

Patient and healthcare team recommended medication adherence strategies for hydroxychloroquine: results of a qualitative study informing intervention development

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ABSTRACT

Objective Patients identified as black and from disadvantaged backgrounds have a twofold higher hydroxychloroquine (HCQ) non-adherence, which contributes to worse lupus outcomes and disparities. Yet, most adherence interventions lack tailored strategies for racially and socioeconomically diverse patients who face unique challenges with HCQ. We aimed to examine a broadly representative group of patients with SLE and physician perspectives on HCQ adherence and adherence strategies to redesign an adherence intervention.

Methods We conducted four virtual focus groups (90 min each) with 11 racially and socioeconomically diverse patients with SLE recruited from two health systems. Additionally, we hosted two focus group meetings with nine healthcare advisors. In focus groups, patients: (1) shared their perspectives on using HCQ; (2) shared concerns leading to non-adherence; (3) discussed strategies to overcome concerns; (4) prioritised strategies from the most to least valuable to inform an adherence intervention. In two separate focus groups, healthcare advisors gave feedback to optimise an adherence intervention. Using content analysis, we analysed transcripts to redesign our adherence intervention.

Results Worry about side effects was the most common barrier phrase mentioned by patients. Key themes among patients' concerns about HCQ included: information gaps, logistical barriers, misbeliefs and medication burden. Finally, patients suggested adherence strategies and ranked those most valuable including co-pay assistance, personal reminders, etc. Patient and healthcare advisors informed designing a laminate version of an adherence intervention to link each barrier category with four to six patient-recommended adherence strategies.

Conclusion We developed a patient stakeholder-informed and healthcare stakeholder-informed tailored intervention that will target non-adherence at the individual patient level.

INTRODUCTION

Hydroxychloroquine (HCQ) is the cornerstone of SLE therapy as it improves

WHAT IS ALREADY KNOWN ON THIS TOPIC

- ⇒ Most adherence interventions lack tailored strategies for diverse patients who face unique challenges with hydroxychloroquine.
- ⇒ Providers and staff perspectives have not been included in current adherence interventions that explains why these are not routinely used in clinical settings.

WHAT THIS STUDY ADD

- ⇒ Our study delivers a patient stakeholder-informed and healthcare stakeholder-informed brief tailored adherence intervention that targets non-adherence at the individual patient level and will have high uptake in busy clinical settings.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

- ⇒ Our patient-informed and healthcare-informed intervention could promote and facilitate adherence discussions via shared decision-making in patients with lupus with their healthcare providers.
- ⇒ Future studies will aim to implement and examine the impact of this intervention on improving adherence and outcomes in clinics with limited resources.

damage-free survival in all patients with SLE.¹ However, non-adherence to the pivotal therapy—HCQ—is alarming.^{2–4} HCQ non-adherence is strongly correlated with a sixfold higher risk of severe lupus flare, 45% higher rate of lupus hospitalisations and an eightfold higher mortality risk.^{2–6} Moreover, patients from black racial group face a twofold higher HCQ non-adherence risk,^{2,7} and those from disadvantaged backgrounds face even worse adherence rates, highlighting that such groups could face unique barriers leading to non-adherence.^{3,8} However, most adherence interventions lack diverse patients' insights

and tailored strategies to address their unique challenges with HCQ.

Investigating patient insights and recommended strategies could address the discordance between patients' and clinicians' perceptions regarding disease activity and treatment adherence.^{9–11} Previous studies highlight that patients' perceptions of and experiences with the health system, physicians, medication effectiveness and side effects influence their adherence to treatment.^{12–14}

Medication non-adherence involves an interplay of different factors and thus requires a qualitative synthesis of different patient experiences and perceptions to develop a conceptual framework model that explains underlying themes and interactions that may lead to non-adherence. Sun *et al* classified medication barriers according to components of the Capability, Opportunity, Motivation, Behaviour change theory.¹⁵ A recent study highlighted that effective patient-physician communication and understanding patients' desires and suggested strategies could improve medication adherence.⁸ Building on this work, an intervention was developed based on the key domains of two gold-standard general adherence interventions (Medication Adherence Self-Report Inventory-Visual analogue scale and Brief Medication Questionnaire).^{16,17} The prior adherence intervention was developed using published information on categorised barriers to assess non-adherence and address barriers (online supplemental figure 1A–B).^{17–19} Furthermore, these barrier categories were linked with key adherence strategies to help clinicians facilitate adherence counselling in visits. The intervention involved a two-step process in which patients completed the brief intervention and reported barriers/concerns followed by clinicians individualising their conversation to address patient responses. This adherence intervention was created to improve clinicians' skills to identify and target SLE non-adherence to improve care; however, feedback from patients and healthcare stakeholders was not included.²⁰ Given that current validated adherence interventions are rarely used during clinic visits, our earlier first step was to determine the feasibility of administering the intervention during routine SLE visits.²¹ In that prior feasibility study, we found that the prior intervention was completed in 97% of 112 consecutive visits and the time spent to address non-adherence was 2.6 min. After establishing feasibility, we aimed now to address the next critical gap by incorporating patient input on adherence strategies that would work for them. We also aimed to collect patient and healthcare advisors' feedback to optimise implementation of the intervention without burdening clinics.

METHODS

Study design

This focus group study was designed to elicit patients' experiences and perceptions regarding lupus medications and to obtain a list of patient-suggested and ranked strategies, and healthcare staff and provider feedback

to inform our intervention. Consolidated Criteria for Reporting Qualitative Research was used to designing this study.²²

Setting and participants

Patient advisors: clinical staff at two universities screened patients with lupus on HCQ using a patient self-report visual analogue scale or pharmacist review during their routine visit to identify eligible patients. Patients on HCQ and reporting concerns with the medication, those who had active or a history of gaps in refills or were missing >5–6 doses per month ($\leq 80\%$ adherence) were eligible to participate in this study. Their provider asked if they would be interested in participating, and interested patients received a study flyer. They were then contacted by the research team via phone. The research team gave: (1) further details about the study, (2) verified eligibility and (3) obtained verbal consent. An information sheet was mailed to recruited patients.

