

# Determinants of Treatment Adherence in Ethnically Diverse, Economically Disadvantaged Patients with Rheumatic Disease

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**ABSTRACT. Objective.** To explore the determinants of adherence to medical recommendations, including drug therapy and appointment-keeping, among ethnically diverse and economically disadvantaged patients with rheumatoid arthritis (RA) and systemic lupus erythematosus (SLE).

**Methods.** Patients with RA and SLE were identified through chart review and were invited to participate in focus groups to examine their attitudes and beliefs regarding adherence to treatment and medical appointments. Eight focus groups (4 RA, 4 SLE) were conducted, with a total of 40 participants (22 SLE patients and 18 RA patients). Transcripts were analyzed using grounded theory techniques and qualitative analysis software to facilitate coding interpretation.

**Results.** The majority of participants reported experiencing difficulty in adhering to their treatment at least occasionally. Both SLE and RA patients reported similar barriers to treatment adherence: fear of side effects, financial problems, difficulty in navigating the public health system, and perceived treatment inefficacy. RA and SLE patients also revealed barriers to appointment keeping, including difficulties in scheduling, financial costs, transportation, and functional impairment limiting their ability to attend the clinic.

**Conclusion.** Patients' perceptions of and experiences with the health system, physicians, medication effectiveness, and side effects influence their adherence to treatment and other medical recommendations. Strategies to improve adherence could include the following: attempting to modify patients' beliefs and perceptions regarding medication effectiveness, promoting realistic expectations about risk/benefit ratios, and improving access to health care by reducing barriers that limit the interaction between patients and the health system. (J Rheumatol 2005;32:913-9)

*Key Indexing Terms:*

RHEUMATOID ARTHRITIS  
TREATMENT ADHERENCE

SYSTEMIC LUPUS ERYTHEMATOSUS  
FOCUS GROUPS

It is well recognized that socioeconomic deprivation is associated with poor health<sup>1</sup>. Cohort studies of patients with rheumatoid arthritis (RA) or systemic lupus erythematosus

(SLE) have shown an association between decreasing socioeconomic status and worse clinical outcomes including mortality<sup>2-11</sup>. The reasons for this disparity must reach beyond access to care because some studies documenting these effects have been conducted in countries with universal health access, such as the UK<sup>5-8,10,11</sup>. In addition, ethnic minorities with rheumatic disease also have worse outcomes than their white counterparts<sup>12-18</sup>, although this effect is difficult to disentangle from the consequences of economic deprivation. It is unclear what determines these differences in outcomes, but conceivably, treatment adherence may play a significant role. Although not well studied in RA and SLE, there is evidence from other diseases that suggests patients from ethnic minorities are less likely to follow physician recommendations<sup>19,20</sup>.

Current therapeutic regimes used in RA and SLE, although not curative, slow disease progression. Patients with RA who are treated early and continue therapy have better functional outcomes than those who are treated intermittently<sup>21,22</sup>. The outcome of SLE is also dependent upon careful management of systemic complications and continuous monitoring of disease activity. A few observational

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studies have suggested an association between poor compliance and increased severity in both RA<sup>23</sup> and SLE<sup>12</sup>.

Studies that have examined adherence to drug therapy in patients with RA mostly report low compliance rates<sup>24-29</sup>. The most recent studies have been conducted in Europe<sup>28,29</sup>. Moreover, to our knowledge, there is scant information about treatment adherence in minorities and economically disadvantaged patients with rheumatic disease.

We conducted a qualitative study to explore potential barriers to adherence to medical recommendations and appointment-keeping in a population of economically disadvantaged and ethnically diverse patients with RA and SLE. We conducted focus groups, a qualitative technique commonly used in exploratory studies, where the goal is to provide rich descriptive information<sup>30,31</sup>. This methodology is particularly appropriate when little is known about the target behavior, as is the case in treatment adherence in RA and SLE. By offering insight into barriers to adherence and assessing whether those barriers differ across ethnic groups, our study offers a first step in developing strategies to improve treatment adherence and subsequent outcomes.

