




Barriers to Taking Medications for Systemic Lupus Erythematosus: A Qualitative Study of Racial Minority Patients, Lupus Providers, and Clinic Staff

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Objective. Underrepresented racial and ethnic minorities are disproportionately affected by systemic lupus erythematosus (SLE). Racial and ethnic minorities also have more severe SLE manifestations that require use of immunosuppressive medications, and often have lower rates of medication adherence. We aimed to explore barriers of adherence to SLE immunosuppressive medications among minority SLE patients.

Methods. We conducted a qualitative descriptive study using in-depth interviews with a purposive sample of racial minority SLE patients taking oral immunosuppressants (methotrexate, azathioprine, or mycophenolate), and lupus clinic providers and staff. Interviews were audiorecorded, transcribed, and analyzed using applied thematic analysis. We grouped themes using the Capability, Opportunity, Motivation, Behavior conceptual model.

Results. We interviewed 12 SLE patients (4 adherent, 8 nonadherent) and 12 providers and staff. We identified capability barriers to include external factors related to acquiring medications, specifically cost-, pharmacy-, and clinic-related issues; opportunity barriers to include external barriers to taking medications, specifically logistic- and medication-related issues; and motivation factors to include intrinsic barriers, encompassing patients' knowledge, beliefs, attitudes, and physical and mental health. The most frequently described barriers were cost, side effects, busyness/forgetting, and lack of understanding, although barriers differed by patient and adherence level, with logistic and intrinsic barriers described predominantly by nonadherent patients and side effects described predominantly by adherent patients.

Conclusion. Our findings suggest that interventions may be most impactful if they are designed to facilitate logistics of taking medications and increase patients' motivation while allowing for personalization to address the individual differences in adherence barriers.

INTRODUCTION

Systemic lupus erythematosus (SLE) is a multisystem chronic autoimmune disease that is more common, severe, and deadly among underrepresented racial and ethnic minority groups (1–4). SLE treatment requires long-term use of medications to prevent disease progression and organ damage. Conventional SLE treatments include the use of antimalarials for all patients and immunosuppressive medications

(i.e., methotrexate, azathioprine, mycophenolate) for those with more severe manifestations, including multiorgan system involvement (5). Nonadherence to immunosuppressive medications is particularly detrimental, as patients requiring these medicines have more severe SLE. Research has shown that up to 75% of patients do not take their lupus medications as prescribed, and medication nonadherence has been linked to increased morbidity and mortality (6–8). Medication nonadherence has also been shown to be particularly high in racial and

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SIGNIFICANCE & INNOVATIONS

- To our knowledge, this study is the first to examine adherence barriers to lupus medications from the perspectives of lupus patients as well as clinicians and staff, with a focus on barriers faced by racial minority patients taking immunosuppressants, the most vulnerable group with known worse outcomes and lower adherence.
- We are also the first to categorize a range of adherence barriers for lupus medications using a health behavior conceptual model to inform intervention development.
- Importantly, we found individual differences in adherence barriers among all patients interviewed, strongly suggesting a need for personalized interventions. Additionally, our results suggest that interventions that facilitate the logistics of taking medications coupled with increasing patient internal motivation may be most effective.

ethnic minority patients, likely contributing to existing racial disparities in SLE outcomes (7–10).

Despite the long-term adverse ramifications of nonadherence to SLE medications, its causes have not been well studied. Prior qualitative research with SLE patients has not specifically focused on racial and ethnic minorities or on those taking immunosuppressive medications, the most vulnerable groups with the lowest adherence (11–16). Additionally, existing qualitative studies did not solicit input from clinicians who treat SLE, thus providing a limited view of adherence barriers. Those studies also did not frequently use conceptual models to facilitate understanding of the relationships among identified adherence barriers. In this study, we identified adherence barriers to taking oral immunosuppressive lupus medications among racial minority patients by exploring the perspectives of the following stakeholders: patients, providers, and clinic staff.

