

Original article

Medication decision-making and adherence in lupus: patient–physician discordance and the impact of previous ‘adverse medical experiences’

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Abstract

Objectives. Medication adherence is critical in the successful management of lupus. There is very limited existing literature on reasons why non-adherence is not reported. This study explores the impact of current and previous medical experiences on patient satisfaction, adherence and reporting of non-adherence.

Methods. Mixed methodology involved thematic analysis of in-depth interviews ($n = 23$) to further explore the statistically analysed quantitative survey findings ($n = 186$).

Results. This study identified five themes: (i) physician–patient discordance and a ‘hierarchy of evidence’ in medication decisions; (ii) the association of adherence with satisfaction with care; (iii) the persisting impact of past adverse medical experiences (AMEs); (iv) the dynamic balance of patient–physician control; and (v) holistic care, beyond a purely medication-based focus. Improving quality of life (43% of participants) and a supportive medical relationship (24%) were the main reasons for adherence. Patient-priorities and self-reported symptoms were perceived as less important to physicians than organ-protection and blood results. Non-reporters of non-adherence, non-adherers and those with past AMEs (e.g. psychosomatic misdiagnoses) had statistically significant lower satisfaction with care. The importance of listening to patients was a key component of every theme, and associated with patient satisfaction and adherence. The mean rating for rheumatologist’s listening skills was 2.88 for non-adherers compared with 3.53 for other participants (mean difference 0.65, $P = 0.003$).

Conclusion. Patients would like more weight and discussion given to self-reported symptoms and quality of life in medication decisions. Greater understanding and interventions are required to alleviate the persisting impact of past AMEs on some patients’ wellbeing, behaviour and current medical relationships.

Key words: SLE, rheumatology, medication adherence, patient behaviour, patient–physician interactions

Rheumatology key messages

- Many systemic lupus erythematosus/systemic autoimmune rheumatic disease patients prioritize current symptom improvement and quality of life over long-term considerations for medication decisions.
- Non-adherers and non-reporters of non-adherence gave significantly lower ratings for physician listening skills.
- Adverse medical experiences, particularly disbelief, psychosomatic misdiagnoses and long diagnostic journeys can reduce longer-term patient satisfaction.

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Introduction

Medication adherence can improve outcomes and reduce costs to health services [1]. It is of particular importance for SLE and other systemic autoimmune rheumatic disease (SARD) patients as these diseases remain incurable, necessitating lifelong medications in those with moderate and severe disease [2]. The timely use of appropriate medications in SLE/SARDs can prevent or slow disease progression [3, 4]. Adverse drug reactions are more common in SLE patients [5], are often exacerbated by multimorbidity and polypharmacy and can also reduce adherence [6, 7]. Medication non-adherence is difficult to accurately quantify, with rates of 3% to 80% previously reported in SLE patients [8–11].

There are multiple models [12–14] relating to adherence and medical interactions, which provide insights into patient beliefs and behaviours. Although the importance of the medical relationship in promoting adherence has been researched, including in SLE [8], the enduring impact of past medical interactions has not been explored in depth.

We have used the concept of ‘adverse medical experiences’ (AMEs) to encompass past experiences that we identified in our previous research [15, 16] as having persisting negative psychological impacts. AMEs include repeated physician dismissal and disbelief of patient-reported symptoms and/or a feeling of being endangered by many physicians lacking the necessary knowledge to assist with these potentially life-threatening diseases. We hypothesized that these AMEs may also negatively impact medical relationships and medication adherence. We also explored the (greatly under-researched) question of why patients do not inform their doctors when they have been non-adherent. Previous studies showed that some SLE patients were not open about non-adherence, even when measurements of serum concentrations of HCQ and MMF definitively demonstrated their non-adherence [9–11].

We sought to gain insights into how clinician behaviour can positively or negatively influence patient behaviour in order to improve medical relationships, adherence and potentially reduce under or over-treatment.

Methods

Data collection

Inclusion criteria: age ≥ 18 years; reporting a diagnosis of lupus, undifferentiated connective tissue disease, mixed connective tissue disease, Sjögrens, or overlap condition on their clinic letters.

Ethical approval was obtained through the Cambridge Psychology Research Committee, and all respondents gave informed written (electronic) consent.

