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A Qualitative Study of Facilitators of Medication Adherence in Systemic Lupus Erythematosus: Perspectives from Rheumatology Providers/Staff and Patients

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Abstract

Objective: Systemic lupus erythematosus (SLE) disproportionately affects patients from racial and ethnic minority groups. Medication adherence is lower among these patient populations, and nonadherence is associated with worse health outcomes. We aimed to identify factors that enable adherence to immunosuppressive medications among patients with SLE from racial and ethnic minority groups.

Methods: Using a qualitative descriptive study design, we conducted in-depth interviews with purposefully selected 1) patients with SLE from racial and ethnic minority groups who were taking immunosuppressants and 2) lupus providers and staff. We focused on adherence facilitators, asking patients to describe approaches supporting adherence and for overcoming common adherence challenges and providers and staff to describe actions they can take to foster patient adherence. We used applied thematic analysis and categorized themes using the Capability, Opportunity, Motivation, Behavior (COM-B) model.

Results: We interviewed 12 patients (4 adherent, 8 nonadherent based on medication possession ratio) and 12 providers and staff. Although each patient described a unique set of facilitators, patients most often described social support, physical wellbeing, reminders, and ability to acquire medications as facilitators. Providers also commonly mentioned reminders and easy medication access as facilitators as well as patient education/communication, and empowerment.

Conclusion: Using an established behavioral change model, we categorized a breadth of adherence facilitators within each domain of the COM-B model while highlighting patients' individual approaches. Our findings suggest that an optimal adherence intervention may require a multi-modal and individually tailored approach including components from each

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behavioral domain—ensuring medication access (Capability), utilizing reminders and social support (Opportunity), while coupled with internal motivation through improved communication and empowerment (Motivation).

Key Indexing Terms:

systemic lupus erythematosus; medication adherence; qualitative research; healthcare disparities; immunosuppressive agents; behavior

Introduction

Research has shown that only 25–57% of patients with systemic lupus erythematosus (SLE) are adherent to their lupus medications, with lower adherence among patients from racial and ethnic minority groups^{1, 2}. Patients from these groups also tend to have more severe SLE compared to White patients^{2–5}, often necessitating treatment with immunosuppressive medications in addition to anti-malarials. Because adherence to SLE medications is associated with better health outcomes⁶, implementing interventions to enhance medication adherence is critical for reducing racial disparities and improving SLE outcomes.

We conducted qualitative research to identify factors that enable adherence to immunosuppressive medications among patients from racial and ethnic minority groups with SLE. We used the Capability, Opportunity, Motivation, Behavior (COM-B) model^{7, 8} to provide a theoretical underpinning for intervention development to enhance medication adherence. The COM-B model recognizes an individual's capability, opportunity, and motivation as important factors that interact with each other and influence behavior change. *Capability* refers to factors that enable an individual to engage in the activity in question. *Opportunity* encompasses external factors that prompt the behavior, such as the environment or social and cultural norms.

Motivation involves conscious and subconscious thoughts that direct the behavior⁷. Many public health interventions, including medication adherence interventions, have successfully utilized this model⁹. Our earlier work using the COM-B model identified adherence barriers spanning all three domains, with the most frequently described barriers being cost, side effects, busyness/forgetting, and lack of understanding¹⁰. In this paper, we describe adherence facilitators categorized by the COM-B model for patients with SLE taking immunosuppressive medications through the perspectives of providers, clinic staff, and patients from racial and ethnic minority groups.

Methods

As described in detail elsewhere¹⁰, we used a qualitative descriptive study design^{11, 12} and conducted in-depth, semi-structured interviews with patients, providers, and staff in an academic lupus clinic in the Southeastern United States. This study was approved by the Duke University IRB (#Pro00100861), and all subjects provided written informed consent.

Patients with SLE were eligible for the study if they self-identified as belonging to a racial or ethnic minority group and were taking immunosuppressive medications

(methotrexate, azathioprine, and mycophenolate). Patients were identified through chart review and purposefully selected based on their adherence level as determined by the medication possession ratio (MPR). MPR was calculated using pharmacy refill data for immunosuppressive medications in the prior 3 months with 80% indicating adherence¹³. We aimed to select both patients with high and low adherence based on their MPR. We also collected patients' SLE characteristics based on chart review.

