Why do patients with systemic lupus erythematosus take or fail to take their prescribed medications? A qualitative study in a UK cohort

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Objective. It has been suggested that low adherence may contribute to poor clinical outcomes in patients with SLE. In this study, we explored the reasons why patients with lupus did or did not take their medications as prescribed.

Methods. Questionnaires including a 10-cm visual analogue scale (VAS) to assess self-reported adherence to prescribed medications were distributed to 315 patients with SLE. The responses were used to select a purposive sample of subjects who participated in interviews to discuss why they did or did not take their medications.

Results. Of the 315 patients, 220 (70%) completed the questionnaire. Thirty-three patients were interviewed. Themes explaining why patients took their medications regularly included: the fear of worsening disease, the belief that there was no effective therapeutic alternative to their prescribed medications, lack of knowledge about SLE to allow confidence in changing medications and feelings of moral obligation or responsibility to others. Themes explaining why patients did not take their medications regularly included: the belief that lupus could and should be controlled using alternative methods, the belief that long-term use of drugs was not necessary, the fear of drug adverse effects, practical difficulties in obtaining medications, and poor communication between patients and doctors.

Conclusion. The patients’ reasons for taking or not taking their medications largely related to previous experiences with the disease and/or drugs. However, improvements in communication between doctors and patients may promote better adherence in patients with SLE.

Key words: Qualitative, Adherence, Compliance, SLE, UK, Medications, Immunosuppressants, Visual analogue scale, Side effects, Doctor–patient communication.

Introduction

Adherence to prescribed therapies is an important determinant of clinical outcomes in chronic illnesses [1]. Poor adherence has been reported to contribute to adverse outcomes in patients with SLE [2, 3]; however, little is known about the reasons for poor adherence in these patients. Understanding the reasons why patients do not take their medications is necessary to develop strategies to improve adherence [4, 5]. Likewise, understanding why or how patients manage to take their medications as prescribed can help caregivers to understand the ways in which patients manage their illness and to what extent the health services are meeting their needs.

Quantitative assessments of adherence may give useful information about the number of patients with poor adherence, how patterns of adherence change with time and the subgroups of patients with poor adherence at a particular point in time. Various self-report scales have been used to assess adherence in chronic diseases [6]; however, some of their disadvantages include their inability to capture the variety of reasons why patients do/do not take their medications, the lack of validation in different populations and diseases, and their inability to estimate medication overuse [7].

Qualitative studies can give rich information about patient behaviours and experiences. Using this methodology, social factors including the impact of patient beliefs, attitudes and experiences, have been shown to be associated with adherence to therapy for diseases, such as hypertension [8, 9] cardiac failure [10] and diabetes [11].

To the best of our knowledge, there are no qualitative studies that explore the reasons why patients with SLE living in UK take or fail to take their prescribed medications.

In this study, we conducted a qualitative analysis of the reasons why patients do or do not adhere to the medications prescribed for their SLE.

Methods

Assessment of adherence and collection of socio-demographic and clinical data

The study was carried out at the Autoimmune Rheumatic Disease Clinic at University College London (UCL) Hospital. This is a tertiary referral centre that currently manages ~400 patients with SLE from a wide geographical area in and around London. The joint UCL/UCL Hospital Research Ethics Committee granted ethical approval for the research. Informed consent was obtained from all the patients.

All patients in the cohort who attended the clinic between 1 June 2006 and 30th September 2006, and who met the revised ACR criteria for SLE [12], were invited to participate in the study by completing a screening questionnaire. Questionnaires were also posted to those patients in the cohort who did not attend the clinic during this period. The questionnaire contained socio-demographic (age, sex, employment status, ethnic group, educational level achieved, religion, country of birth) and clinical questions (number of years since diagnosis of SLE, types of immunosuppressants and number of different types of medications being taken).