A questionnaire was made available online in December 2019, using Qualtrics, to LUPUS UK forum members and an online Facebook lupus support group.

Questions elicited quantitative (rated from 1–5), and qualitative responses, and included: perceptions of medical support, reasons for adherence, non-adherence and non-reporting of non-adherence. Interviewees were purposively selected from the questionnaires to ensure a range of socioeconomic and disease characteristics, (including age, gender and severity of disease) adherence behaviours and views of medical support. The interview schedule was semi-structured and explored views of the relationship between satisfaction with care and adherence. M.S., an experienced, qualitatively trained researcher conducted the interviews. They continued until thematic saturation was reached (no novel insights arising from subsequent interviews). Interviews lasted for ≈ 1 h and were transcribed verbatim.

Analysis

Quantitative data were analysed using SPSS v.26, using comparison of means (t-tests) and Spearman’s rank correlations. Thematic analysis [17] was used for the interviews and qualitative data from the surveys to further explain quantitative findings. M.S. coded data using NVivo12, after immersion in the transcripts. R.H. double coded 25% of interviews, and E.L. reviewed all interview extracts, to enhance agreement and reliability. Themes were discussed and agreed by the wider team, including five patient representatives. Validity was strengthened by considering deviant cases [18], member checking [19] and triangulating quantitative and qualitative results. Detailed methods, the criteria for reporting qualitative research (COREQ) checklist [20], and the questionnaire are included in the [supplementary material](#), available at *Rheumatology* online.

Results

Survey respondents were predominantly from the UK, white and female (>92%), and 83% had SLE (Table 1). The most prescribed medication among the 186 survey respondents was HCQ, with 69% currently taking. Self-reported adherence rates (by asking if they always take/took as prescribed) were ascertained for each medication and ranged from 71% for HCQ to 86% for oral steroids. Reasons elicited for adherence and non-adherence were for any of their SLE/SARD-specific medications. Any percentages quoted within the text refer to survey data.

Themes

Five main themes were identified: (i) physician–patient discordance and a ‘hierarchy of evidence’ in medication decisions; (ii) association of adherence with satisfaction with care; (iii) the persisting impact of past adverse medical experiences (AMEs); (iv) the dynamic balance of patient–physician control; and (v) holistic care, beyond a purely medication-based focus.

TABLE 1 Participant characteristics (survey: $n = 186$; interview: $n = 23$)

Characteristic	Number (survey, $n = 186$)	% (survey)	Number (interview, $n = 23$)	% (interview)
Age band (years)				
18–29	17	10	3	13
30–39	27	15	1	4
40–49	53	28	7	30
50–59	52	28	7	30
60–69	28	15	4	17
70+	5	3	1	4
Diagnosis				
SLE	155	83	19	83
UCTD/unspecified CTD	12	6	4	17
Sjögrens	6	3	0	0
MCTD	4	2	0	0
Cutaneous/discoid lupus	4	2	0	0
Overlap	6	3	0	0
Current main medications^a				
HCQ	128	69	14	61
Oral steroids	61	33	13	57
Steroid injections	43	23	6	26
MMF	28	15	4	17
MTX	27	15	3	13
AZA	19	10	4	17
Biologic	12	7	2	9
CYC	6	3	0	0
Frequency of reporting non-adherence to their doctor				
Always	78	53	10	59
Usually	19	13	2	12
Sometimes	15	10	2	12
Occasionally	10	7	0	0
Never	26	18	3	18
Missing	38		5	
Delays to diagnosis				
<1 year	40	25	3	14
1–2 years	23	14	4	18
3–5 years	22	14	1	5
6–9 years	18	11	6	27
10+ years	57	36	8	36
Missing/unsure or non-quantitative response given	26		1	

^aInfusions/injections were classified as 'current' if they were within the previous 12 months. MCTD: mixed connective tissue disease; UCTD: undifferentiated connective tissue disease.

Theme 1: physician–patient discordance and a 'hierarchy of evidence'

They just tend to treat what they think you have rather than what you tell them that you've got (Ppt Q, Male, 70s)

Many patients perceived that physicians prioritized blood results and their judgement over patient-reported symptoms and priorities. Examples of how this was considered to create a 'hierarchy of evidence' and generated barriers to being prescribed and/or adhering to an optimal medication regimen included the following.