PATIENTS AND METHODS

We conducted a qualitative descriptive study using in-depth interviews with a purposive sample of 1) racial minority patients with SLE taking oral immunosuppressive medications (including methotrexate, azathioprine, and mycophenolate), based on their adherence levels (adherent versus nonadherent), and 2) lupus clinic providers and staff at the Duke University Lupus Clinic. Adherence levels were determined by pharmacy refills in the past 3 months; a medication possession ratio (MPR) of $\geq 80\%$ for all oral immunosuppressive medications was considered adherent (17). Our sample size for each group was based on the number of interviews typically needed to reach idea saturation when no new topics of significance are described (18). Using a semistructured interview guide, we asked patients to describe barriers they

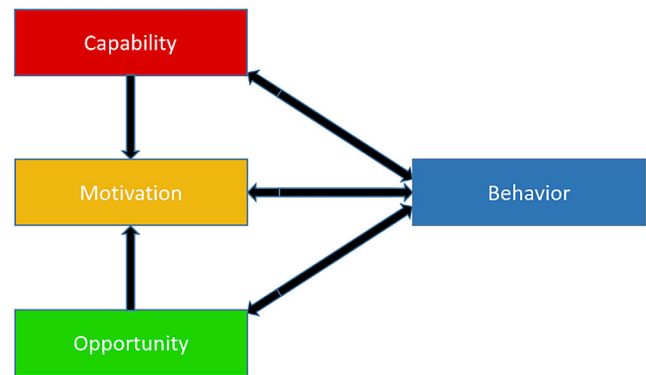


Figure 1. The Capability, Opportunity, Motivation, Behavior (COM-B) conceptual model.

experienced in obtaining and taking their immunosuppressive SLE medications, including factors that contributed to skipping or stopping their medications and situations that make taking their medications more difficult. We also probed on common barriers described in the literature, if those barriers were not initially mentioned by patients, including cost, busyness, side effects, beliefs about medications, communication with providers, and how lupus makes them feel (11–15). We asked providers and staff to describe their perceptions of the adherence barriers faced by patients, including reasons patients do not take their lupus medications as prescribed and situations during the clinic visit that hinder adherence. Patient interviews lasted ~60–90 minutes, and provider and staff interviews lasted 30–45 minutes. A trained qualitative interviewer conducted the patient interviews in a private conference room outside of the lupus clinic or by phone. As a method to limit socially desirable answers to the adherence questions, the interviewer was unaffiliated with the lupus clinic. The lead author (KS), who is also a provider in the lupus clinic, conducted the provider and staff interviews in-person in a private area or over the phone. Interviews were audiorecorded, transcribed verbatim, and were deidentified for analysis.

Two coders (CD, TS) used applied thematic analysis to code and interpret data. NVivo 11, a qualitative data analysis software program, was used to first apply structural codes to the transcripts, segmenting participants' narratives into broad categories related to the overall objectives. Intercoder reliability assessments were conducted on 20% of the transcripts, discrepancies were discussed, and structural coding was revised accordingly. Next, 1 analyst identified and applied content codes (e.g., codes that represent participants' described experiences) to the text within structural codes, to identify themes and subthemes related to adherence barriers and to organize the data into emergent thematic groups. Patient and provider data were analyzed separately.

To facilitate clustering of themes as well as future development of targeted interventions, we used the Capability, Opportunity, Motivation, Behavior (COM-B) conceptual model to guide

Table 1. Patient demographics (n = 12)*

Characteristic	Values
Age, median (IQR) years	36 (30–48)
Female	10 (83)
SLE disease duration, median (IQR) years	12 (8–17)
Race	
African American	11 (92)
Native American	1 (8)
Insurance	
Private	6 (50)
Medicaid or Medicare	5 (42)
None	1 (8)
Marital status	
Single or separated	9 (75)
Married	3 (25)
Education	
≤High school degree	5 (42)
Some college or college degree	4 (33)
Graduate degree	3 (25)
Employment	
Full-time or part-time	6 (50)
Home maker or retired	3 (25)
Unable to work	3 (25)
Immunosuppressants	
Mycophenolate	7 (58)
Azathioprine	3 (25)
Methotrexate	2 (17)
Number of oral SLE medications, median (IQR)†	2 (2–3)

* Values are the number (%) unless indicated otherwise. IQR = interquartile range; SLE = systemic lupus erythematosus.