All lupus clinic providers and staff were eligible. We included all physicians and advanced practice providers and purposefully selected at least one of medical assistants, nurses, and clinical pharmacists, to provide complementary views based on their varying clinical experiences working in the lupus clinic. When multiple candidates were eligible, we aimed to include clinic staff who self-identified as belonging to a racial or ethnic minority group. Participant sample size was chosen based on previous research that demonstrated the number of interviews required for idea saturation, beyond which no new topics of significance arise¹⁴.

Patient interviews lasted 60 to 90 minutes and were conducted by a trained qualitative interviewer (TS) unaffiliated with the lupus clinic in a private space outside of the clinic or over the phone. Patients were asked broadly about their experience with lupus, including reasons to take their immunosuppressive medications and their communication with lupus doctors. Patients were asked about specific factors that help them take their lupus immunosuppressive medicines regularly and were queried about specific approaches such as reminders and family support. Based on common barriers described in the literature, we also probed about any approaches they may have used to overcome challenges due to cost, side effects, and feeling ill, if these topics were not initially mentioned by patients^{15–19}.

Provider and staff interviews lasted 30–45 minutes and were conducted privately, in person or by phone, by the senior author (KS) who is also a lupus clinic provider trained to conduct qualitative interviews. Providers and staff described their perceptions of immunosuppressive medication adherence and adherence facilitators among lupus clinic patients and were asked their thoughts on how they might help patients take these medicines more consistently.

We audio-recorded, transcribed verbatim²⁰, and de-identified all interviews. Narratives from patients categorized as adherent and nonadherent were analyzed together; provider/staff narratives were analyzed separately following the same analytical approach as patients. Using applied thematic analysis, two coders (CD, TS) applied structural codes²¹ to the transcripts based on broad categories. To ensure inter-coder reliability, 20% of transcripts (n=5) were double-coded; discrepancies were resolved through discussion, and the revised structural codebook was applied to the remaining transcripts. Next, content codes were used to categorize individual participants' described experiences within each structural code. Reports of coded text were reviewed to identify salient themes and subthemes related to adherence facilitators, primarily based on concept salience. We used NVivo 11²², a qualitative software program, to aid with analysis.

Based on the content, we organized patient- and provider/staff-identified adherence facilitators into the three main categories of the COM-B model^{7, 8}: 1) Capability—external

factors that allow patients to access their lupus medications; 2) Opportunity—factors that enable adherence on a regular basis; and 3) Motivation—factors that affect conscious and unconscious beliefs and attitudes about medication adherence. We also listed facilitators for each patient and compared them across all patients to identify patterns of facilitators.

Results

Participant Demographics

We interviewed 12 patients with SLE (4 adherent, 8 non-adherent) and 12 providers and staff. Patients' median age was 36 [range 20–67]. The majority were female (n=10, 83%) and self-identified as Black (n=11, 92%); one patient (8%) self-identified as American Indian; half had private insurance. The average time since SLE diagnosis was 12 years. Patients were taking mycophenolate (n=7, 58%), azathioprine (n=3, 25%), and methotrexate (n=2, 17%). Patients' SLE manifestations included serologic (positive anti-Smith or anti-double stranded DNA antibodies n=9, 75%; low complements n=3, 25%), and organ involvements (renal n=9, 75%; musculoskeletal n=8, 67%; mucocutaneous n=7, 58%; serosal n=5, 42%; lung n=4, 33%; and neuropsychiatric n=1, 8%). Patients generally had low disease activity at the time of their interviews; all had a physician global assessment²³ of 1.5 (on a scale from 0–3, with 0 indicating no activity and 3 severe activity).

Providers (n=7, 58%) included five physicians and two advanced practitioners, and staff (n=5, 42%) included two nurses, two medical assistants, and one pharmacist. The majority were women (n=9, 75%) and self-identified as White (n=9, 75%). One provider and one staff self-identified as Black, and one provider self-identified as Asian. The average time working in the lupus clinic was 3.5 years.

Facilitators of adherence

The following sections describes themes on adherence facilitators identified in patient and provider/staff interviews, categorized according to the domains of the COM-B model. Participant quotes for the most commonly described facilitators are included in Table 1.