Discordance between patient and physician priorities: While physicians were perceived to be focused on preventing organ damage and death, less than 10% of respondents cited these long-term impacts as reasons for adherence. As Fig. 1 shows, far more (43%) gave improving their immediate QoL/reducing symptoms as a reason for adherence:

I just want to maximise my quality of life now ... I don't want [my children] to remember me being ill all the time and in bed constantly. (Ppt 94, Female, 40s)

Diagnostic delays/misdiagnoses: The lack of definitive diagnostic tests combined with the frequent dismissal of early patient-reported symptoms was felt to have led to misdiagnoses that

Fig. 1 Main reasons given for adherence, non-adherence and non-reporting

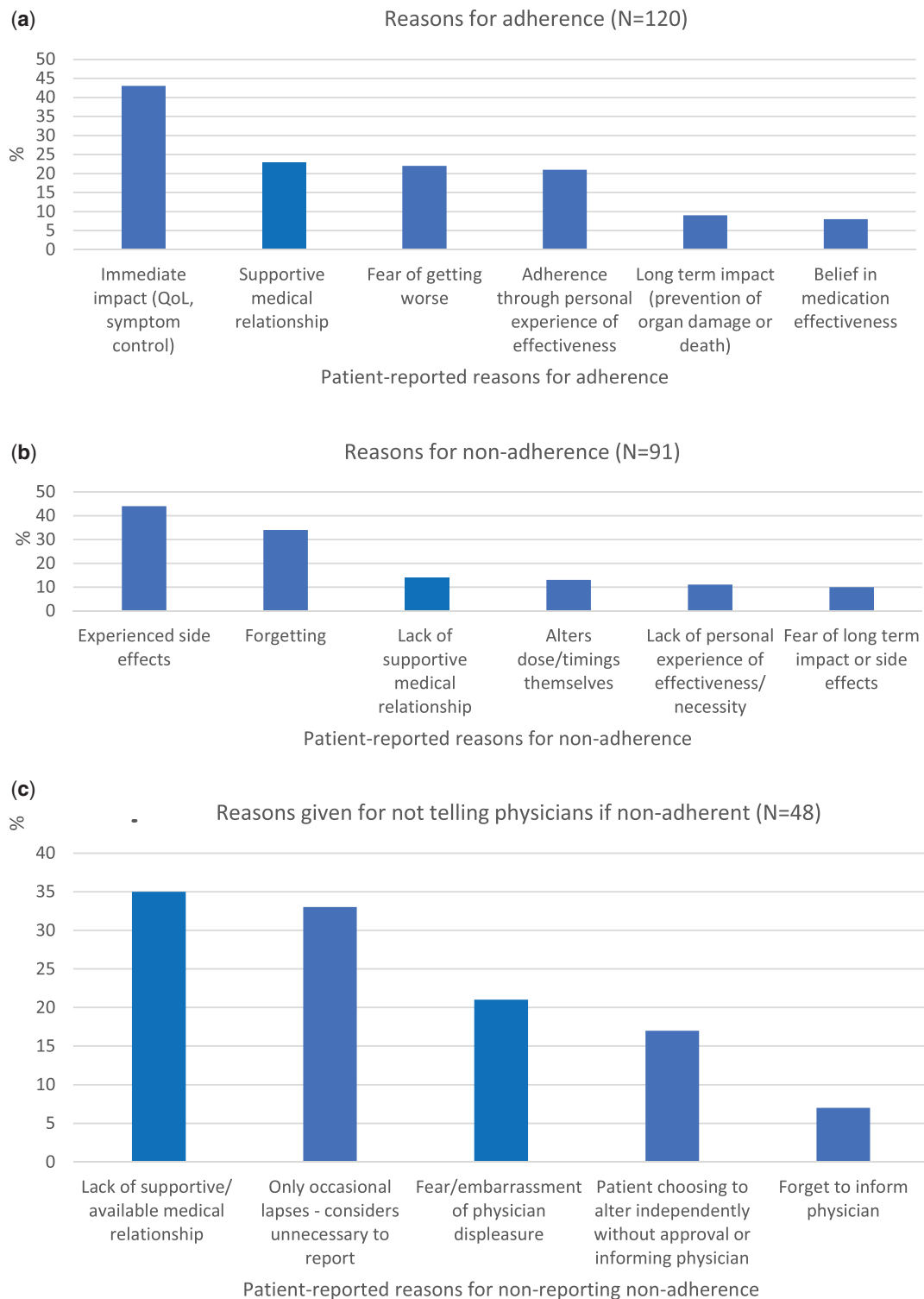


Figure 1 depicts the main reasons given by participants for medication adherence (a), non-adherence (b) and non-reporting of non-adherence to clinicians (c). Note: These graphs were generated from responses to open-ended questions, e.g. ‘Please give any reasons for taking your medication as prescribed’. Some participants gave more than one reason. QoL: quality of life.

delayed the correct diagnosis and relevant treatment (approx. 50% took >5 years to diagnosis). Patients reported enduring physical and psychological damage as a consequence (Table 2, quote 1).

Difficulties accepting disease and medications: The initial physician and societal disbelief of the often 'invisible' symptoms could increase post-diagnosis self-doubt and delays in accepting the disease and medications (Table 2, quote 2).

Insufficiently accurate tests for diagnosis and monitoring: Blood tests were reported to often not correspond with how unwell participants felt yet were required as 'evidence' for treatment initiation/continuation by some clinicians. This reliance on blood markers over patient-reported symptoms affected those at both extremes of the serological spectrum, leading to perceptions of under- and over-treatment (Table 2, quotes 3a,b,c).