The sample size selection and the number of focus groups were determined based on our team's prior qualitative work,^{23,24} and feedback from our community advisors and expert facilitators. We purposefully recruited representative patients from two racially and socioeconomically diverse Wisconsin cities: Madison and Milwaukee. We recruited a broadly representative group of 11 patients from different age groups. We sought to include at least one male member, from non-white racial/ethnic groups, with severe lupus defined as ≥ 1 vital organ involvement, and with social challenges identified using social determinants of health documents in the electronic health record (EHR), as such factors can affect adherence. All 11 patients were invited to participate in all 4 focus group meetings.

Healthcare advisors: we recruited nine healthcare team members with equal representation from four clinics from two diverse academic centres (University of Wisconsin (UW)-Madison and Medical College of Wisconsin). Members from each centre included a registered nurse (RN), a medical assistant (MA), a physician, a pharmacist and the medical director (MD) of the UW rheumatology clinics.

Data collection

We developed six semi-structured virtual focus groups; four patient focus groups and two healthcare advisor focus groups. The interview guide was developed based on a literature review of patients' and providers' experiences with HCQ and other medications,^{13–15} and by adapting a focus-group guide used in a prior study on smoking cessation in patients with autoimmune diseases and communication in paediatric diabetes clinics.^{23,24} Leveraging blueprints from our team's prior qualitative work²³ and expert facilitators, we planned an onboarding session and a series of four meetings for continuous stakeholder engagement. Three investigators facilitated six consecutive focus group meetings. Each virtual focus group meeting lasted for 90 min and was audio recorded.

All audio recordings were subsequently transcribed. During focus groups, notetakers (NK, SGo) documented the order of speakers and non-verbal cues (eg, body language) to supplement the transcriptions.

Patient focus group: interviewers used a semi-structured interview guide to gather information regarding patient experiences with lupus medications, especially HCQ, their beliefs and assumptions, challenges encountered with HCQ use, emotions elicited regarding lupus and medications and experiences with the healthcare team. Furthermore, patients discussed and prioritised their desired interventions, facilitators and motivators that they believed would be the most valuable and actionable to address underlying concerns to improve adherence. Patient feedback was incorporated to redesign our prior adherence intervention (online supplemental file 1A–B).

Healthcare advisors focus group: the objectives of two sequential healthcare staff and provider focus groups were to obtain feedback to optimise the adherence intervention. We shared the revised adherence intervention after incorporating patient feedback and current workflows with healthcare advisors to obtain feedback on content, language, format of use, feasibility and other recommendations to optimise and deliver a stakeholder informed adherence intervention.

Final survey: a final survey was sent to healthcare and patient advisors to endorse the final revision of the adherence intervention and implementation workflow.

Analytic framework and plan

Descriptive statistics were calculated for patient and healthcare staff demographics.

1. *Patient focus group:* we sought information from patient focus group meetings in two major domains: (1) patients' insights and experiences with lupus medications (HCQ); (2) patient-recommended adherence strategies. An a priori coding scheme reflecting these domains was used. Consistent with a content analysis approach, we used the structurally coded text as an entry point into understanding the range of experiences, perspectives and needs that were identified by patients. Three study team members (SGa, NK, SGo) developed and tested the coding scheme by applying it independently to all focus group transcripts. Adjustments to the coding scheme were made iteratively between each reading until thematic saturation was reached. Discrepancies in coding, codebook structure and generated themes were resolved via discussion to enhance trustworthiness and rigour. Furthermore, we reviewed our analysis with the focus group members during subsequent focus group meetings to obtain advisors' feedback on the findings. Transcripts were coded using NVivo software.²⁵ Listed frequencies of coded categories for patient insights and patient-recommended adherence interventions were calculated. A list of the frequency of themes was generated from the analysis of patients' insights about HCQ adherence and the presence of codes for two or more themes in a single

patient phrase. From these, a conceptual framework was developed to show the inter-relationships between themes and how these lead to non-adherence. Finally, patients suggested adherence strategies to target non-adherence during clinic visits. These strategies were coded by the study team and a list of adherence strategies was created. Using member checking, we assured that patients endorsed all strategies and their associated placement in respective adherence barrier categories.²⁶ Patients then ranked these adherence strategies in each category from most valuable to least valuable in addressing underlying barriers in the real world.

2. *Healthcare team focus group:* healthcare team data were analysed to identify key steps using content analysis to optimise an adherence intervention to deliver a patient-informed and healthcare team-informed adherence intervention and an implementational workflow for clinics.

RESULTS

In total, across six focus groups we engaged 20 stakeholders (11 patient advisors and 9 healthcare staff) from four clinics in two health systems (table 1).

A. *Patient focus groups:* the group of 11 patients included 90% females, 55% identifying as black, 45% with social barriers and 55% with severe lupus (table 1A); all 11 patients were invited to participate in 4 sequential focus group meetings. All 11 patients attend first three focus groups, and 10 patients attended the fourth meeting (90% attendance).

Analysis across the two domains of adherence barriers and strategies generated eight barrier themes and six strategy themes.

Patient barriers and concerns about HCQ and lupus medications

'Long-term concerns', 'worry' and 'side effects from HCQ' were the most frequently mentioned words or phrases during the initial focus group meeting in which patients shared their perspectives and insights about HCQ (figure 1). Qualitative analysis identified eight themes regarding adherence based on patients' concerns about HCQ as shown in table 2 by frequency.