The questionnaire also included an assessment of adherence that had been specifically devised for this study. This was a 10-cm visual analogue scale (VAS), whose boundaries were 0 = ‘I never take my medications as prescribed’ and 10 = ‘I always take my medications as prescribed’. Patients marked the scale to reflect their general pill-taking practice in the previous 6 months.

Participants were asked to indicate whether they would be prepared to take part in a semi-structured interview to discuss their medications and the reasons why they did/did not take them as prescribed. Those who were willing to participate provided their contact details and they were then contacted to further determine their eligibility for interview. The eligibility criteria are explained in further detail below. The identity of all other study participants remained anonymous.
**Selection of patients for qualitative interviews**

A purposive (non-random) sample of respondents was selected from the patients who consented to interviews. Purposive sampling is designed to allow the study population to include subjects representing a wide range of the characteristics under consideration. This aim might not be achieved by random sampling particularly if the sample size is small. This approach enabled us to include participants whose clinical and socio-demographic characteristics could potentially enrich the data gleaned at interview [13].

Our aim was to include patients with varying levels of self-reported adherence to medications based on their VAS scores. Inclusion criteria included patients who had SLE for >1 yr, who self-administered their medications and who were taking at least one immunosuppressant.

Exclusion criteria were cognitive impairment, based on a history of cerebral lupus involving memory impairment (identified by telephone discussion); being too ill to participate in an hour-long interview (determined by telephone discussion) or not administering their own medications (identified by the screening questionnaire).

We selected participants for interview so as to include individuals with a range of self-reported VAS scores from different ethnic groups, men and women and people covering a range of ages, years of education, country of birth (UK or elsewhere), employment status, years of SLE, number of different types of tablets and types of immunosuppressants.

**Interview protocol**

The interviews were conducted by one of the investigators (S.A.C.). Each interview followed a written protocol, lasted ~60 min and was audiotaped and transcribed verbatim. A copy of the interview schedule is shown (Fig. 1). S.A.C. made field notes immediately after each interview. To some extent,
interviewees were encouraged to lead the discussion so that themes could be raised spontaneously by them. However, certain issues (e.g. the importance of religion, use of complementary and alternative therapies, and of access to and affordability of medications) were addressed in all interviews. Previous research suggests that these are important factors influencing adherence in other clinical conditions [14–16]. Although provision was made for interpreters to assist with interviews for non-English-speaking patients, this service was eventually not required as all the volunteers spoke English.

Analysis of qualitative data

Analysis was conducted from a realist viewpoint, which focuses on the mechanics of explanation. This perspective recognizes that there are facts and truths about the world and that these are shaped by both researcher and the respondent in order to make observations meaningful [17, 18]. A Framework approach [19] was used to analyse the data. This approach developed by the National Centre for Social Research in Britain is geared towards generating policy and starts from pre-set aims and objectives. The analytical process is strongly informed by a priori reasoning and involves five stages of data analysis: namely, familiarization, thematic analysis, indexing, charting and mapping and interpretation. In accordance with these stages: (i) the transcripts underwent independent scrutiny by two investigators (S.A.C. and R.R.) in order to gain familiarity with the data and to identify key themes; (ii) the investigators then met to compare and discuss the themes that were then identified as codes. Any differences were resolved in the first instance by contacting the patients for clarification of statements followed by further discussion between investigators S.A.C. and R.R. until a consensus had been reached; (iii) transcripts were further analysed by applying the coding frame to all the data; and (iv) the data were then arranged according to the thematic content. We gave specific attention to the patients’ explanations of why they took their medications regularly and/or why they did not. Finally, (v) generalizations that represented the total set were developed. We maintained constant vigilance for statements that might conflict with emerging thematic and conceptual relations.

Results

Questionnaires were sent by post or distributed in the clinic to 315 patients and returned by 220 (70%). One hundred and ninety-nine respondents completed the VAS. The distribution of VAS scores is shown in Fig. 2. The median (interquartile range) was 9.7 cm (8.8, 10.0).