† Includes immunosuppressants, antimalarials, and steroids.

the grouping of adherence barriers (19,20). According to the COM-B model, capability, opportunity, and motivation interact to generate behavior change that in turn influences each of the 3 components (Figure 1). Capability is defined as an individual's capacity to engage in the activity, opportunity covers factors that lie outside the individual which make the behavior possible or prompt it, and motivation involves internal factors that compel the patient to action. This model has been effectively applied to many health behaviors and intervention programs, including medication adherence (21).

Using the COM-B model, we grouped barriers into 3 main categories: 1) external barriers to acquiring medications corresponding to capability, which included cost-, pharmacy-, and clinic-related issues; 2) external barriers to taking medications corresponding to opportunity, including schedule- and medication-related barriers; and 3) intrinsic factors corresponding to motivation, encompassing knowledge, beliefs, attitudes, and the patient's physical and mental health. Lastly, we examined each patient's set of barriers described during the interview to explore whether barriers clustered or whether sets of barriers were unique to each patient.

RESULTS

Participant demographics. We interviewed 24 individuals: 12 patients and 12 providers and staff. Eight patients were

considered nonadherent and 4 were considered adherent. Patients' median age was 36 years, and 83% (n = 10) were female, 92% (n = 11) were African American, and 50% (n = 6) had private insurance. On average, patients had SLE for 12 years. Of the 12 patients, 58% (n = 7) were taking mycophenolate, 25% (n = 3) azathioprine, and 17% (n = 2) methotrexate (Table 1). Providers (n = 7) and staff (n = 5) were primarily women (75%) and White (75%) and have worked in the lupus clinic for a median of 3.5 years (Table 2). Providers included 5 physicians and 2 advanced practitioners. Staff included 4 nurses or medical assistants, and 1 pharmacist.

Capability: external barriers to acquiring medications. *Insurance and costs.* Half of patients (n = 6) said they could not always afford lupus medications due to insurance issues or out-of-pocket costs. Notably, 50% of interviewed patients had private insurance, and only 1 patient was uninsured. Patients described high deductibles, insurance lapses, lengthy application processes for social support services such as Medicaid, and circumstances in which their insurance would not pay for all their lupus medications because they missed doctor visits. These challenging situations led some participants to fill only a portion of their prescription at a time, fill some prescriptions but not others, or go without any medications. Some patients described rationing medications, and at times making the difficult choice between allocating income for their families or paying for their SLE medications. Patients said that even modest medication copays would add up due to multiple prescriptions, and they highlighted difficulties with patient assistance programs, specifically needing to pay first and get reimbursed later, as well as the small window of time to apply for assistance. One patient noted:

I had to stop taking [my medicine] because of insurance problems and that's when I got kidney failure... I was calling the doctors and my pharmacy and the insurance

Table 2. Provider demographics (n = 12)*

Characteristics	Values
Age, median (IQR) years	44 (35–50)
Female	9 (75)
Race	
White	9 (75)
African American	2 (17)
Asian	1 (8)
Role in clinic	
Physician	5 (42)
Advance practice provider	2 (17)
Pharmacist	1 (8)
Nurse or medical assistant	4 (33)
Years in lupus clinic, median (IQR)	3.5 (1.7–6)

* Values are the number (%) unless indicated otherwise. IQR = interquartile range.

company and I just couldn't get it. (patient 9, female, age 30s, nonadherent)

Providers and staff identified many of the same financial barriers that patients described, although in less detail. They also explained that while there are resources to help patients to obtain SLE medication for lower cost, providers and staff often do not ask about financial barriers, and patients frequently do not volunteer cost-related difficulties to them.

Pharmacy. One-fourth of patients (n = 3) described pharmacy-related barriers, including the need to use a specialty pharmacy, the pharmacy running out of an SLE medication, poor or inconsistent communication from the pharmacy, and restrictions on the number of pills that can be dispensed at a single pharmacy visit. One patient described his experience as follows:

CVS told me that CellCept was a specialty medication so I have to get it from a specialty pharmacy, but they're kind of difficult to communicate with. Just hearing different things from different people all the time, it's been going on for months, I still can't get anything. (patient 10, male, age 20s, nonadherent)

Clinic. Three providers and staff noted clinic-level barriers, including the need to provide clear communication about medication refills and ensure that the patient's active prescriptions are updated in the medical records. Additional participant quotes on capability are in Supplementary Table 1, Section 1, available on the *Arthritis Care & Research* website at <http://onlinelibrary.wiley.com/doi/10.1002/acr.24591>.