Theme 1: medication information gaps and conflicting information

Patients described that receiving incomplete or conflicting information about medications profoundly impacted their decision to start HCQ or discontinue after starting. Furthermore, patients reported that if they were given incomplete information about HCQ, they often resorted to unreliable information sources, like 'the internet' (table 2), to gather more information which fueled anxiety about HCQ. A patient stated that "I had to go to the internet... not a great place to get information!"

Theme 2: reasons for stopping or logistical barriers

Commonly, patients starting HCQ reported they experienced early side effects with HCQ and a lack of early

Table 1 Patient and healthcare advisors' characteristics (n=20)

A. Patient advisors' characteristics	N=11
Age, years, median (range)	42 (30–60)
Female, n (%)	10 (91%)
Race	
Black n (%)	6 (55%)
White, n (%)	4 (36%)
Asian, n (%)	1 (9%)
SLE disease duration <5 years	5 (45%)
Severe SLE*	6 (55%)
Area	
Madison, n (%)	6 (55%)
Milwaukee, n (%)	5 (45%)
Social barriers reported, n (%)†	5 (45%)
B. Healthcare advisors' characteristics	N=9
Age, years, median (range)	36 (30–48)
Female, n (%)	7 (78%)
Race	
Black n (%)	1 (11%)
White, n (%)	6 (67%)
Hispanic, n (%)	2 (22%)
Role in clinic, n (%)	
Physician	2 (22%)
Medical assistant	2 (22%)
Clinic director	1 (11%)
Registered nurse	2 (22%)
Pharmacist	2 (22%)
Years of experience in lupus >5 years	7 (78%)

*Severe SLE defined as central nervous system, renal or other major organ involvement.
 †Social barriers or determinants of health in EHR defined as unstable housing, food insecurity, outstanding medical bills, lack of transportation, etc.

perceivable benefits. One patient mentioned that “I started losing hair; I thought it is from HCQ, so I stopped it.”

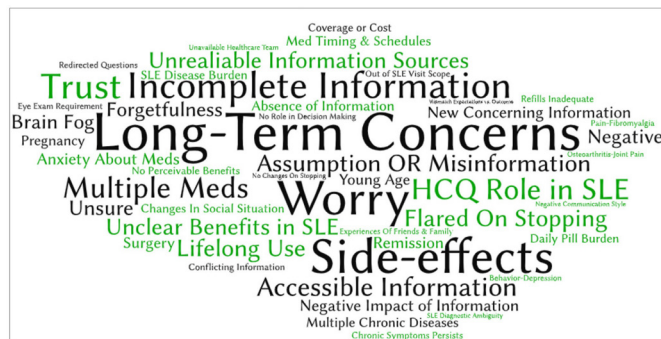


Figure 1 Patient perspectives and insights about hydroxychloroquine. The size of the word/phrase matches the listed frequency.

This reduced their motivation to continue HCQ and led them to interrupt therapy. Moreover, patients with severe lupus (eg, renal and central nervous system lupus) were often started on several medications at the same time, which resulted in the logistical barrier of having complex medication schedules. Finally, another major logistical barrier leading to non-adherence was change in social situation such as losing a job or health insurance, lacking transportation to get refills or having unstable housing.

Theme 3: misbeliefs and assumptions

As an overarching theme, patients shared that the role of HCQ in lupus was not clear. Several had knowledge gaps and one patient said that she was completely unaware that HCQ improves survival and prevents blood clots in lupus. Moreover, patients were confused whether the routine blood and urine labs were to monitor lupus or HCQ toxicity. Thus, some assumed that routine labs were to monitor for HCQ toxicity which amplified their concerns that HCQ might lead to multiorgan damage.

Theme 4: emotions and attitudes

Worry regarding potential eye toxicity with HCQ was the most common emotion described by most of the patients. Other patients described how symptoms such as upset stomach or presumed allergic reactions with HCQ led to negative emotions about its use.

Theme 5: comorbidities

Patients also reported their concerns regarding HCQ's safety with other chronic medical conditions. In particular, they reported that chronic symptoms such as fatigue and brain fog did not improve with HCQ use, or change with missed doses, decreasing their motivation to take HCQ regularly.

Theme 6: medication burden and timing

Patients reported that medication schedules were not individualised based on their preferences and lifestyle. Thus, medication regimens often conflicted with their work schedules leading to non-adherence.

Themes 7–8: duration of use and young age

Patients expressed unsettling feelings and doubts about short-term and long-term HCQ use, especially when they were diagnosed at a younger age and when they had to continue HCQ over the life course even when their symptoms improved.

Conceptual framework of how concerns with HCQ lead to non-adherence

The flow diagram in figure 2 depicts current workflows in our clinics and how patients' concerns were inter-related and affect adherence at different points. For example, we found that initial gaps in information or ineffective patient-provider communication or insufficient time to describe safety and benefits of HCQ, resulted in negative emotions contributing to reluctance to start HCQ. Moreover, adherence and logistical barriers were not assessed