Limited availability of evidence-based medications: Limited medication options and high costs were sometimes reported to have been given as reasons for not prescribing medications:

I said about the mycophenolate. 'I'm not prescribing an expensive drug like that' she [rheumatologist] said' (Ppt L, Female, 30s)

Theme 2: association of adherence with satisfaction with care

Supportive and empathetic ... always makes time to listen (Ppt F, Female, 40s)

Support, trust and feeling 'cared about'

Almost a quarter (Fig. 1a) of participants reported adhering due to a supportive medical relationship:

I respect my rheumatologist, he's knowledgeable, up to date and I believe he has my best interests at heart (ppt 62, Female, 50s).

Trust in doctors was multi-faceted and discussed in interviews as being influenced by physicians listening, believing patient symptoms, being accessible in an emergency, sharing information, and showing that they care. Trust was correlated with multiple other measures of patient satisfaction with care (Fig. 2), and highly correlated with ratings of physicians' listening and knowledge ($r_s > 0.8$).

Feeling 'cared about' by their clinicians was extremely important to patients, and reported by many to improve their adherence, while perceptions of uncaring, inattentive doctors were reported to have led to reduced adherence to medications and advice:

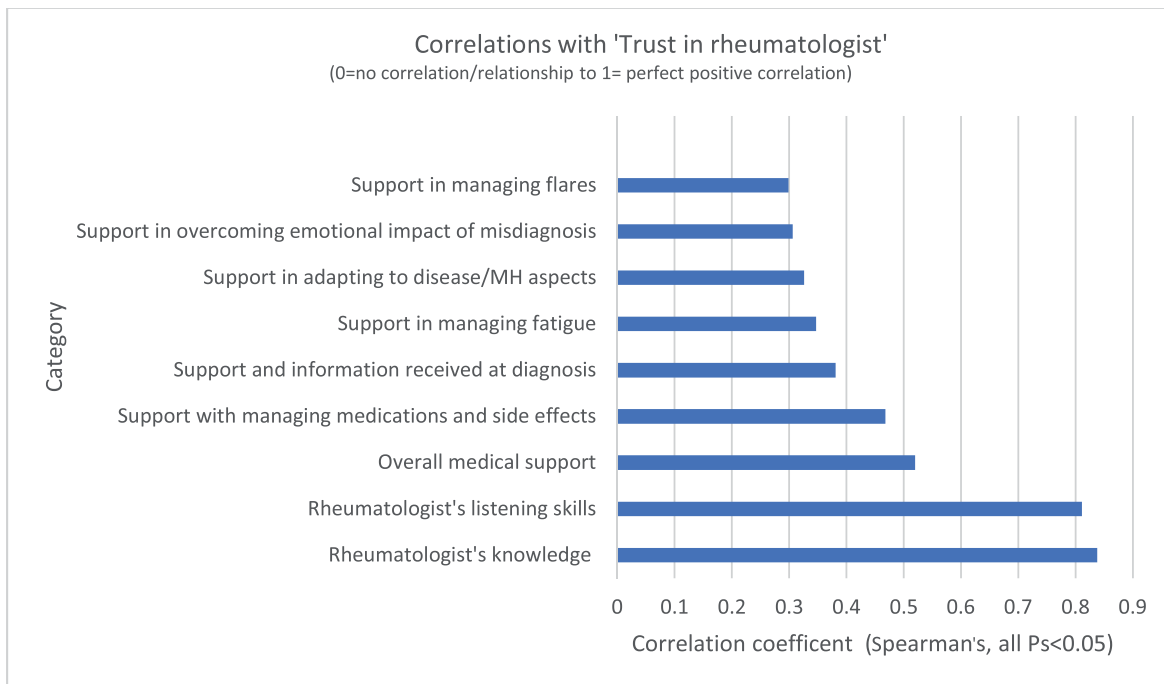
I feel that she [rheumatologist] doesn't care about me and so I no longer care about my lupus treatment and medication either. The result is that I am a lot more patchy in taking my meds. (Ppt D, Female, 50s)