Opportunity: external barriers to taking medications. *Logistics.* More than half of patients (n = 7) described difficulties in remembering to take medications and/or to pick up refills on time. Patients attributed forgetting to "brain fog," irregular work schedules, and the logistic challenges of taking medications with food due to early morning appointments, lack of time to eat, or lack of appetite.

I'm always running, so I'm never at home, so I'll either run out, forget to take my medicine, or I come home and pass out. (patient 8, female, age 30s, nonadherent)

Forgetfulness as a barrier was echoed by slightly less than half of providers and staff (n = 5), who additionally linked forgetting to taking a more complex medication regimen, noting that some patients may reliably take their morning dose but then forget the evening dose.

Side effects. Some patients (n = 4) said that nausea, the most mentioned side effect, lead them to skip medications when they were unable to eat first. Two patients also expressed a concern about the potential for side effects keeping them from taking

their medications, describing feeling frightened and discouraged by the possibility of severe reactions and adverse effects listed on medication package inserts. Almost all providers and staff members (n = 10) also said that medication side effects were barriers to patient adherence, the most common being gastrointestinal discomfort. One-third (n = 4) said patients' concerns about the possibility of side effects were also barriers. One provider also said that hair loss was a particularly distressing side effect for female patients.

Medication attributes. Some patients (n = 5) and providers (n = 4) also expressed the idea that the number, size, and frequency of pills were barriers, particularly with mycophenolate.

That CellCept pill is not little at all! I can pop my prednisones all day because they're itty-bitty. But just having to take 3 of those twice-a-day, on top of all these other pills, it makes you not want to do it. (patient 6, female, age 20s, adherent)

Additional participant quotes on opportunity are in Supplementary Table 1, Section 2, available on the *Arthritis Care & Research* website at <http://onlinelibrary.wiley.com/doi/10.1002/acr.24591>.

Motivation: intrinsic factors. *Mental and physical fatigue.* One-fourth of patients (n = 3) said they had become tired of taking their SLE medications. They described the idea that at times, they simply did not want to take medicine everyday, knowing that they will need the medications for the rest of their lives.

Some days, I'm like, "I'm tired. I don't want to take any pills." I truly feel like there's something mental that I'm sick of this, I just want to go back to when I didn't have to worry about taking any pills at all. (patient 8, female, age 30s, nonadherent)

Similarly, one-fourth of providers and staff (n = 3) said they sensed patients' pill fatigue, attributing it to patients' denial of illness, because taking medications regularly is a reminder of chronic illness. Other providers and staff (n = 2) thought patients may not be ready to prioritize health or may have a "defeatist attitude," believing that even if they take active steps to improve their health it will not change the final outcome. Two providers linked many of these attributes to the patients' younger age. One provider also linked high rates of depression among the lupus population with medication nonadherence. Several patients (n = 3) described fatigue and mobility issues, leading to falling asleep before their evening medication dose or making it difficult to get out of bed or eat before taking medications.

Medication necessity and effectiveness. One-fourth of patients (n = 3) reported that they did not perceive the need to take SLE medications when feeling well. Patients explained that

they lose motivation to take their medications when their SLE does not appear active. Two providers and staff echoed this concern. One patient shared:

I didn't see the activity of my lupus. So, I'm thinking, "Why do I need CellCept? I'm fine, I'm great, I don't have lupus, what are y'all talking about?" It's probably a mistake.
(patient 6, female, age 20s, adherent)

Perceived poor medication effectiveness was also described as a barrier by several providers and staff ($n = 6$) and 1 patient. Providers and staff noted that because immunosuppressive medications do not provide immediate relief and may not alleviate all symptoms (e.g., fatigue, depression), patients may perceive that medications are not working and stop taking them. Elaborating on their concern about perceived limited effectiveness, 2 providers explained that when patients stop their SLE medications, they may not experience any immediate consequences due to the long effect-lives of the drugs.