Capability: external facilitators of medication access—Nearly half of patients identified strategies that helped them obtain medications. These included using programs to help with affordability like grants, pharmacy assistance programs, or GoodRx; filling the most important medications when funds are limited; and using pharmacies that have sufficient quantities of their specialty pills.

Some patients also commented on lupus clinic resources that helped them obtain medications, including having easy access to providers through a secure online patient portal and the availability of clinic staff to connect them with financial aid programs and medication tracking apps.

Half of providers and staff also focused on patients' ability to obtain medication as an adherence facilitator, noting that patients are more likely to comply with a regimen when the medications are affordable. One provider described that having an on-site pharmacist to navigate insurance-related issues and medication-fill challenges enabled adherence.

Opportunity: external factors that enable adherence on a regular basis

Medication Reminders

All patients said medication routines and reminders were important as adherence facilitators. The most common strategy described was to enroll in a pharmacy's automatic refill or reminder program. Patients explained that this often ensured that medications were ready for pick-up when they arrived at the pharmacy, which was particularly important as specialty medicines are not always available. Other strategies included carrying medicines on hand in case of delay getting home and daily reminders such as pillboxes, alarms, mobile apps, calendars, or visual reminders to incorporate the medication into their daily routine.

Numerous providers and staff discussed many of the same reminder strategies as patients. Providers also suggested using a personalized pre-sorted medication service such as PillPack.

Social Support

Many patients described that support from family and friends facilitated adherence, ranging from simple encouragement to tangible physical assistance. One patient with reduced mobility relied on a family member to bring her medications on a bad day, and another patient who described herself as forgetful received phone call reminders from family members about her medications. Two patients also described receiving material support to pay for their lupus medications and supplies to make taking pills easier.

Some providers and staff also highlighted the importance of having family and friends check in to make sure the patient is taking their medications. A staff member noted that this type of support is particularly important for older patients.

Medication Properties

Two patients and two providers/staff discussed aspects of the treatment regimen that could serve as facilitators to adherence. Patients noted that smaller pills were easier to take, and a once-a-week regimen was easier to comply with than a daily regimen. Providers and staff noted that adherence was better for medications with fewer adverse effects, even if these medications had lower efficacy.

Motivation: conscious and unconscious beliefs and attitudes

Physical and Mental Health

Many patients said they were motivated to take lupus medication out of concern for their own health and wellbeing. Patients described wanting to avoid a recurrence of active disease and, to a lesser extent, to maintain a feeling of wellness.

Several providers also commented that patients were motivated by noticeable positive effects of lupus medications or hopes of improving their quality of life. They described both negative motivations, such as fear of feeling worse, and positive motivations, such as wanting to stay healthy and avoid hospitalization so they can continue caring for their children and not burden family members. As a result, some providers emphasized the

importance of tapping into patients' future goals as a source of motivation for medication adherence.

Two providers and a staff member identified having access to mental health care as a promoter of adherence, noting that poorly controlled mental health comorbidities can negatively impact medication adherence.

Patient-Provider Relationship

Two patients described close personal relationships with lupus clinic personnel that helped facilitate medication adherence, using terms such as "Mama Doctor" or "family." Specifically, patients described feeling supported when providers spent time to offer additional resources and extended an open invitation to contact the clinic with any issues.

Several providers and staff also suggested that adherence can be fostered through trusting and caring relationships that extended to include the healthcare team at all levels. They noted that patients were more motivated to take their medications if they felt that the healthcare team at all levels were engaged, truly cared about them, and treated them as partners through shared decision making.

Medication Monitoring and Accountability

Several providers described checking blood levels or pharmacy refill histories to verify adherence, particularly when patients do not admit to nonadherence. Two patients also described being motivated by a sense of accountability to their provider, specifically knowing that their doctor could track adherence by checking medication blood levels.

Patient Education and Communication

Numerous providers and staff described patient education during the clinic visit as an important adherence facilitator, particularly for patients with limited health literacy. They emphasized using patient-centered communication techniques, such as active listening, avoiding jargon, using the teach-back method, providing positive reinforcement, visually demonstrating lab values, and presenting information in both verbal and written forms. One staff member directly linked the improvement in medication adherence they observed to lupus clinic providers and personnel devoting more time during visits to patient education.