Eighty-seven respondents who fulfilled the eligibility criteria volunteered for interview. A further seven volunteers did not meet the eligibility criteria and were excluded from interviews. Eligible volunteers included patients with VAS scores ranging from 2.2 cm (which was the lowest score recorded by any of the 199 respondents) to 10 cm.

Thirty-three patients were invited for interview. Two of these attended for pilot interviews designed to finalize and refine the protocol. These interviews were not included in the final analysis. The characteristics of the other 31 patients interviewed are shown in Table 1. The table shows that the purposive sample contained individuals with all the characteristics identified as being important in the selection process. We particularly sought to interview patients at the lower end of the range of VAS that we identified and invited all patients who had VAS scores of <8.8 cm (the lower limit of the interquartile range).

Data saturation (i.e. no new information was being gleaned) [20] was achieved by the 24th interview. The themes that emerged for why patients did or did not take their medications as prescribed did not appear to differ for patients whose self-reported adherence was higher or lower than 8.8 on the VAS.

Four main themes emerged to explain why patients took their medications as prescribed. These are described below with quotations from individual patients to exemplify each theme. The patients were anonymized and have been identified by their study number only.

(i) Fear that the disease would get worse if medications were not taken: many patients were resigned to the fact that they had to take medications for the sake of their health (‘...it’s a need thing ... you need to take them.’) (Patient 003). They had developed the belief that it was necessary to adhere to their medications largely as a result of their own previous experiences. This was particularly true of patients who had suffered severe or life-threatening episodes of SLE requiring intensive care. A typical response from an individual who had survived such an event was:

The reason I do all this is that I haven’t got a choice. It’s either you take them or you are not here. There is no in between. No black or white.

(Patient 023)

Others had not been so severely ill and had tried discontinuing medications, only to suffer flares of disease. This encouraged

![Frequencies](https://academic.oup.com/rheumatology/article-abstract/48/3/266/1786852/1786852)

FIG. 2. Distribution of VAS scores in the cohort.

TABLE 1. Characteristics of the 31 interviewees

<table>
<thead>
<tr>
<th>VAS, mean (range), cm</th>
<th>Over 8.8 cm</th>
<th>7.9 (2.2–10.0)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean (range), yrs</td>
<td>40.2 (19–70)</td>
<td>18</td>
</tr>
<tr>
<td>Ethnic group</td>
<td>White, n = 16</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Black, n = 13</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Indo-Asian, n = 2</td>
<td></td>
</tr>
<tr>
<td>Born in UK</td>
<td>25</td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>19</td>
<td></td>
</tr>
<tr>
<td>Belief in a religion</td>
<td>Christianity = 18, Jewish = 1 Hindu = 1</td>
<td></td>
</tr>
<tr>
<td>Males</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Duration of SLE, mean (range), yrs</td>
<td>11.2 (2–41)</td>
<td></td>
</tr>
<tr>
<td>Immunosuppressants</td>
<td>HCQ</td>
<td>22</td>
</tr>
<tr>
<td></td>
<td>Prednisolone</td>
<td>20</td>
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<td></td>
<td>AZA</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>MTX</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Mycophenolate mofetil</td>
<td>4</td>
</tr>
<tr>
<td>Other medications</td>
<td>NSAIDs</td>
<td>17</td>
</tr>
<tr>
<td></td>
<td>Bisphosphonates</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Calcium tablets</td>
<td>9</td>
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<tr>
<td></td>
<td>Anti-hypertensives</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Warfarin</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Anti-epileptics</td>
<td>1</td>
</tr>
</tbody>
</table>

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them to adhere subsequently. One patient expressed her experience thus:

I stopped taking the steroids and the hydroxychloroquine and within six months, I had a flare up and I was in hospital again. Those were the only two times I have been in hospital.