Table 2 Eight themes highlighting patients' insights and concerns about HCQ

Themes*	Theme subcategories	Illustrative quotes (1–3)
Theme 1: medication information gaps and conflicting information	Incomplete medication information	"Nobody told me that I could take both HCQ doses together. If I would have known, I would not have missed so many HCQ doses."
	Unreliable sources	"I had to go to the internet... not a great place to get information!"
	Negative impact of information	"I read drowsiness as a side-effect from HCQ. It was very concerning."
	Absence of information	"My providers did not talk with about what med response to expect. I never knew if my symptoms were from meds or lupus."
Theme 2: reasons for stopping or logistical barriers	Concerning or conflicting information	"I saw on the internet that HCQ is an anti-malarial drug. I freaked out that I have malaria, and no one ever told me!"
	Side effects	"I had extremely bad nausea with the medication, I had to stop for a few days." 'I started losing hair, I thought it is from HCQ, so I stopped it."
	Multiple medications	"I have to take 8 different meds at 3 different times. I work 3 shifts a day. Sometimes I forget taking the morning doses... I wonder if I can take it with the afternoon pills or not."
	Lack of perceivable benefits	"What does HCQ do for me or my disease?" "I have not noticed much difference with HCQ." "Prednisone helps, I can't say the same for HCQ."
	Forgetfulness	"Lupus affects memory and causes overwhelming fatigue. I sleep often... when I wake up, I forget if I took HCQ or not."
	Changes in social situation	"I was in between providers, and I could not get medications as prescribed. It was overwhelming." "I lost insurance; I could not afford HCQ." "I was in between insurance, I could not get my meds and ended up in the hospital."
Theme 3: misbeliefs and assumptions	Cost or refills inadequate	"I am not sure why we cannot get 90-day fill and several refills."
	Long-term concerns about HCQ	"I am worried about losing vision with HCQ use." "I am worried about the long-term side effects... on my organs and eyes." "Dark urine, concerns me if HCQ is affecting my kidneys."
	Assumption-misinformation	"I got cataracts; I have increased power of my glasses. This is HCQ related, got to be." "As I undergo regular urine tests, I am concerned about kidney or other organ damage from HCQ."
Theme 4: emotions and attitude	Unclear HCQ role in lupus	"I get confused about HCQ and SLE, not sure how long it will be in their system, what exactly it is doing, and how it is helping." "I was unaware that HCQ improves survival and prevents blood clots in lupus"
	Worry	"Will HCQ be safe for long-term use, I need more reassurance."
	Negative or unsure	"I started having several allergic reactions. I did not know what it really was coming from." "When I started HCQ, my hair fell out. I was not sure if it was HCQ or something else."
Theme 5: comorbidities	Experiences of family or friends	"It was hard for me to start HCQ, as my mother had suffered from muscle weakness with HCQ."
	Multiple chronic diseases	"I need to know if HCQ could interact with my other chronic diseases?" 'My fatigue and pain are still there. I am not sure if HCQ is working or not."
	Brain fog	"I often forget taking HCQ due to brain fog."
Theme 6: medication burden and timing	SLE disease burden	"I had severe disease and my SLE led to kidney disease, blood clots, skin rashes, and heart disease. I take several medications. It is overwhelming."
	Medication schedules and pill burden	"My medication timing and schedules are skewed. If I miss a medication, then it is very hard for me to pick back up." "I stopped HCQ as it was honestly hard to keep up with the medications at different times of the day."
Themes 7–8: duration of use and patient age	Anxiety about medications	"I find it annoying to take 1.5 tabs a day. I am worried if this will change med effects." "I am worried if my eyesight changes are related or not."
	Life course risk Duration of use	"I was distraught with the idea that I have to take a medication for the rest life." "The idea of taking a medication for the rest of my life was unsettling." "I could not understand why I needed to take a medication even when I was feeling better."

*Themes arranged from most common to least common listed frequency. Only key subcategories for each theme are shown. HCQ, hydroxychloroquine.

during follow-up visits, thus, lingering concerns and difficulties led to misbeliefs, fear and non-adherence over

time. Finally, changes in their appearance, for example, weight gain, hair loss, that started after taking HCQ were

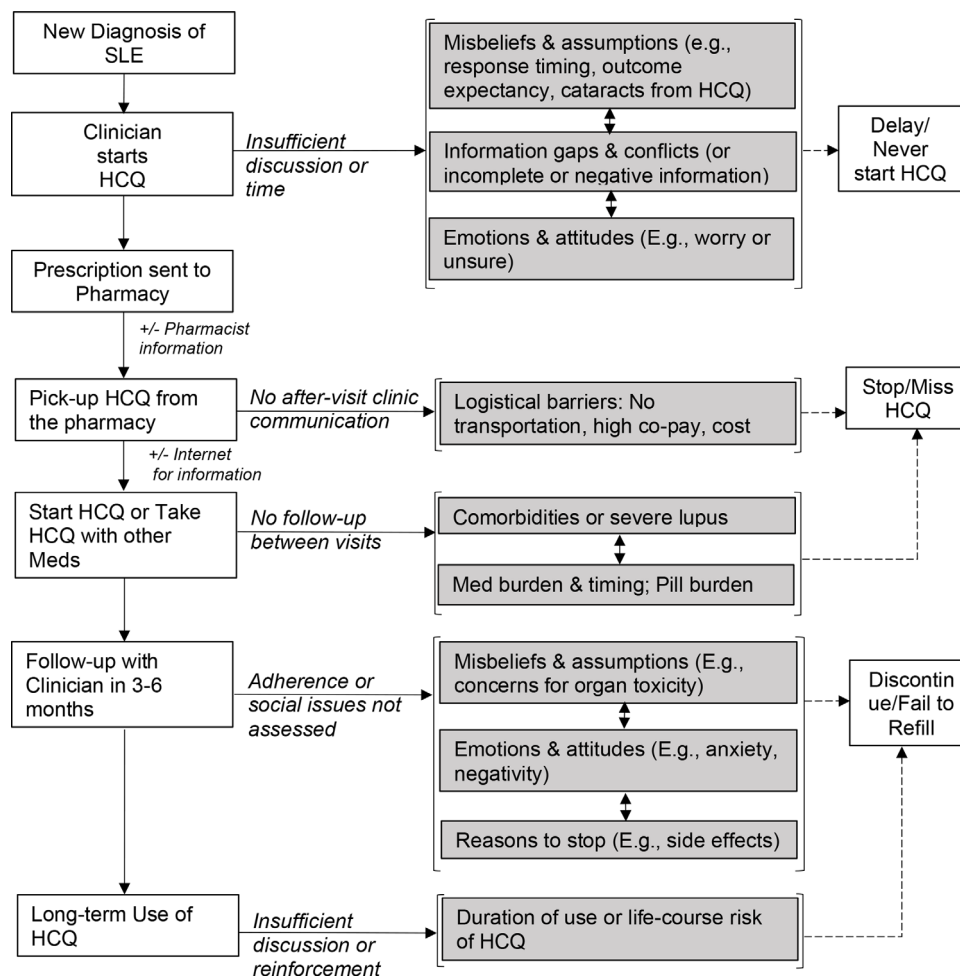


Figure 2 Flow diagram showing current workflow in clinics, and how patient concerns and themes are inter-related (shown with double arrow) and affect adherence at different time points. HCQ, hydroxychloroquine.

commonly attributed as side effects from the medication rather than lupus or steroids. Lack of provider discussion about side effects or concerns during follow-up visits accelerated their worries about continuing medication. Additionally, we noted that each patient faced different challenges that were multifaceted, particularly in those experiencing social barriers, comorbidities and/or severe lupus at a young age.