Many providers and staff proposed further educational/communication changes to facilitate adherence. These included clinic-level changes (follow-up telephone calls and access to a clinical pharmacist) and system-level changes (hiring a social worker and additional staff to focus on patient education), and provision of supplemental patient resources in the form of patient support groups, a comprehensive handout, and online educational resources.

All patients spoke about experiences of positive communication with providers in general and preferred providers to be informative, attentive, caring, encouraging, and not rushed, but they did not specifically describe education or communication as adherence facilitators.

Patient Empowerment

Half of providers and staff emphasized that efforts to foster adherence are most productive in patients who feel empowered to make positive changes and take control of their own health. A few noted that patient personality or life circumstances enabled some to be more motivated than others. Several commented that such patients simply decided on their own, for whatever reason, that they were going to take their lupus medication as directed.

Patients did not specifically discuss empowerment as an adherence facilitator.

Most frequently described facilitators

The most frequently described adherence facilitators by patients in order of frequency were medication reminders, social support, physical wellbeing, and medication access. Although patients shared many of the same facilitators, no patient's profile of facilitators was completely identical to another (Table 2). The most frequently described facilitators by providers and staff were medication reminders, patient education and communication, empowerment, and medication access. Supplemental Table 1 shows the adherence facilitators matched to previously published barriers according to the COM-B model.

Discussion

In this study, we described a variety of factors that may improve SLE medication adherence among patients from racial and ethnic minority groups, specifically Black and American Indian patients. The most emphasized facilitators were medication access, medication reminders, social support, and patient education/communication and empowerment. . Facilitators spanned all domains of the COM-B model and each patient interviewed described a unique set of adherence facilitators. Combined with our previously published adherence barriers, these data provide a roadmap for designing adherence interventions, and suggest that the optimal intervention may require individualization of components from each domain. Multi-level interventions may also be needed to address contributors on the levels of the patient, clinician, clinic, and system, that often exist in areas with healthcare disparities such as medication nonadherence^{24, 25}. For example, both patients and providers/staff emphasized that adherence can be improved with consistent medication access. Related to this, most providers/staff also recognized the need for changes on the societal and organizational levels, such as more effective insurance coverage, more affordable sources for medications, and funding to support social workers and other staff so the healthcare system can be more responsive to patients' needs.

Similar to our work on barriers to medication adherence¹⁰, we found that patients and providers/staff offered complementary views about adherence facilitators. While both patients and providers emphasized medication reminders and access, patients additionally highlighted social support and physical wellbeing, whereas providers/staff focused on education, communication, and empowerment. This difference may suggest that patients focus on external circumstances while providers/staff focus on internal motivations, reflecting participants' differing roles in ensuring medication adherence—the day-to-day needs and feelings of patients at home versus the education- and counseling-centered role

of providers/staff. Both perspectives are valuable and should be considered in designing adherence interventions.

Interestingly, while most providers/staff emphasized the importance of patient education and communication, patients did not discuss these in relationship to medication adherence. Effective communication with patients provides an opportunity both for patients to better understand lupus and lupus medications and for providers to gain a more nuanced and accurate sense of the patient's experiences. Having shared understanding is essential to forging therapeutic alliance and trust, a promotor for adherence depicted in the literature^{26, 27}. Effective communication may be particularly important for improving adherence for patients from racial and ethnic minority groups who tend to rate doctor visits as being shorter, less participatory, and less satisfactory^{28, 29}. Future studies should explore patient perspectives on education and communication as an adherence facilitator.

Our findings echo other adherence facilitators described in previous studies, including medication affordability, patient education, improved quality of life, social support, and positive patient-provider relationship^{17, 30-35}. Our results also add to the existing literature by identifying empowerment as an adherence-related concept. Although patient empowerment has been linked to medication adherence in other chronic diseases such as hypertension and diabetes^{36, 37}, these concepts have not been extensively discussed in the rheumatic disease adherence literature. As qualitative research is not intended to be generalizable, our findings may not be transferable to different patient populations. Our study focused on patients from racial and ethnic minority groups who take immunosuppressive medications, and the predominant racial minority makeup in our tertiary clinic population is Black. Therefore, the most common themes and the range of facilitators may differ for other SLE patient populations. Additionally, we used pharmacy refill information to group patients into adherent versus nonadherent groups, and we recognize that MPR is an imperfect surrogate for medication-taking behaviors. Nonetheless, our observations pave the way for future intervention development and testing to improve medication adherence for patients with SLE, particularly those from racial and ethnic minority groups.