## MATERIALS AND METHODS

**Patients.** Patients were recruited from the outpatient Rheumatology Clinic at Ben Taub General Hospital, which provides medical care for economically disadvantaged patients in the Harris County Hospital District (Houston, TX, USA). The majority of patients receiving care in this hospital are indigent, ethnic minorities who have limited state provided health coverage (Medicaid/Gold Card) or no insurance. Patients were identified through chart reviews. Inclusion criteria included age between 18 and 80 years old; disease duration of less than 15 years; current treatment with steroids, disease modifying antirheumatic drugs (DMARD), or biologic agents; and compliance with the American College of Rheumatology criteria for the diagnosis of RA or SLE<sup>32,33</sup>. Patients were required to have adequate mental status and either English or Spanish language proficiency, as determined by the research assistant who recruited them. A patient's ethnic background was identified initially by hospital records and confirmed by patient self-report. Patients who met the inclusion criteria were contacted at the time of the clinic visit or by phone. If the patient agreed to participate in the study, a research assistant conducted a brief interview to verify the patient's data from the hospital records and to ask the patient about his/her language preference (English or Spanish).

**Focus groups.** We conducted separate focus groups for African-American, Hispanic, and white non-Hispanic patients. We conducted a total of 8 focus groups of patients, 4 SLE groups and 4 RA groups. By ethnicity, 4 focus groups (2 SLE, 2 RA) were Hispanic, 3 (2 SLE, 1 RA) African-American, and 1 (RA) white. The Hispanic focus groups were conducted in Spanish, which was the participants' preference. The same facilitator, a native Spanish speaker, led all of the Hispanic groups. The 3 African-American groups and the white group were led by facilitators of the same ethnic background as participants.

Based on a literature review and the investigators' clinical experience, we developed a list of guiding questions for the focus groups, regarding patients' understanding of their disease, treatment expectations, treatment barriers, medical appointment barriers, and doctor-patient communication. Patients were also encouraged to discuss and express their opinions so that new or unexpected domains could emerge. Guiding questions regarding treatment adherence and appointment-keeping are shown in Table 1. The conceptual framework used for the conduct and analysis of the focus groups was the Health Beliefs Model<sup>34</sup>.

**Analysis.** All focus group sessions were audiotaped and lasted approximately 2 hours. An observer was present to take notes and assist with the audiotaping. The Hispanic focus groups were transcribed in Spanish and then translated to English. The focus group facilitator reviewed the transcripts to ensure the accuracy of the translation. The remaining audiotapes for the African-American and white focus groups were transcribed verbatim. At the beginning of the coding process, all study investigators reviewed a representative focus group transcript and underlined natural language statements to ensure consistency in the definition and selection of statements. After independently reviewing the transcripts, the investigators met and agreed on the natural language statements and codes to be included in the analysis. Responses were coded according to the study's guiding questions about treatment and medical appointment barriers. Transcripts were then imported into ATLAS.ti© software, which is used to organize and classify codes and patients' verbatim quotations, to search transcripts for specific components, and to generate analyses in the form of frequencies and summaries.

## RESULTS

After reviewing outpatient clinic charts, 217 patients with either SLE or RA met the study inclusion criteria. Of these, we were unable to contact 76, 26 were found to be ineligible, and 4 were deceased. Of the remaining patients, 25 refused to participate in the study. Of the 86 patients who agreed to participate in a focus group, 29 patients were unable to fit the meeting date into their schedule and 57 agreed to participate on the selected date. Of these, 40 attended a focus group session, and 17 missed their scheduled session. No significant differences were observed between participants and eligible non-participants: 90% of the participants and 86% of non-participants were female ( $p > 0.20$ ); of the participants, 10% were white, 48% Hispanic, and 42% African-American compared to 17%, 55%, and 28% respectively in non-participants ( $p > 0.20$ ); mean age for participants was 44 years compared to 45 in non-participants ( $p > 0.20$ ). We were unable to obtain additional clinical characteristics in these patients because of the Health Insurance Portability and Accountability Act (HIPAA), which became enforceable after starting the study and precludes us from reviewing the records of non-participants.