Patient recommended and ranked strategies to improve SLE medication adherence

This domain included six themes highlighting patient-suggested adherence strategies to address underlying barriers and enhance adherence including motivators, filling information gaps and resolving conflict, facilitators, personal reminders, improving communication and building rapport and trust (table 3).

Theme 1: motivators

Patients perceived positive symptom response with HCQ use as the most valuable motivator to take HCQ regularly. Framing the time and outcome expectancy can help that. One patient mentioned that “*knowing that HCQ can take several weeks to months to help my symptoms, encouraged me to take HCQ even when I felt my lupus was active.*”

Theme 2: filling information gaps and resolving conflict

Patients suggested that sharing complete or adequate medication information could address patient concerns about HCQ and positively impact adherence. Likewise, sharing reliable curated medication information resources could reduce conflicting information that accentuates worry and misbeliefs about HCQ.

Theme 3: facilitators

Patients expressed that personalisation of adherence strategies facilitated adherence, such as placing their pillbox near their toothbrush. They also conveyed that receiving reassurance on the safety of HCQ and data regarding medications and lupus outcomes were other important facilitators of adherence, ‘*Basically, it came down to the lesser of two evils, med is a lot less bad than active lupus.*’ Furthermore, they noted that easier medication schedules tailored to their lifestyle and work schedules could help patient adherence to complex medication regimens. Receiving care in multidisciplinary clinics with skilled nurses, social workers and pharmacists facilitated adherence as their concerns and social barriers were addressed swiftly by the team.

Table 3 Six themes highlighting patient-suggested and ranked strategies to address patient concerns

Themes*	Theme subcategories	Illustrative quotes (1–3)
Theme 1: motivators	Positive symptom response	“After taking HCQ, I get less easily tired and have energy. I think HCQ response motivates me to take my medication.”
	Fear of disease or hospitalisation	“I take my medications; I don't want to be admitted again with SLE flare.” “I do not want flares, so I take it.” “I just want to feel normal, so I take HCQ.”
	Knowledge about HCQ role	“I was taking [it] I think you know it did help, you know contribute to helping my body be in remission” “I think it reduces flare-ups and pain and prevents damage.”
	Time and outcome expectancy	“Knowing that HCQ can take several weeks to months to help my symptoms, encouraged me to take HCQ even when I felt my lupus was active.”
	Dialogue with healthcare team about concerns or side effects	“I was in remission, and I stopped taking HCQ. It was hard for me to talk with my doctor, but I did discuss with my rheumatologist about my concerns and if I need to start it or if we can monitor for now.”
	Family support	“I take meds regularly so that I feel less tired, and I can play with my daughter.” “My husband accepted my disease so, I accepted it as well.”
	Better SLE labs	“I think the biggest thing for me was really, you know, seeing the positive test results knowing that you know, these medications were actually doing something good.”
Theme 2: filling information gaps and resolving conflicts	Reliable and curated information sources	“I think people have to be cautious with social media sites.” “I follow lupus sites where professionals and lupus experts share their opinion. It is helpful!”
	Positive impact of information	“I got diagnosed at a young age. I wanted to have kids and was concerned with medications. My doctor said that HCQ will not be an issue. It alleviated my stress.”
	Complete adequate medication information	“My rheumatologist and my pharmacist give me all med details, like take meds with food.”
Theme 3: facilitators	Personalisation of strategies	“I have different alarm tunes for different meds scheduled to be taken at different time of the day.” “I keep meds near my toothbrush so that I take it in the morning.”
	Increased knowledge about lupus and medication	“I feel the correlation between taking meds and feeling better.” “Basically, it came down to the lesser of two evils, med is a lot less bad than active lupus.”
	Easier schedules	“I was told to take meds at the end of the day, I take HCQ as the last thing after I crawl into my bed. Works for me” “I was told to take both tablets together, so much easier.”
	Reassurance on safety	“I would like my healthcare team to reassure me that HCQ is safe, and the long-term use would not affect my organs.”
	Multidisciplinary clinics	“I like the one-stop clinic, if I need a nephrologist or pharmacist or a social worker - they have it, it's easy!”
Theme 4: personal reminders	Personalise reminders	“I leave pillbox lid open so that I remember to take the med.” “I keep water near my pillbox to remind me to take meds.”
	Simple strategies	“Taking both tablets together.” “Using multiple pillboxes helped me.”
	Reinforcement (two reminders)	“I have a pillbox and I always have an alarm on my phone.”
Theme 5: improving communication	Attentive provider and focus on patient	“My rheumatologist makes sure I get my eyes checked regularly so they can kind of look at those results and make sure that they're [eyes] ok.”
	Non-judgemental and positive communication	“I think, if the clinicians start with open questions like what's going on? Any stress? Can I help? It would help patients to open up.”
	Team engagement	“Both times I was pregnant and was high risk pregnancy. I think my OB and my rheumatologist were talking a lot”
	Tailored discussions per patient-relevant details	“I was having drowsiness with HCQ. I doctor told me to take it at night. I felt much better.”
	Connectivity through EMR	“I pick up my medications if I've got questions, I message, and their response is right there.”
Theme 6: building rapport and trust	Trust	“I trust my caregiver and their knowledge and experience; I think building that trust is very important for all patients with lupus.”
	Personal link with healthcare team	“We had that relationship, when he [rheumatologist] could just look at me and say you're not feeling good today right?”