(Patient 005)

Some patients chose to take their medications as prescribed due to information received from doctors or from printed literature rather than due to personal experience:

I have a card telling me not to stop the steroid suddenly, you know, it’s not something I am going to take the risk with, it’s too frightening so I’m doing as I’m told.

(Patient 009)

(ii) The belief that there was no effective therapeutic alternative: patients who believed that Western medicines were the only effective treatment for their SLE tended to take their medicines regularly. This belief arose from their personal experience of improvements in health after taking their prescribed medications, for example:

...they solve the problem and they help me so much...

(Patient 006)

Although some patients believed that herbal remedies were ‘more natural’ and ‘less damaging’ (Patient 002), most were reluctant to substitute complementary and alternative medicines for their prescribed tablets. This was either due to perceived poor effectiveness

...over the years I’ve tried various herbal remedies, I’ve never found anything that helped I have to say...

(Patient 013)

or concerns about lack of monitoring,

...if I take noni (herbal remedy) there is no-one monitoring me every three months.

(Patient 017)

(iii) Lack of knowledge about the disease: although patients were aware of some of the possible complications of lupus, it was generally considered to be a complex and potentially dangerous disorder that they did not fully understand. They did not therefore feel confident about changing their medications against the advice of healthcare staff. Typical views included:

...I’m not clever enough to know the ins and outs of lupus and I don’t believe in messing around with medications. I would be guided by the experts.

(Patient 009)

(iv) Feelings of moral obligation and responsibility to others: some patients felt obligated to take their medications because family members/partners and health care workers had invested so much time and effort into helping to manage their disease:

...people around me, like my mum will take off so much time from work and she will give so much of herself and my dad and just, even like my family friends who I had never met before would give so much of themselves, so I just thought ‘you are being selfish’ (by not taking the tablets), so it kind of clicked, so I just take the drugs.

(Patient 008)

Five themes were identified to explain why patients did not take their medications regularly:

(i) The belief that lupus should and could be controlled using alternative methods: whilst some patients believed that prescribed medicines were most appropriate to manage acute presentations or flares of lupus; in the absence of an acute event, they believed that other, non-pharmacological means should be used to control lupus. These included personality and lifestyle factors:

...part of keeping it (lupus) at a sustainable level, for me anyway, is the way I live. A big part of it is the personality of the people, big part, forty percent at least, is the way they live and their personality.

(Patient 021)

Such patients were inclined to take drug holidays to test whether they were able to control the disease without prescribed drugs:

...I wanted to give it (azathioprine) a break, even if it is just for six months, even if I fall flat on my face, just to see if I stop taking the tablets if my immune system would kick in and do what it’s supposed to do.

(Patient 001)

(ii) The belief that continuous long-term medication was not necessary: just as patients who had suffered severe manifestations of lupus activity cited this as a reason why they took their medications regularly, some of those who had remained relatively well believed that there was no need to take their tablets as prescribed. This was particularly the case where patients had previously discontinued medications successfully without adverse effects:

...before when I started taking it (hydroxychloroquine), my lupus cleared up quite quick and then I felt better and then I stopped taking it.

(Patient 016)

(iii) Fear of the adverse effects of medications: many patients were aware that prescribed drugs had potential adverse effects, and fear of or previous experience of side effects prevented them from taking medications as prescribed:

With the prednisolone, I kept putting on weight and I didn’t like that. I would not take it necessarily as prescribed.

(Patient 015)

Some patients therefore chose which medications to take, and took some other than the prescribed doses in an effort to strike a balance between the beneficial and adverse effects of drugs:

I also reduced (prednisolone dose) to 7.5, which means I’m tired all the time. I know I have only got to take the 2.5 mg more and I know I will lead a normal life... but as I say with the old osteoporosis that scared me witless. So that’s what I’m doing.