Demographic characteristics of focus group participants are shown in Table 2. The majority of participants were female (90%). RA patients had a mean disease duration of 5.7 years (3 mos to 14 yrs), and SLE patients had a mean disease duration of 5.4 years (4 mo to 14 yrs). All participants were being treated with steroids, DMARD, or biologic agents. Eighteen patients (45%) had not completed high school, 14 (35%) had a high school diploma with no further education, and the remainder (20%) had some college or a bachelor's degree. Only 9 (22%) were working full or part-time, and the others were disabled, retired, or unemployed.

### Barriers to Drug Treatment Adherence

Most patients reported several occasions on which they did not take their medications either because they forgot or because they chose to discontinue, often due to the large quantity of medication they were taking. This was common

Table 1. Focus group questions.

Treatment Barriers	
What difficulties have you experienced in following your treatment plan?	Probes: Costs, getting an appointment, side effects of the treatment, do you think it doesn't work?
How hard is it to remember to take the medications?	Probes: Do you forget? When does this happen? How does this affect your disease?
Have you ever stopped taking the treatment? When? Why?	How does this affect your disease?
What might help you take the medications on a regular basis?	
Medical Appointment Barriers	
Do you ever miss your appointments? When?	What are some of the reasons that could make you miss an appointment?
	Probes: Are financial costs/money a problem? How hard is it to get an appointment?
What are the benefits of keeping regular appointments to control your RA/SLE?	What might help you keep your scheduled medical appointments?
Is language a problem in the communication with your doctor? How does the presence of a translator affect your relationship with your doctor?	

Table 2. Demographic characteristics of the focus groups participants.

	Focus Group							
	1	2	3	4	5	6	7	8
Disease	SLE	RA	SLE	RA	SLE	RA	SLE	RA
Participants, n	7	3	5	5	8	6	2	4
Mean age, yrs	35.3	43	39.6	49.8	43.1	51.8	37.5	48.2
Gender, female	7	3	5	5	7	4	1	4
Ethnicity*	H	H	H	H	AA	AA	AA	White
Disease duration, mean (range), yrs	4.4 (2–9)	9 (7–10)	4.5 (0.33–8)	6 (2–14)	7.2 (0.66–14)	5 (1–10)	4 (3–5)	3.6 (0.25–8)

\* AA: African-American; H: Hispanic.

to all ethnic groups and to patients with RA or SLE. Patients frequently stated that they were taking too many different medications at different times of the day, and that it was difficult for them not to accidentally skip a dose. As one patient with RA said, “Well, since there is a lot, too many, I say, well I am going to take these, and in an hour I will take the other ones, and I forget and I don't take the other ones. And that's what happens to me.” A patient with SLE added, “The ones I forget sometimes are the ones I have to take twice a day. I don't know if I can take the 2 at the same time. That is what I want them to tell me.” Several other patients mentioned the large amounts of medications they had to take as a reason for stopping their treatment: “I've been at that point, you know, I'm taking 8, 9 pills a day... You get tired of swallowing medicine... I got to the point mentally I just got tired of it... and I just said, forget it. I stopped taking everything.”

Patients were more likely to forget to take afternoon and evening doses. Many patients noted that they would frequently omit medication doses when they were in a hurry or busy with work inside or outside the home. The fact that most patients liked to take their medicines along with a meal was also the cause of missed doses when their meal schedule was disrupted. Nevertheless, some patients mentioned that knowing the consequences of not taking their medica-

tions made them more alert and less forgetful. For example, a patient shared, “You don't forget ‘cause you've got a little reminder back there that goes like, ‘Pain in 2 minutes if you don't take this’.”

We identified 4 major barriers that patients encountered in following their treatment regimen: fear of side effects, perceived lack of efficacy of therapies, financial costs of drug therapy, and problems with the health system environment and logistics. We found these barriers to be universal for all 3 ethnic groups and both disease groups. Among Hispanic groups, language barriers resulted in difficulty communicating with the doctor and also acted as a barrier to good adherence. Major barriers to drug therapy adherence and appointment-keeping are shown in Table 3, with numbers of quotations for each barrier, all groups combined.