*Themes ranked from most valuable to least valuable by patients. Only key subcategories for each theme shown. EMR, electronic medical record ; HCQ, hydroxychloroquine.

Theme 4: personal reminders

Simple strategies such as embedding taking doses at the same time as current habits at bedtime was viewed positively as was using a pillbox to help improve adherence. Using two strategies together helped reduce their forgetfulness to take medications.

Theme 5: improving communication

Patients noted that a non-judgemental approach encouraging positive communication with their healthcare team, and personalised adherence discussions to address concerns at the individual level could improve adherence (table 3).

Theme 6: building rapport and trust

The importance of psychosocial support from a healthcare team for patients was emphasised, given their central role in their lupus care.

Patient ranked barriers and recommended strategies for clinics

Eight categories of adherence barriers were identified based on literature and patient experience, and ≥ 4 patient-suggested strategies were linked to each category of adherence barrier. During ranking of adherence strategies, patients unanimously ranked discussion on SLE labs and symptom response with HCQ as the most important strategy to address understanding about HCQ adherence barrier. Ninety per cent of patients ranked co-pay assistance and 90-day prescription as the most valuable strategy in the pay or refill barrier category. Patients shared positive experiences with co-pay assistance programme and highlighted the importance of discussing this strategy during visits. Patients shared personal examples of visual reminders to take meds (eg, keeping the pillbox lids open) and prioritised visual and personal reminders to address timing and schedule barriers. Highly ranked strategies for other barrier categories are shown in figure 3B.

Healthcare advisors focus group

A group of nine healthcare advisors from four clinics (table 1B) participated in two sequential focus group meetings. Four clinics included two lupus clinics and two general rheumatology community clinics from two institutions. Providers in lupus clinics were supported by an MA, RN and a pharmacist, while in general rheumatology clinics, they were supported by an MA and RN only. All advisors participated in both meetings to review our modified adherence intervention that patient advisors had revised, and shared feedback to optimise the adherence intervention for clinical use.

Content

All advisors reported that they often face difficulty starting a non-judgemental adherence discussion with patients and thus, they noted that the content of the intervention would be helpful during visits. Additionally, they suggested avoiding adding extremely rare side effects to prevent undue anxiety. All advisors recommended reducing

content by including the top four to six most valuable strategies for each barrier category, and combining categories with similar strategies, such as side effects and drug interactions (figure 3A–B).

Language and readability

Advisors recommended simplifying and revising the language of the intervention using the summary for patients with low literacy by the Agency of Healthcare Research and Quality.²⁷ Additionally, advisors recommended reducing verbiage to improve readability. Finally, advisors recommended including specific numbers (natural frequencies) in adherence assessment and strategies for easy understanding.

Format of use

Compared with paper and online versions of adherence intervention, most advisors (90%) recommended using a laminate version of the intervention with a sliding bar to highlight strategies for each specific reported adherence barrier category. Additionally, most advisors suggested using a paper version along with the laminate so that patients and clinicians could complete the forms during the visit, which could be scanned in the EHR for future reference. A few recommended using electronic forms and sharing forms via patient message portals.

Feasibility

Important questions were raised regarding feasibility, including the timing of sharing the adherence form with patients during visits and who should review the findings. All advisors recommended sharing the paper version of the intervention with the patients at the time of check-in so that patients have enough time to review and complete the form. Clinician advisors suggested leaving the completed paper version of the adherence intervention on the keyboard as a visual cue for the clinician to review during the visit. Additionally, physicians reported that pharmacists, when available, should follow-up with the patients between visits after a new medication was started and to discuss and address barriers between visits. Ultimately, clinicians felt that an intervention that takes <5 min to assess and address non-adherence would be feasible for use in busy clinics. This feedback informed the five-step workflow to implement our adherence intervention in clinics.


Other recommendations

After reviewing the intervention, no significant concerns were raised and there was good consensus support. All advisors agreed that the intervention with eight categorised barriers each cross-walking to four to six specific patient-recommended adherence strategies would be a highly useful in-clinic intervention. As a minor change, a recommendation was made to incorporate other medications in the intervention as well.²⁸ Finally, all healthcare advisors recommended including a short (5–10 min) case-based video training for all

A

Patient Name: _____
 DOB: _____
 MR #: _____

UW Health (University of Wisconsin Hospitals and Clinics Authority)

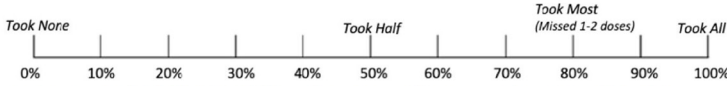


Index to Notes/Encounter _____
 Date: _____

LUPUS MEDICATION ASSESSMENT

We understand that for many reasons people may or may not take their medicine(s) exactly as prescribed. **Your input is very important and valuable** for your healthcare team, so:

1. Please think about your medicine use during the past week. Please mark how many doses that you took of the recommended amount of medicine in the last week.



If you reported 80% (Took Most) or less, then continue to #2A-2B.