Limited patient knowledge. Many providers ($n = 8$) shared their belief that patients may not fully understand the seriousness of SLE, how SLE medications work, or what can be expected from SLE treatment. Providers associated this lack of understanding with patients who have insufficient health literacy, impaired cognitive function, limited educational attainment, and less experience with managing lupus, also citing patients who received insufficient education by SLE providers. Several providers and staff ($n = 4$) commented on contributing clinic factors, such as limited time with patients, noting that time for patient education about SLE medications and adherence strategies planning may be rushed or curtailed on busy clinic days. When providers can educate patients about SLE medications and adherence strategies, patient fatigue, exacerbated by long appointment waiting times, may make it difficult for patients to take in new information.

External influences. Several providers and staff ($n = 5$) noted that patients may prioritize outside information from the internet, family, friends, and non-lupus clinic providers over information from lupus providers and staff. They explained that family and friends may discourage a patient because they do not believe that the patient is really sick, or they may know others with SLE who experienced poor outcomes from conventional treatments or who received different treatments. One patient described family and friends discouraging SLE medication use and encouraging alternative therapies or diets instead:

You have friends that do the Google research, or a friend of a friend who has lupus, and they're not taking any medications. Numerous people try to tell me, "Go gluten free, go vegan, you'll be fine, you don't have to take all these medicines polluting your body. That's what's making you sick."
(patient 8, female, age 30s, nonadherent)

Two providers also noted that personal beliefs, such as belief in prayer, natural therapies, or letting the illness run its course without intervention, may be influential among patients who mistrust the medical system. Three providers explained that weak interpersonal relationships between patients and providers could lead to patients mistrusting providers. The weak patient-provider relationship may be due to patients' physical distance from the clinic, lack of provider-patient communication between clinic visits, lack of full disclosure by patients of problems taking medications, and insufficient provider discussion of alternative treatment options.

Additional participant quotes on motivation are in Supplementary Table 1, Section 3, available on the *Arthritis Care & Research* website at <http://onlinelibrary.wiley.com/doi/10.1002/acr.24591>.

Most frequently described barriers and individual barriers by patient.

The most commonly described themes

Table 3. Participant quotes for the most common themes of barriers to adherence described*

Themes (COM-B domain)	Quotations
Cost of medication (capability)†	"I know many of them can't afford it, so they take their Plaquenil for half the month or spread it out." (provider 1) "It was a concept of, 'Are me and my son and my family gonna eat or am I gonna get this medicine?' I outweighed my medicine sometimes so we can eat. I know that was bad, but I had to do what I had to do at that time." (patient 5, female, age 60s, nonadherent)
Side effects (opportunity)†	"Nausea comes with CellCept sometimes, and occasionally with azathioprine. I think people are just, for good reason, less inclined to take them if they feel worse." (provider 6) "They really mess with your stomach...it feels like gas pressure, and my stomach is bloated most of the time." (patient 4, female, age 60s, adherent)
Busyness and forgetting (opportunity)†	"They may always take the morning dose, but then I think they often forget the evening dose just because of life. I mean life is busy." (provider 1) "I forget every now and then to take it because either I'm busy or it's just not on my mind." (patient 9, female, age 30s, nonadherent)
Lack of understanding (motivation)‡	"They just don't understand that not taking [the medicine] the way you're supposed to be can lead you into renal failure; dialysis; kidney transplants and...I think because they're young, they just don't understand how bad things can get." (provider 6)

* COM-B = Capability, Opportunity, Motivation, Behavior.

† Reported by both patients and providers/staff.

‡ Reported by providers only.

Table 4. Adherence barriers reported by each patient (by patient number)*

Barriers	Nonadherent								Adherent			
	7	10	5	9	1	2	8	11	3	12	4	6
External to acquiring medications (capability)												
Insurance issues	x	x	x	x	-	-	-	-	-	-	x	x
Cost of medication	-	x	x	x	-	-	-	-	-	-	x	x
Payment assistance program	-	-	-	-	-	-	-	-	-	-	-	x
Pharmacy issues	x	x	-	-	-	-	-	-	-	-	x	-
External to taking medications (opportunity)												
Busyness and forgetting	x	x	x	x	-	x	x	x	-	-	-	-
Not refilling on time	x	-	-	x	-	x	-	x	-	-	-	-
Schedule variability	-	-	-	-	-	-	x	-	-	-	-	-
Food requirements	-	-	x	x	-	-	x	-	-	-	x	-
Nausea	-	-	-	-	-	x	-	-	x	-	x	x
Stomach pain	-	-	-	-	-	-	-	-	-	-	x	x
Worry about possible side effects	x	-	-	-	-	-	-	-	-	x	-	-
Number of pills	-	-	x	-	-	-	x	x	-	-	-	-
Large pill size	-	x	-	-	-	-	-	-	-	-	-	x
Pill frequency	-	-	-	-	-	-	-	x	-	-	-	-
Intrinsic factors (motivation)												
Tired of taking medicine	-	-	x	x	-	x	x	-	-	-	-	-
Fatigue	-	-	-	x	-	x	-	-	-	-	-	-
Mobility issues	-	-	-	-	x	-	-	-	-	-	-	-
Medicine not needed if feeling good	-	-	-	-	-	x	x	-	-	-	-	x
Medicine not working	-	-	-	-	-	-	-	-	-	-	-	x
External influences	-	-	-	-	-	-	x	-	-	-	-	-