*Side effects.* Patients' fear of side effects was by far the most commonly mentioned theme. Most patients were experiencing only mild side effects but were extremely worried about severe organ damage from their treatment. One patient with SLE remarked, “There is a lot of fear within us that our organs will be destroyed because of the medicine along with the disease, in other words, we have 2 things that are attacking us, the medicine and the disease.” Another patient stated, “If the arthritis doesn't kill me, the medicines will kill me.” For several patients, this fear had been the reason for

Table 3. Major barriers to treatment adherence and appointment-keeping.

Barriers to Drug Treatment Adherence	Barriers to Appointment-Keeping
Fear of side effects, n = 65*	Difficulties with scheduling system, n = 57
Perceived lack of efficacy of therapies (n = 8)	Scheduling an appointment
Lack of a cure for the disease	Overlap of appointments on same day or week
Lack of satisfactory pain relief	Long wait to get an appointment and at the clinic
Problems with the health system environment, n = 31	Appointments only available on certain days
Difficulty obtaining Medicare/Medicaid insurance	Conflict with sporadic employment
Application for disability denied	Too many appointments with too many different doctors
Difficulty accessing the hospital pharmacy	
Financial costs of medications, n = 44	Costs of medical care, n = 18
Language barriers (Hispanics), n = 8	Financial difficulties/unable to pay for appointments
Difficulty finding a translator	Parking fees
Patient perceived physician to be disinterested in using a translator	Hispanic patients more concerned about costs than those of other ethnicities
Embarrassment of having a stranger present for a medical visit	Lack of transportation, n = 22
When translators used, patients generally satisfied	Symptom severity, n = 12

n: number of quotations for all groups combined.

discontinuing their treatment without seeking more information from their doctors regarding the side effects.

*Perceived lack of efficacy of therapies.* For some participants, their dissatisfaction with their treatment led them to stop taking their medications. Frustration and disappointment with their treatments and the lack of a therapy to cure their disease and/or to satisfactorily relieve their pain were common themes among participants. Another patient clearly stated: “When I was 17 I stopped taking it, the medicine, because I was tired, I was frustrated. I couldn’t see that the medicine was curing me. I thought that I was just taking and taking medicines and that they weren’t helping me.”

*Financial costs of medications.* Costs of medications were a concern among focus group participants and clearly acted as a barrier to adherence. Our study population was low-income and the majority of the participants were unemployed because of disability. They were either on Medicare or Medicaid insurance or were uninsured, with some financial assistance for health care through the Harris County Gold Card program. Most patients had to pay a small co-payment in order to receive their medications at the hospital’s pharmacy. One patient explained, “My medication was 2 dollars per prescription and you see how many prescriptions I have to get. So, it was hard for me to get them sometime. So, they would look at me like, why aren’t you taking this? Well, if you give me the money, I will go buy it right now.”

*Health system environment.* Patients also reported difficulty in obtaining treatment in a publicly funded health care environment. Many patients mentioned difficulties in fulfilling all the requirements to obtain Medicaid insurance. Other patients had applied for disability and been denied. Many others complained about the lack of continuity of care with the same doctor. As one patient explained, “Every time I see a doctor, they prescribe something. Then when I come back,

it would be another doctor and they would prescribe something else. For a while, it’s been a problem with me ‘cause they’re trying to change all the medicine and not knowing if everybody was really paying attention to my chart, ‘cause it’d be 15, 20 days maybe would pass and I’d have a new doctor, new medication, and it just kept on building up.”

Patients frequently mentioned difficulties accessing the hospital’s pharmacy, the inconvenience of having to make monthly trips to the hospital to refill their medications, and the long wait there in order to get their refills. One patient remarked: “Well, they don’t fill them at the time I need them so I have to stop taking it for a day...If I had to buy them or get them in one day and then return to refill them all on the same day that would be good. But the way it is, I have to go every week for refills for some, so that is a problem as well.”

*Language barriers.* For many of the participants in our Hispanic focus groups, language barriers between Spanish-speaking patients and non-Spanish-speaking doctors led to poor communication. Some of the patients were able to communicate with their doctor through a translator, and they were quite satisfied. Others complained of difficulty in finding a translator, the physicians’ lack of interest in using a translator, and the embarrassment of having a stranger present at their medical visit. One patient stated, “I haven’t been able to have an interpreter and I don’t feel satisfied...she (the doctor) asks me, ‘You don’t know English,’ and I say no. I think that when she asks me that, that she is going to bring someone to help me, but no, she just writes, and then she just sends me with the prescription and that is it. And I feel very uncomfortable because you don’t know anything.” None of the patients reported stopping or not being able to take their treatment because of the language barrier, but it was clearly an obstacle to satisfactory care that was mentioned across all the Hispanic focus groups we conducted.