TABLE 2 Barriers to being prescribed and/or taking appropriate medication

Barriers	Illustrative patient quotes
Diagnostic delays/Misdiagnoses Quote 1	<i>Very angry that I had been told it wasn't lupus all those years ago and that the rheumatologist diagnosed me within minutes ... It ruined decades of my life and has had a lasting impact ... also lost 6 babies ... which I believe could have been prevented if I had been diagnosed and on treatment. (Ppt R, Female, 40s)</i>
Difficulties accepting disease and medications Quote 2	<i>They kept banging on take steroids, take steroids ... I refused for a very long time ... Because as a lupus patient, on the whole, you look fine, you know? ... you don't have anything that people can see ... I guess I doubted myself. Am I making this up? Is it in my head? (Ppt N, Female, 50s)</i>
Discordance in patient-physician views of disease severity and activity from blood test results Quote 3a, 3b, 3c	<p>Potential under-treatment – Quote 3a <i>I am told [only] hydroxychloroquine is a proportionate response ... I feel once I have evidence of liver or kidney damage then someone will take it seriously but it will be a bit late then. I am still left with [multiple symptoms] ... No actual interest at improving my quality of life ... like the doctors don't care ... I am sent away year after year to continue to suffer. (Ppt S, Female, 50s)</i></p> <p>Potential over-treatment – Quote 3b <i>[Rheumatologist] tried on two occasions to oblige me to take Aza because 'I'm nervous' he said. My dsDNA had increased ... to 97, but I felt very well and had no symptoms ... He would have prescribed what is a toxic drug without justification and then as my dsDNA went down, as it did, would have declared it was a success and kept me on it (Ppt G, Female, 50s)</i></p> <p>Misunderstandings of significance of blood test results – Quote 3c <i>[Local rheumatologist said] I'd not had a positive ANA since 2016, so my lupus wasn't active and therefore she'd be taking medications away ... but [Lupus specialist] made it very clear that ANA is not a good indicator of lupus activity (Ppt C, Female, 40s)</i></p>

Fig. 2 Trust in doctors and medical support

(a)



(b)