* Patients 3, 4, 6, and 12 regularly refilled all oral immunosuppressant lupus medications, while the rest of the patients did not.

of adherence barriers by patients were cost, side effects, and busyness and forgetting. The first 2 themes were also frequently described by providers and staff, who additionally described lack of understanding as a common barrier. Participant quotes on the most frequently described barriers are in Table 3.

Examining barriers reported by each patient, we observed that every patient described a different combination of barrier categories to taking SLE medications and clustering of barriers (Table 4). Insurance and cost barriers were present among half of adherent and nonadherent patients. In comparison, logistic-related and intrinsic barriers were discussed almost exclusively by nonadherent patients, while barriers related to side effects were described almost exclusively by adherent patients.

DISCUSSION

Through in-depth interviews with SLE patients, clinic providers, and staff, we identified a range of adherence barriers to SLE immunosuppressive medications among racial minority SLE patients. We classified these barriers according to components of the COM-B behavior change theory, providing an important framework to future development of adherence interventions. The most frequently described barriers were affordability, side effects, busyness and forgetting, and lack of understanding, although major barrier categories differed by patient and patterns of barriers differed by adherence level.

Our qualitative study is the first to examine adherence barriers in SLE from the perspectives of both patients and lupus clinic providers and staff. We found that patients, providers, and staff provided complementary information on adherence barriers. Affordability and side effects were frequently described by both groups of participants. However, providers and staff were more cognizant of clinic-related obstacles, while patients were more acutely aware of the inner workings of their daily struggles with patient assistance programs, irregular working and eating schedules, and physical barriers of fatigue and mobility issues. Overall, we observed that patients' discussions of barriers tended to focus on external factors that were often beyond their control, while providers and staff emphasized patients' internal factors of lack of understanding and incorrect beliefs, knowledge, and attitudes. Providers and staff may be mistakenly attributing nonadherence to intrinsic barriers; however, we believe that probably neither patients nor providers and staff alone have the complete picture of adherence barriers. Barriers that patients express as busyness and forgetting (external barriers), may be actually driven by a lack of motivation or priority (intrinsic barriers). Future studies should specifically probe patients regarding their understanding of intrinsic barriers. Future qualitative studies on adherence barriers should also attempt to include both patient and provider perspectives in order to most comprehensively inform adherence interventions.

In examining the set of challenges described by each patient, we recognized that every patient reported a distinct set of

predominant barriers. This finding strongly suggests the need for adherence interventions to take an individualized approach based on each patient's main barrier categories. Indeed, evidence indicates that tailored interventions are more effective for changing behavior (22,23). Additionally, internal beliefs, knowledge, and attitudes are known to affect a patient's view on the necessity of medications, and therefore their motivation for taking medications (24). Therefore, interventions targeting external and intrinsic barriers may need to be used in combination to most effectively address nonadherence. The failure of intervention studies in adult SLE patients that are described in 2 recent systematic reviews may be in part due to the use of one-size-fits-all rather than tailored and comprehensive approaches (25,26).

Interestingly, we found that side effect barriers were described predominantly by adherent patients, and financial barriers were equally represented among adherent and nonadherent patients. This finding suggests that perhaps side effects and certain financial barriers, though common, are not insurmountable drivers of nonadherence. In contrast, logistic and intrinsic barriers were described predominantly by nonadherent patients but not adherent ones, suggesting that they may be more intransigent and require innovative approaches to address. Future studies should investigate whether adherence interventions that place an emphasis on recognizing and overcoming logistic and intrinsic barriers would be more effective compared to ones that mainly address side effects and financial difficulties.