2A. Please mark the medicine(s) causing problem(s):

Hydroxychloroquine or Plaquenil
 Mycophenolate or Cellcept or Myfortic
 Azathioprine
 Other Medicine(s); Please list _____

2B. Please think about your experience with medicine(s) in the last week. Please mark how often each of the following statements have been true for you:

	Never	Some-times	Often	Always
a) I find it hard to pay or get enough refills for this medicine.				
b) I have difficulty taking all my medicine doses on time as prescribed.				
c) I'm concerned about side effects I get from this medicine. <i>E.g. stomach pain, weight loss, eyesight problems etc.</i>				
d) I worry about interactions with my diet, diseases, other medicine(s), & supplements.				
e) I am unclear about the benefits of this medicine for my disease.				
f) I worry about the long-term effects from this medicine.				
g) I don't understand if this medicine is working for me .				
h) Describe other concerns or information needs:				

B



LUPUS MEDIC ATEGIES

Following are patient-preferred strategies for each barrier category (bolded word) from the paper form completed by the patients. Please move the slider to identify the barrier category reported by the patients on the paper form, and review strategy options with patients to prepare an adherence plan with your patient. The most valuable strategy reported by the patients is marked with an asterisk (*). Please circle the strategy selected to prepare an adherence plan on the paper form and give to staff for scanning.

(A) PAY OR REFILLS	(B) MED TIMING / DOSE SCHEDULE	(C) & (D) SIDE EFFECTS (S/E) & INTERACTIONS	(E) UNCLEAR BENEFITS	(F) LONG-TERM EFFECTS & INTERACTIONS	(G) UNDERSTANDING EXPECTATION VS. OUTCOME	(H) OTHER CONCERNS & INFO NEEDS
Pay or Cost <ul style="list-style-type: none"> Co-pay Assistance or Coupons* (E.g., GoodRx) Generic or Free Drug Programs Refills <ul style="list-style-type: none"> 90-day Prescription* Synchronize Refills for Multiple Meds* Mail-order Pharmacist/Social Worker Assistance (E.g., Financial or transportation) 	Reinforce with 2 Strategies at-a-time <ul style="list-style-type: none"> Visual Reminders* (E.g., Open pillbox, flashing cap) Personal Reminders* (E.g., Near bed/ toothbrush, different alarms) Multiple Pillboxes* (E.g., 31- or 7-day pillboxes or Pill packs or pre-filled meds) Consolidate Meds* (E.g., Daily vs. BID) Add Details to Personalize Rx (E.g., Take with dinner to limit drowsiness) Synchronize Refills for Multiple Meds 	<ul style="list-style-type: none"> Strategies to Overcome S/E* (E.g., Take with dinner) Communication Between Visits* (E.g., FU call or MyChart) Reassure with Tailored Information or Clarifying S/E (E.g., Vision changes <1 in 100,000; Visual acuity is not related) Dietary Suggestions (E.g., Take with food) Interactions with Supplements (E.g., Turmeric & LN) Rare Medicine Interactions (E.g., Tamoxifen & HCQ) 	Reinforce with Teach-back <ul style="list-style-type: none"> Explain Long-term Benefits & Response lag* (E.g., 6 wks-6 mos) Focused Discussion on SLE Labs & Symptom Response to Meds* Engage Team (E.g., PCP, pharmacist) Motivational Interviewing (E.g., Stress? Concerns?) Visual Graphs & Pictogram (E.g., Rbk vs. Benefit pictogram) 	<ul style="list-style-type: none"> Clarify Rationale for Testing* (E.g., Urine test for SLE, not HCQ monitoring) Eye Exam Reminders* Team Strategies for Comorbidities (E.g., PCP, PharmD, RN) Reassurance About Role in SLE & Safety (E.g., Vision changes <1 in 10,000) Visual Graphs & Pictogram (E.g., Graphs - High benefits, low-risk) 	<ul style="list-style-type: none"> Focused Discussion on SLE Labs & Symptom Response to Meds* Motivational Interviewing* (E.g., How would you like med response to be?) Visual Graphs (E.g., HCQ reduces flares & mortality) Comorbidity Management (E.g., Fibro, OA) Teach Using Patient Stories (E.g., Past experiences) 	<ul style="list-style-type: none"> Motivational Interviewing* (E.g., Stress? Overwhelmed?) Clarifying Conflicting Information* (E.g., News, pandemic) Address Changes in Social Situations (E.g., Insurance, job) Guide with Surgery, Vaccine Tailored Handouts Pharmacist/RN Check-in

Figure 3 (A) Final version of our patient stakeholder-informed and healthcare stakeholder-informed adherence intervention with eight items to assess adherence and categorise adherence barriers. (B) Eight barrier categories crosswalk to top four to six patient-recommended adherence strategies to facilitate adherence discussions between clinician and patient and develop an individual adherence plan using shared decision-making.

clinicians including MA, RN, MDs, fellows, pharmacists or residents, before implementing this intervention in clinical settings.

All feedback was incorporated to revise the final adherence intervention and implementation workflow, which were approved by the group. Finally, designers developed the final laminated (printed copy covered with plastic for use) and paper versions for single use.

Final survey

Qualitative feedback was elicited in the final electronic survey which was incorporated to deliver the final version of the intervention. All patient and healthcare advisors endorsed the final version of the adherence intervention (figure 3A–B) and workflow (online supplemental file 2). Most advisors, 90%, reported that the intervention was feasible based on the proposed workflow and knowing that the time spent to complete the intervention was <3 min in our pilot study across 112 consecutive visits.²¹

DISCUSSION

Medication non-adherence in chronic diseases like lupus is a key clinical gap according to the National Institutes of Health and Centers for Disease Control and Prevention leading to worse clinical outcomes, higher mortality and perpetuating health disparities.^{2–4 29} Yet, adherence is often *not routinely* assessed or addressed during clinic visits.^{30–32} Current general adherence interventions used in patients with chronic diseases are time consuming and not tailored to individual patient needs.³¹ Furthermore, adherence intervention, including our prior adherence intervention, lack patients' and healthcare advisors' perspectives to increase usability in rheumatology clinics including those with low resources (staff, time, pharmacy or social support).^{31 32} These are the existing gaps that limit use of these interventions in clinics that are addressed in our study. Our study is one of the few studies that directly incorporated patient and healthcare advisors' feedback to deliver a stakeholder-informed adherence intervention by: (1) incorporating patient insights on barriers contributing to non-adherence; (2) incorporating patient-recommended and ranked adherence strategies for each barrier category to target non-adherence with strategies that work in the real world; (3) incorporating healthcare advisors' feedback to optimise the intervention to enhance feasibility, usability and adoption of the intervention in busy clinics; (4) facilitating personalised adherence discussion via shared decision-making at the individual patient level during visits.