(Patient 026)

(iv) Poor communication between doctors and patients: the way that clinicians introduced new medicines to patients, clinicians’ perceived sensitivity to their concerns/questions, the clarity of instructions and the regularity of follow-up, also influenced adherence. Dissatisfaction with these aspects of communication between patients and healthcare staff led
to doubts about the need to take the medications prescribed. For example:

Before, (before coming to xx (name of hospital)) I had this sadistic rheumatologist who told me with a gleeful look on his face that it (cyclophosphamide) would make my hair fall out and make me permanently infertile... so I wouldn’t take it.

(Patient 020)

I think with the aspirin I was told I needed to take it twice a week and then I was told ok, I only needed to take it if I was going on really long trips... so I think the reason I don’t take it is because I wasn’t really given a definite answer as in when to take it.

(Patient 032)

...I thought I should have more regular follow up so that I could reduce it (prednisolone) more quickly, but like sometimes, he said I should come back in 2 months, and I was thinking well, what if it has worked in like 3 weeks? So I just used to adjust it myself.

(Patient 005)

Specific factors that did not influence adherence

During the interviews we asked whether cost of medications or religious beliefs influenced adherence. Neither was reported to be influential. Although the majority of patients described themselves as believing in a religion (Table 1), we did not find that people preferred prayer or other spiritual forms of healing to prescribed medications.

Discussion

Our study suggests that in the UK system where healthcare is provided free at the point of entry, and medications for lupus are affordable to most patients, their decisions to take or not take these medications largely depend on their personal experiences with the drugs or the disease itself. There are, however, important external factors that affect adherence including the influence of care-givers, and the provisions for renewing prescriptions and follow-up visits with clinicians.

Methodological issues

An important strength of this study is that, unlike previous research that depended on clinicians’ perceptions of patients’ adherence [2, 3], we explored reasons for varying adherence amongst patients who reported their own levels of adherence. We screened the UCLH SLE patients for eligibility and level of adherence and were thus able to recruit a purposive sample of patients with a range of levels of adherence and diverse clinical and socio-demographic characteristics.

Robust research methods were used throughout including independent analysis by two researchers, one of whom had no connection with the Autoimmune Rheumatic Disease clinic and had not met the subjects.

This study had several limitations. Self-reported adherence may exceed true adherence, partly because of social desirability bias because patients may believe that researchers and clinicians expect and desire high adherence levels [21]. However, those who consented to interview were likely to be genuine high/low adherers because they were aware that they would be asked to explore their pill-taking behaviour. It is also possible that by excluding patients with cognitive impairment (in order to ensure the reliability of responses), we may have excluded patients who do not take their medications because they have difficulties remembering to do so as a result of central nervous system lupus.

We did not explore in detail the issue of whether there are differences in factors affecting adherence to different medications. Differing levels of adherence to various medications have been noted in patients with SLE [22].

We asked participants about their use of medications during the previous 6 months. This time frame for recall of adherence is longer than that typically used for assessment of daily behaviour in other studies (commonly 1-4 weeks [23, 24]). Accuracy of recall over this period may have been suspect in some cases, and this recall bias may have contributed to the high number of people reporting high adherence. We chose this time period because our patients typically take medications for years and we were more interested in long-term patterns of adherence than in adherence over shorter periods which might be transient. The use of the long recall period did not prevent us from identifying clear reasons for either high or low adherence in the qualitative analysis. Patients at both ends of the range of VAS could express opinions relating to either high or low adherence e.g. even those with high VAS mentioned themes that might make them less likely to adhere. There was no clear distinction between the themes obtained from interviews with high and low adherers.

We did not confirm self-reported adherence by more objective measures, such as medication prescription refills [25, 26]. Some of our patients do not get all their refills from our hospital pharmacy, but from GPs as well, and even if patients fill their prescriptions, this does not guarantee that they will take the medications. Furthermore, the emphasis of this study was to determine why patients did/did not take their medications rather than how many did/did not do so.