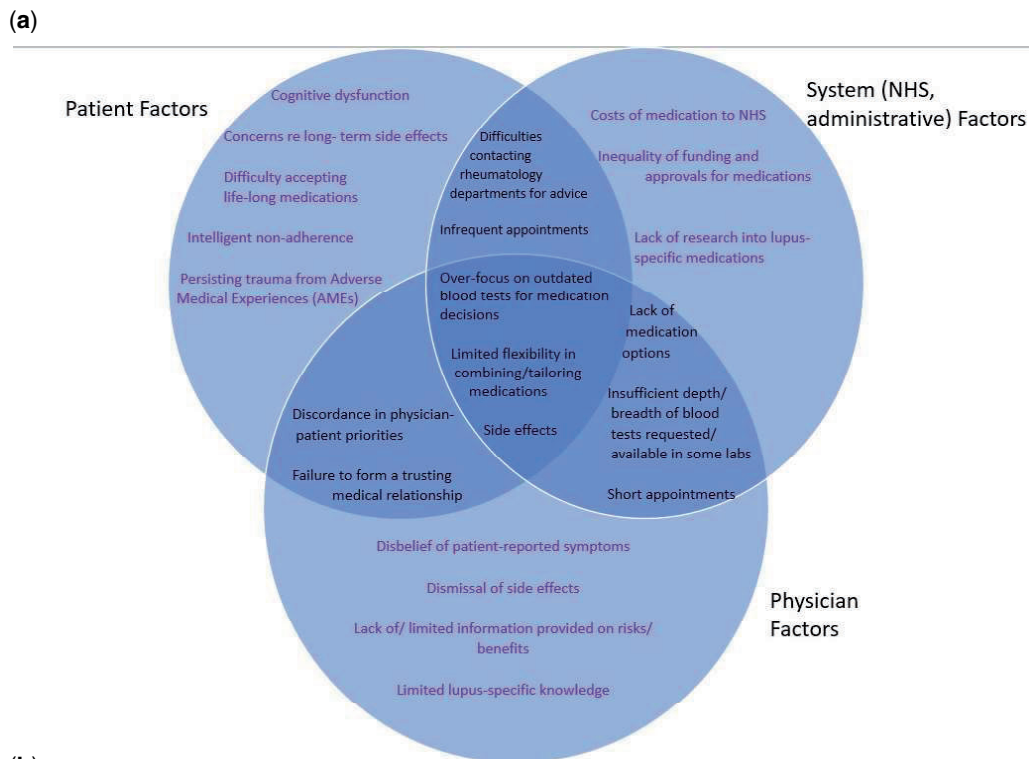
Positive Medical Experiences	Adverse Medical Experiences
<i>I have total trust in her diagnostic expertise & great respect for her instincts... during my first 5 or so years with her, she showed great caution in gradually designing the combined therapeutic meds (Ppt K, Female, 60s)</i>	<i>I suffered in silence and overwhelming fear for years without a diagnosis....cruel and uncaring experiences in hospital by doctors who are unrelated to my usual care, especially in A&E (Ppt 90, Female, 60s)</i>
<i>The relationship I had with [rheumatologist] was incredibly strong. This definitely impacted on my own approach to my medication and I always took all medication exactly as prescribed (Ppt D, Female, 50s)</i>	<i>Listen and do not presume that patients may have psychological symptoms. I was told for so many years that I did not fit the bill for the symptoms that I was describing. Shockingly, I began to doubt myself (Ppt 159, Female, 70s)</i>
<i>If there was a problem or emergency I can contact her team and she will be there for me. I enjoy her positive attitude and she reassures me...trust my rheumatologist...made real efforts to help me...her ability to reassure me by careful listening and going through the facts, tests, meds etc. is important (Ppt T, Female, 50s)</i>	<i>I have felt angry for the best years of my life, as too many Doctor's told me there was nothing wrong with me and 'go away and get on with my life'. People do not enjoy going to the doctor, so if you see a patient repeatedly, there is something going wrong in their body (Ppt 14, Female, 40s)</i>

(a) graphical presentation of correlations between 'trust in rheumatologist' with other patient-reported measures of support and satisfaction with care. (b) Physician behaviours influencing patient wellbeing and trust; contains patient quotes relating to positive and adverse medical experiences that have altered trust.

Although only a minority directly reported on the survey that a negative or unsupportive medical relationship was the cause of non-adherence (14%, Fig. 1b), interviews revealed that non-adherence involved complex inter-linked relationships between patient, system and

physician factors (Fig. 3a). Most participants reported adhering in order to improve their condition, regardless of the quality of the medical relationship. Non-adherers had significantly lower levels of satisfaction with care in most domains (Fig. 3b). For example, the mean rating

Fig. 3 Inter-linking factors contributing to non-adherence and/or poor satisfaction with care and comparison (t test) of satisfaction with care ratings between non-adherers and other Ppts



(b)