### Barriers to Appointment-Keeping

The majority of the focus group participants admitted they had missed medical appointments on several occasions. The most frequent reasons for this were difficulties with the scheduling system, transportation, and costs of medical care. These 2 barriers were common for patients with either RA or SLE, and for all ethnic groups, although Hispanic patients seemed to be more concerned about the costs of medical care than patients of other ethnicities.

*Difficulties with scheduling system.* Common patient concerns regarding the health care system environment were difficulties in scheduling an appointment, overlap of appointments on the same day or the same week, a long waiting period (to get an appointment and after arriving at the clinic), and the availability of appointments only on certain days. Some patients reported having sporadic jobs, like housekeeping or babysitting, only a few days per week. They were then forced to choose between keeping their scheduled appointment and going to work. Patients complained of having too many appointments with different doctors in order to take care of their various comorbidities, which made their care more challenging and expensive.

*Costs of medical care.* Most focus group participants mentioned financial difficulties as a barrier to care. Several patients reported missing appointments because they had not been able to pay for them. In addition to the cost of the medical visits, parking fees were also a major concern.

*Lack of transportation.* A lack of transportation seemed to be a frequent reason for missed appointments among the Hispanic patients that participated in the focus groups, and it was mentioned among the African-American groups as well (albeit less frequently). Many Hispanic patients reported living quite far from the hospital, in areas without bus connections, and they were dependent on a family member or friend to drive them to their appointments. A few patients had cars and were able to drive to their appointments, but 2 patients mentioned that their disease and treatment interfered with their ability to drive a car.

*Symptom severity.* A major cause of missed appointments in the African-American groups was the severity of their symptoms and their resulting functional inability to get to their appointments. As a patient with SLE explained, "I've missed appointments and the reason why I missed that appointment is because it was just one of those days I knew I had to come, but that energy level wouldn't let me go down the stairs." Both RA and SLE patients across all ethnicities described their disease as a disease with "good days and bad days," and having a bad day was a common cause of missed appointments.

### DISCUSSION

Several studies have documented outcome differences by socioeconomic status and ethnicity in both RA and SLE

patients<sup>2-18</sup>. Callahan and Pincus have extensively studied the impact of formal education on rheumatic patients' outcomes, and have consistently shown significant associations between low education levels and mortality, morbidity, and disability<sup>2-4,9</sup>. Criswell, *et al* reported significant differences in the outcomes of patients with RA according to educational level; in contrast, the use of specific therapies did not systematically differ among patients with different educational levels<sup>35</sup>. Ethnic disparities in outcomes are also well documented. Minority patients with RA are at greater risk for disability than white patients<sup>18</sup>, although at least one study did not find significant differences in disability or fatality rates between African-American and white patients<sup>36</sup>. The outcome of SLE varies significantly across ethnic groups, with African-Americans experiencing the worst prognosis. Genetic differences could explain some of these disparities, but psychological and sociocultural factors may influence outcome as well. African-American patients with SLE have higher frequency of severe renal disease than white patients, but this difference is in part explained by hypertension and poorer compliance in this group of patients<sup>12</sup>. Other studies that have examined psychological and sociocultural variables did not find race as an independent factor for prognosis after adjusting for other factors<sup>16,17</sup>. These findings suggest that poor treatment adherence may mediate outcome disparities in disadvantaged groups.

In general, treatment adherence in patients with chronic disease is poor and this appears to be true in rheumatic disorders. In a French prospective cohort study of patients with RA, 36% were consistently compliant and 24% consistently non-compliant<sup>29</sup>. Recently, de Klerk, *et al* explored compliance in patients with RA and other rheumatic diseases by utilizing electronic medication event monitors. Large differences in compliance were found and in RA patients, compliance ranged between 72 and 107%, depending on the medication<sup>28</sup>.

