symptoms Reduction in hospitalizations 	<p>"And sometimes when I wake up the joints just locked, and it takes me a while"</p> <p>"It was so painful like I said with the knives sticking in it, turning it and grinding in the bone. That's the most severe flares up. I don't like having those."</p> <p>"To me I would love to be where I don't have flares but I doubt that will happen."</p> <p>"I did anything to keep from coming to the hospital. And if it (the flare) was really bad, I will come then."</p>
Maintenance of normal activities	<p>"I know I'm never going to be the way I was before. But just as long as I can continue to be on the medication and they work and that I can get up every single day and get on that MARC train and go to my job."</p> <p>"You know those are the things that I should be able to do, I should be able to make dinner for my wife. I should be able to go for an art fair; We should be able to have the same life as any other couple can experience but we have limitations"</p>
Minimization of treatment side effects	"The medications that we have access to that helps maintain and control our Lupus have all these horrific side effects so I mean I wish there were other treatment options that didn't create other problems"
Prevention of organ damage	<p>"So one of my organs already having problem but you know, ... I just hope it doesn't affect something else."</p> <p>"My kidneys...that shut down and that's it."</p>
Finding a cure	"I rather have my cure than a treatment"

Table 3

Themes and Exemplary Quotes Describing SLE Patients Concerns with Corticosteroids

Themes	Exemplary Quotes
Weight gain	<p>“When I’m on prednisone, this is going to sound completely shallow but the thing that affects me most is the weight gain.”</p> <p>“Not just because of the weight gain but the rapidity of the weight gain, like how fast it came on...I probably didn’t even bother to look in the mirror for maybe 8 to 9 months just because I felt so horrible”</p>
Organ damage	<p>“My biggest concern is bone loss because I am osteopenic and I have lost a bit of bone and I’m getting older and also cataracts”</p> <p>“Definitely for me (the most concerning is) the bone loss. The bone loss is the reason for my knee replacement”</p> <p>“I think I was reading something about how prednisone can start to affect other parts of your body...I don’t want other stuff to start shutting down”</p>
Mood swings/irritability	<p>“If you would ask my family and ask myself (about prednisone), it’s the mood swings that are debilitating”</p> <p>“When I was on like 60mg of prednisone, 40 even 20,...I would get really angry at things and I would start throwing things across the room”.</p>
Sleep disturbances	<p>“Whenever I’m on prednisone and I’m up at 12 o’clock I’m like this is not right and that’s the main reason I don’t like prednisone”</p> <p>“My biggest problem is I can’t sleep. I sleep at the same time every night like 9, 10 whatever but now I go to sleep at like 2?”</p>
Dental issues	<p>“My teeth are breaking...that’s why I have prosthesis”</p>