	Non-adherers compared with all other Ppts (Total N=185)			
Satisfaction with care*	Mean for Ppts specifying non-adherence **	Mean for all other Ppts	Mean Difference	P values
Support with managing medication/side effects	2.7	3.4	0.71	<0.001
Support/information received at diagnosis	2.47	3.15	0.68	<0.001
Listening skills of rheumatologist	2.88	3.53	0.65	0.003
Knowledge of rheumatologist	3.4	3.94	0.54	0.007
Overall level of medical support	3.06	3.59	0.53	0.001
Trust in GP	2.87	3.33	0.46	0.022
Trust in rheumatologist	3.17	3.6	0.43	0.027
Listening skills of GP	2.94	3.37	0.42	0.035
Support in overcoming psychological damage from misdiagnoses/delays	1.51	1.92	0.4	0.019
Knowledge of GP	2.33	2.65	0.3	NS
Support with MH and adapting	1.79	2.05	0.26	NS
Support with managing fatigue	1.91	2.16	0.25	NS
Support in managing flares	2.75	2.91	0.16	NS

*Calculated from Ppt-reported ratings of satisfaction from 1=lowest rating to 5=highest rating.

**Includes all Ppts specifying a reason for non-adherence

NS=Statistically non-significant

(a) shows inter-linking factors contributing to non-adherence and/or poor satisfaction with care. (b) statistically compares (t-test) mean satisfaction with care between those reporting non-adherence and other participants. *Calculated from Ppt-reported ratings of satisfaction from 1 = lowest rating to 5 = highest rating. **Includes all Ppts specifying a reason for non-adherence. *** N: Statistically non-significant.

for listening skills of rheumatologist was 2.88 for non-adherers compared with 3.53 for other participants (mean difference (MD), 0.65, $P = 0.003$).

Communication and information sharing

Poor physician communication about medication risks/benefits, insufficient monitoring and not sharing test results were widely reported, and contributed to non-adherence:

My appointments kept getting cancelled and I just stopped taking the meds, I thought I was falling through the cracks, my bloods weren't getting done, no-one was telling me the results (Ppt A, Female, teens)

This contrasted with other participants who reported feeling informed and reassured by being given sufficient information on a new medication and the opportunity for discussion:

She [lupus nurse] was brilliant, she started me on [DMARD] and she went through absolutely everything with it ... a leaflet, when to take it, these are the risks, the benefits ... a time frame. (Ppt P, Male, 40s)

Clinician impact on side effects and non-intentional non-adherence

Although less explicitly identified by participants, non-adherence due to cognitive dysfunction and side effects could be reduced by clinicians' being supportive, non-judgemental, encouraging discussion and offering advice.

Reports of non-intentional non-adherence were almost wholly related to cognitive difficulties (35% giving as a reason for non-adherence). Embarrassment was often expressed about memory problems, which reduced the likelihood of reporting their difficulties and accessing support:

Embarrassingly as I'm a nurse I regularly mis-dose myself, either forget or overdose due to my memory problems. I still struggle with the idea of a Dosette box as I don't feel old (Ppt R, Female, 40s)

Discussions revealed that physicians could also reduce non-adherence arising from side effects (which 44% gave as a reason for non-adherence). Many participants reported an unsympathetic response to reports of side effects, leading to patient-physician conflict and non-adherence:

I refused to take the medication that I was allergic to ... Well it's your fault you're in pain because you won't take the tablets ... she [rheumatologist] said ... didn't even listen ... her own agenda (Ppt N, Female, 50s)

Impact of medical relationships on openness in reporting non-adherence

Only 53% of respondents reported always informing their physician if they did not take their medication as prescribed. An unsupportive or insecure medical relationship, including difficulty in accessing support or fear of disapproval, was reported by over 50% of those specifying a reason for non-reporting:

But I only see [rheumatologist] every 6 months and I've given up trying to talk to my GP ... not seen them in 3 years ... so I'm on my own (Ppt 4, Female, 40s)