In all of our focus groups, regardless of disease or ethnicity, most patients reported occasions when they forgot to take their treatment or they had voluntarily stopped their treatment. They also reported missing scheduled clinical appointments under several circumstances. RA and SLE patients from the 3 different ethnic groups shared major barriers to treatment compliance: (1) fear of side effects, (2) perceived lack of efficacy of therapies, (3) economic costs, and (4) difficulties with the health care environment.

Patients seemed to be informed about the possible side effects of the different medications, either because they had read about them or been informed about them by their physician. However, there was not a clear understanding of the ratio between possible benefits and toxicity. Frankel, *et al* evaluated risk aversion to toxicity in patients with RA and found that patients may consider any risk of particularly worrisome side effects, no matter how small, as unacceptable potentially leading to poor decision-making<sup>37</sup>. This

focus on drug therapy toxicity versus the beneficial effects of drug therapy could negatively affect patients' adherence to treatment. African-American participants seemed to be most concerned about the side effects of the medication, although Hispanic and white participants also expressed concerns. Mosley-Williams, *et al* compared barriers to treatment adherence between African-American and white SLE patients and reported that African-Americans were more concerned about the longterm effects of the medication than white patients<sup>38</sup>.

A high number of pills and frequent dosing have been previously reported as predictors of nonadherence behavior<sup>39-41</sup>, especially in chronic diseases. The participants of our focus groups frequently mentioned the high number of pills they had to take as a reason for noncompliance. We did not identify this factor as one of the major barriers to treatment compliance because we focused on the socioeconomic and psychological variables that could elicit ethnic differences in treatment nonadherence. Nevertheless, the multiple comments made by numerous individuals in our groups corroborate the findings of previous studies: patients are less likely to adhere to multiple drug regimens and complex dosing<sup>39-41</sup>.

Very few studies have investigated appointment-keeping in rheumatic diseases. Mirotznik, *et al* used the Health Belief Model to study clinic appointment-keeping in mostly African-American SLE patients and found that general health motivation, perceived disease severity, and perceived costs (defined as difficulties associated with seeing doctors, the degree to which doctor visits interfere with everyday life, and the result of iatrogenic effects) were associated with appointment-keeping in the theoretically predicted direction<sup>42</sup>. The participants of our focus groups attributed most of their missed visits to difficulties with the health system and financial problems. We also noted that African-American patients frequently reported episodes of severe pain, fatigue, and functional incapacity as a cause of not keeping scheduled medical appointments. This was also observed by Mosley-Williams, *et al* in their recent study<sup>38</sup>. We were not able to determine if this could be caused by greater disease severity in African-Americans or cultural differences in attitudes towards the disease.

We chose to use focus groups as our research methodology, as they have been shown to be an efficient method of exploring patients' experiences and opinions about barriers to treatment adherence in other diseases<sup>43</sup>. Although qualitative studies may have some limitations with respect to generalizability because of the small sample usually involved, they provide important in-depth information for developing subsequent quantitative studies that can specifically target relevant issues. Our qualitative study provides a critical first step to understand barriers to treatment adherence in disadvantaged populations. All of our focus group participants came from the same clinical setting, a county

hospital in a large urban area. We were only able to convene one focus group of white patients, which largely reflects the demographics at the hospital, which provides care primarily to minorities, and we may not have reached thematic saturation in whites. Yet, no unique themes were raised by white patients, and barriers were generally similar across the 3 ethnic groups, and for patients with RA and SLE. Many of the barriers discussed appear to be a reflection of the disadvantaged socioeconomic status of the patients.

Most participants in our study expressed difficulties in adhering to medical therapy and keeping appointments. Our study suggests that this is influenced not only by external variables, such as the health care system and financial difficulties, but also by patients' perceptions and experiences with medication effectiveness and side effects. We believe our findings have clinical implications. Strategies to improve adherence should include attempts to modify patients' beliefs and perceptions regarding medication effectiveness and the risk of side effects. Emphasizing the benefits of the treatment could diminish patients' extreme fear of side effects and therefore enhance treatment compliance. The increased concern about physical symptoms and function among African-Americans could also indicate a need for different approaches to overcoming barriers to treatment adherence in different ethnic groups.

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