Our findings confirmed a number of barriers described by prior research on medication adherence in SLE, including practical difficulties in obtaining medications, financial strains, pill burden, side effects and fear of side effects, use of alternative medicine, temporary improvement, perceived treatment inefficacy, denial, depression, and debilitating physical symptoms (11–16). We also identified several unique barriers related to the patient and his/her experiences in the clinic that have not been well described in prior studies, including having a defeatist attitude, lack of trust or understanding, and insufficient patient education. These factors may be particularly relevant to the racial minority patients who are the focus of this study, as social inequalities and discrimination experienced by racial minorities have been linked to worse patient-provider communication (27), distrust in medical professionals (28), mood disturbance (29), and a sense of powerlessness (30). A sense of powerlessness is in contrast to a desire to exert control, a barrier described elsewhere in the literature that was not identified by participants in this study (15).

As with all qualitative studies, the generalizability of our findings to other patient populations and clinical settings may be somewhat limited. We conducted our study among patients, providers, and staff at a single tertiary medical center with a focus on the experiences of racial minority SLE patients taking immunosuppressants. Therefore, the most common themes and range of barriers among our patients may not hold true for all SLE patients. For instance, the racial minority makeup in our clinic is

predominantly African American, and therefore barriers we found may not be inclusive of all barriers faced by other minority groups. Further, while we designed the study based on the number of interviews typically needed to reach idea saturation (18), we learned that patient experiences were quite varied, such that patients had different combinations of adherence barriers. We recognize that with a larger sample size we may have been able to identify additional themes, explore existing themes in more depth, and/or group patients and themes differently. On the other hand, we found the breadth and variation of patient experiences to be extremely valuable for intervention development because they likely represent the range of patient experiences that interventions must address. Also, the use of pharmacy refill data is an imperfect surrogate for adherence, which may affect the distribution of barriers we found among adherent and nonadherent patients. Finding ways to capture adherence more easily and accurately is an ongoing area of research.

Another limitation is the possibility that participants felt the need to provide socially desirable answers. However, we think this effect should be minimal, as patients were interviewed by an interviewer unaffiliated with the lupus clinic in a conference room outside of the clinic to ameliorate this potential issue; further, provider and staff interviews were conducted in a non-threatening environment by a peer, and participants freely spoke about barriers related to the clinic. Finally, because this is a qualitative study with purposive sampling, we are unable to draw conclusions about the impact of race on adherence barriers, as our goal was to examine in depth the experiences of minority SLE patients, a vulnerable group known to have worse SLE outcomes and lower medication adherence. Although racial disparities in medication adherence have been well described, little is known about whether adherence barriers differ by race, and what limited literature exists suggests that minorities have more intrinsic barriers (31). Future studies should investigate differences in adherence barriers among racial groups with cohorts comprised of both White and specific categories of minority patients.

Despite these limitations, based on the most common themes described by participants and the distribution of barriers by adherence level, our findings suggest that interventions to facilitate the logistics of taking medications coupled with increasing patients' internal motivation to take SLE medications may be most impactful. Importantly, the individual differences in adherence barriers we observed suggest a need for personalized interventions tailored to each patient's predominant barriers. More broadly, while the impact of systemic racism and implicit bias on medication adherence among minority lupus patients is outside the scope of this analysis, existing research clearly shows that these factors result in racial disparities in socioeconomic and health care outcomes (32,33). Our data demonstrate that adherence barriers are frequently extrinsic to the patient due to circumstances outside of their immediate control. Acknowledging the

potential financial and logistical barriers that patients face along with increased cultural competency and implicit bias training can help create grassroots change to promote equity in an otherwise inequitable health care system.

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 submitted for publication. Dr. Sun had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Study conception and design. Sun, Corneli, Bosworth, Clowse.

Acquisition of data. Sun, Swezey, Rogers, Criscione-Schreiber, Sadun, Doss, Clowse.

Analysis and interpretation of data. Sun, Corneli, Dombeck, Rogers, Criscione-Schreiber, Sadun, Eudy, Doss, Bosworth, Clowse.

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