The volunteer rate for interview was relatively low. This low response rate may have affected the themes generated at interviews. We did not identify any distinct differences between the socio-demographic characteristics of those who volunteered for interview and those who did not. We noted, however, that a higher percentage of non-volunteers compared with volunteers (25 vs 15%) had VAS scores in the region of 5.0–6.0 cm.

In spite of these caveats, ours is the first study of its kind among patients with SLE in the UK and does offer some interesting insights into the reasons for both high and low adherence to the prescribed therapies.

Comparison with other studies

Our findings concur with other studies which report that the fear or experience of side effects of medicines [27] and the doctor–patient relationship/communication have an impact on adherence in rheumatic diseases [28]. In keeping with the findings of a qualitative study of the reasons why patients adhere to their anti-hypertensive medications, we noted that some of our patients preferred to leave decisions regarding medications to the professionals involved in their care and in whom they had confidence [29].

We found that some patients took their medications regularly because of a fear of an adverse outcome. Generally, a perceived risk of serious flares of the disease led to a sense of vulnerability which in turn promoted high adherence. Other studies also suggest that individuals will take action regarding their health based on perceived susceptibility to an illness and the perception of control over their own health. We found that patients who had a low perception of control over their medications and who had higher adherence levels were more likely to have a higher level of perceived susceptibility to their illness. This finding supports the work of Fisher and colleagues, who noted that patients who had a low perception of control over their illness were more likely to have a high level of perceived susceptibility to their illness [30].
of the severity of the consequences of the disease. This is one of the tenets of Rosenstock’s Health Belief Model [30]. There was no evidence that the cost of medications influenced adherence in these interviewees. This is in contrast to the findings of a previous qualitative study of adherence to medications in rheumatic diseases in the United States [31] and our own recent qualitative study in patients with SLE in Jamaica [32]. This may be because the UK National Health Service provides free health care for all at the point of entry to the system, whereas complex medical insurance schemes limit access to healthcare in the United States and many Jamaican patients have to pay for their medications directly. All our respondents would have been entitled to either free prescriptions or to pre-payment certificates, which restrict the cost of medicines to £90.00 per annum.

Implications

The challenges of taking medications in the long term are not to be underestimated and patients are under no obligation to take their medicines as prescribed. We found that some patients reported problems with their interactions with clinicians which either made them feel like unequal participants in decisions regarding their care or led to uncertainty regarding the need to take their medications. This suggests that improvements in doctor-patient interactions are required. This includes the need for clinicians to identify and discuss any questions and concerns which the patient may have regarding their medications and their disease. This should be done in a non-judgemental way. Steps should be taken to ensure that the patient clearly understands the doctor’s rationale for prescribing the drugs and the benefits of taking each drug (supported wherever possible with evidence from their own clinical records and laboratory tests). Where side effects of prescribed drugs are a concern, these and the management options should be fully discussed with the patient in a way that the patient feels comfortable with. It is important thereafter to review the patient’s pill-taking practice, so that clinical changes can be interpreted in the light of the patient’s reported adherence to the medical regimen, and any new concerns can be addressed.

Conclusion

We identified important reasons why patients did or did not adhere to medications for SLE. Our findings suggest that improvements in the doctor-patient communication, including the way in which we give information about lupus and the drugs used to treat it are likely to be important in improving adherence in these patients.

Rheumatology key messages

- Adherence to medications prescribed for SLE is often determined by the patients’ experiences with their medications and with the disease itself.
- Good doctor–patient communication may improve adherence to medications for SLE.

Acknowledgements

We would like to thank Susan Charman from the Department of Statistical Sciences, University College London, and Suzanne Parsons, Senior Research Associate from the Picker Institute Europe for their advice and help with various aspects of this project. This work was undertaken at UCLH/UCL who received a proportion of funding from the Department of Health’s NIHR Biomedical Research Centres funding scheme.

Funding: This study was supported by a Grant from LUPUS UK.

Disclosure statement: The authors have declared no conflicts of interest.

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