In conclusion, we took a theory-based approach to describing adherence facilitators to immunosuppressive medications from the perspectives of patients from racial and ethnic minority groups and the providers/staff who care for them. Both perspectives are vital for designing and adapting adherence interventions. Findings from our study suggest that multi-modal and individualized approaches may be optimal to address nonadherence. For the appropriate patient, this may include verifying that their medications can be readily filled, capitalizing on reminder tools and available social support, along with effective patient-provider communication for education and empowerment. To successfully achieve this goal, changes are also needed on multiple levels of influence, not only between patients and providers, but also on the system and societal levels, to facilitate adherence and ideally reduce healthcare disparities in patients with SLE.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1.

Participant quotes for the most common themes of facilitators to adherence described.

Themes (COM-B domain)	Quotations
Medication Access* (Capability)	<i>When I realized the severity of not taking my medication, then my mom or my aunts and uncles, they tried to pull together and send me money so that I could get my medicine. [female, age 40s, nonadherent]</i>
Medication Reminders* (Opportunity)	<i>I keep it visual where I see it every day in the main room. So, I see it and I know I have to take it. It's not thrown in a drawer somewhere where I forget... No, it's right here in the kitchen. I'm here 10 times a day and I know to take it. [female, age 60s, adherent]</i>
Social Support* (Opportunity)	<i>I actually talk to my ex when I'm struggling. Even though he's not a big pill person, he is on me about taking my medicine. He talks me through it, and he like, "Trust me, you just need to take it. You know what happens when you're in a flare, so we don't wanna see that again." [female, age 30s, nonadherent]</i>
Physical Health* (Motivation)	<i>... I just don't want to feel like I have before, that I'm not dragged down to that point again... so I'm gonna take it regardless of how I feel, up or down, whatever, I take my pills at the same time because I do not want to do that again. [male, age 40s, adherent]</i>
Patient Education and Communication [^] (Motivation)	<i>I wish we had some online videos [about what the medications are] for, the possible side effects, how to manage side effects, outcomes of people who took them successfully... like [patient] testimonials in both directions... being able to provide education that is accessible to patients... because people can't remember everything. [Physician]</i>
Empowerment [^] (Motivation)	<i>I had one person, he had really bad lupus two years ago.... He wasn't taking his meds, and we put him on CellCept and now he's on Myfortic and things are better. And so, I asked why? Part of it was he felt like he trusted me, and I cared about him. But the other part was him. He just decided he can do this. He can take his meds, he can live with it, and he can change his own life. [Physician]</i>

* Reported by both patients and providers/staff;

[^] Reported by providers only; COM-B = Capability, Opportunity, Motivation, Behavior

Table 2.

Adherence facilitators described by each patient.

	Facilitators	Patients													
		Nonadherent						Adherent							
		1	2	5	7	8	9	10	11	12	6	3	4		
Capability: External facilitators of medication access	Medication access														
	Payment assistance programs							x				x	x		
	Ability to pay for medication			x											
	Prioritizing paying for most important medications											x			
	Using pharmacies with sufficient quantities of pills								x			x			
	Lupus clinic resources			x				x			x				
Opportunity: External factors that enable adherence on a regular basis	Medication reminders														
	Automatic refills	x		x		x	x	x	x	x	x	x	x		
	Pillbox	x				x		x			x	x	x		
	Visual reminders	x		x		x	x			x	x	x			
	Setting an alarm			x		x			x	x			x		
	Establishing a routine				x	x	x	x					x	x	
	Using a mobile app								x				x		
	Always keeping a supply of meds on hand									x			x		
	Social support	x	x	x	x	x	x	x	x	x			x		
	Medication properties														
	Small pill size													x	x
	Once-a-week medication schedule														x
Motivation: Conscious and unconscious beliefs and attitudes	Physical and mental health														
	Maintaining physical wellbeing							x				x		x	
	Avoiding consequences of not taking medication			x	x	x	x	x				x		x	
	Maintaining caregiver role												x		
	Medication monitoring and accountability			x										x	
	Patient-provider relationship					x	x								