Validated adherence interventions are not routinely used in busy clinical settings as they take >10 min and lack patient and healthcare staff informed implementation strategies.^{16 31–35} Clinicians report that planning adherence strategies in clinics is challenging, noting single ready-made solutions are insufficient to address the adherence barriers that are unique to each patient.^{31 36} Objective adherence measurement, such as HCQ blood

levels, can effectively measure non-adherence.^{37–41} However, clinicians reported that they face difficulty in starting non-judgemental conversations with patients about non-adherence during visits. Thus, the overarching goal of our intervention development process was to develop a patient-centred approach beginning with the patient identifying their concerns followed by facilitating and tailoring adherence discussions using patient-recommended strategies between patients and clinicians. Additionally, we focused on respecting clinician concerns about consultation time.

Similar to the published literature, we found that worry and anxiety about side effects and long-term use of HCQ were the most common barrier phrases mentioned by patients.^{13 14 42} Moreover, patients reported that without provider discussions about HCQ's role in lupus, anticipated time to response and outcome expectancy, patients sometimes received conflicting information from other resources exacerbating their worry and leading to non-adherence. We found that each patient faced different challenges and most of the patient concerns were multifaceted. This could explain why previous interventions that used a single 'one-size-fits-all' adherence strategy did not report sustained improvement in medication adherence over time.^{36 43} We found that developing a multifaceted, personalised adherence plan with individual patients during clinic visits did improve and sustain adherence in a pilot study.⁴⁴ Thus, findings support the need for a tailored multifaceted adherence intervention that targets non-adherence at the individual patient level.

To develop a generalisable intervention, incorporating racially and socioeconomically diverse patient feedback is important since medication adherence is lower, and outcomes are worse in such groups.^{2 45} We purposefully oversampled patients with lupus to recruit a broadly representative group with racial and socioeconomic diversity. Similar to previous findings, we found that patients in our study reported that changes in social situation, such as lack of transportation, high co-pays or unstable housing, contributed to higher non-adherence.¹⁵ Furthermore, patients in our study mentioned that clinics offering social and pharmacy services provided them with immense support to address logistical barriers and improve adherence. These findings support the need for a multifaceted approach that assesses and addresses social barriers along with knowledge to target non-adherence, which informed the development of our brief adherence intervention.

Limited information is available regarding adherence strategies that would work for patients with lupus in real-world clinical settings.⁴³ This study is one of the first to report patient-suggested strategies, motivators and facilitators of adherence. We noted that the key strategies highlighted by the patients included effective communication with the healthcare team to explain response time and outcome expectancy with HCQ use and personalise a plan to address barriers. Similar to the findings from a previous lupus study, we found that patients with severe lupus often felt more motivated if they were included in

medication decision-making, and when the healthcare team valued their input.⁸ This supports the need for an intervention that facilitates non-judgemental dedicated adherence discussions via shared decision-making with patients, including those who are the highest risk of non-adherence. Most adherence interventions currently lack any guidance for clinicians on how to start feasible personalised adherence discussions with patients. Having patients complete a brief form immediately before the visit gave the foundation for a meaningful, individualised interaction. Thus, using these findings and engaging our patient advisors, we included the top four to six patient-recommended adherence strategies mapped for each of the eight patient-informed adherence barrier categories in our revised adherence intervention.

Despite patient and healthcare staff engagement from the two health systems, we acknowledge limitations. Although our study included racially and socioeconomically diverse members with lupus, we did not compare barriers by race or other characteristics. We used anonymised transcripts based on community advisors' feedback to enhance patient engagement. However, we incorporated insights and recommended strategies from a broadly representative group of patients so that the refined version of the intervention could assess barriers faced by different groups of patients with lupus and can tailor adherence strategies at the individual patient level. Next, we specifically examined patients' experiences and perception regarding HCQ use, although based on advisor feedback other lupus medications were included in the final version of the intervention. This is consistent with high non-adherence and similar barriers for other medications.^{13 14 28} Future studies will examine the effectiveness of this intervention in assessing and addressing non-adherence to HCQ and other lupus medications. Third, only 10% of patient advisors were men and patients with important factors, such as pregnancy, breast feeding or depression, were not specifically included in our study. Adherence strategies could differ in such groups and should be explored in future studies. Fourth, although we included two healthcare advisors from community rheumatology practices, our findings might not be generalisable to all rheumatology practices and will be addressed in future studies. Additionally, we did not include objective adherence assessment, such as HCQ blood levels, as an alternative method to measure non-adherence in SLE.³⁷⁻⁴¹ Measuring only patient-reported adherence could miss some patients who do not report medication non-adherence because of social desirability effect. Thus, future studies will aim to examine comparative effectiveness of using this intervention with and without therapeutic drug monitoring to improve adherence and outcomes in lupus.

In conclusion, our study delivers a healthcare staff-informed and patient-informed and endorsed adherence intervention that assesses adherence and facilitates tailored adherence discussions using patient-recommended strategies to clarify misbeliefs and encourage HCQ use. Our

multifaceted intervention is informed by eight patient-recommended adherence barrier categories and top four to six patient-recommended strategies to guide clinicians to target non-adherence.

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Contributors All authors critically reviewed the study proposal. SGa, NK, SGo, BC, DG and CB were involved in collecting or supervising data collection and analysing data. All authors participated in review of analysed data and summarising findings. All authors reviewed and approved the final version of the manuscript. SGa is the guarantor.

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