Those not informing physicians about non-adherence (excluding the 33% who gave the reason it was too infrequent to mention) had a statistically significantly lower satisfaction with care in every domain (minimum $P = 0.05$), with the exception of support with fatigue and mental health (MH). The difference was particularly pronounced in ratings of listening skills for GPs (non-reporters = 2.5, all other participants = 3.3, MD = 0.8, $P = 0.016$) and rheumatologists (non-reporters = 2.6 vs 3.3, MD = 0.7, $P = 0.032$). This was explored further in interviews where multiple participants discussed how their diagnostic difficulties and perceptions of poor physician listening skills led to non-adherence and/or non-reporting of non-adherence:

Sometimes I feel it is pointless being honest as doctors never seem to listen properly and believe they know best rather than listening to suggestions and how I feel ... Doctors don't seem to care. (Ppt B, Female, 20s)

Conversely, physicians who had built up trust by being available and listening attentively were felt to improve openness in reporting difficulties, including with medication:

We have a good relationship and he [GP] has an idea of who I am as a person and my health ... even the little things ... I generally feel I can be very open with him (Ppt J, Male, 20s)

Theme 3: the persisting impact of past AMEs

'Literally terrified ... no confidence whatsoever' (Ppt S, Female, 30s)

Although the majority of interviewees reported current secure medical relationships, past 'adverse medical experiences' (AMEs) were found to have a persisting impact on medical security, psychological wellbeing, trust (Fig. 2b, column 2) and satisfaction with care, including in support in managing medications/side effects.

We defined AMEs as stressful healthcare-related experiences, including long diagnostic journeys (>1 year) and previous MH or medically unexplained or 'in your head' type misdiagnosis (MH/MUS), which were commonly reported to have had persisting negative psychological impacts.

AMEs and satisfaction with care

Those whose diagnosis was delayed (using >1 year of symptom onset) gave statistically significantly lower ratings in many areas of support, including: support received at diagnosis (2.7 vs 3.18 for those diagnosed <1 year, MD = 0.48, $P = 0.031$), support with managing flares (2.72 vs 3.31, MD = 0.6, $P = 0.018$) and support in overcoming psychological impact of delays/misdiagnoses (1.58 vs 2.13, MD = 0.54, $P = 0.019$). The MH/MUS misdiagnosed gave significantly lower ratings for GPs' listening and knowledge (both $P = 0.037$), likely because

they were the physicians most frequently misdiagnosing early SARD symptoms.

AMEs and adherence

There was no significant difference in adherence for AMEs categories despite lower satisfaction with care. However, when looked at individually, some of the most traumatized by multiple AMEs, were either highly avoidant:

I don't go to doctors or hospitals if I can avoid it, I've lost too much and feel scared what will happen when I do (Ppt 95, Female, 50s)

or highly adherent:

I scored very high in the PTSD [post-traumatic stress disorder] scale [from multiple AMEs] ... spent too much of my life just plain fighting to give in now ... so I never take less than prescribed ... greedily take whatever treatment I can get (Ppt V, Female, 50s)

Theme 4: the dynamic balance of physician–patient level of control of medications

My body, my life, my illness (Ppt H, Male, 60s)

Preferences for degree of control over medication decisions varied between participants. The vast majority preferred a fully-informed collaborative approach, and felt it improved acceptance and adherence:

Looked at all the pros and cons of a medication ... before a final decision was reached. It felt like a kind of joint brainstorming session and it meant that I felt entirely on board with the result (Ppt T, Female, 50s)

Many participants also strongly felt that they should be given more input into medication decisions in order to improve, often very poor, QoL:

Surely the balance of risk should be discussed and assessed by both, and patients allowed an informed opinion as to an acceptable level of risk ... I'd risk a lot, almost anything, because this is no life ... few years of goodish life would be worth so much more than endless risk-free sofa years (Ppt E, Female, 60s)

'Intelligent' non-adherence

Medical insecurity was frequently indicated to have resulted from doctors having insufficient knowledge of lupus (only 16% of participants rated GPs as having good/very good knowledge of lupus). Patients therefore reported having to acquire knowledge and advocate for themselves:

I brought up that I needed an eye test, because I've been on Hydroxychloroquine for a long time, and [GP] was like, 'Well, I've not heard of that, did you read it on the internet?' ... they're out of their depth (Ppt M, Female, 50s)

Some participants reported taking control and being 'intelligently' non-adherent for their own safety:

I have no trust at all, particularly when I felt an interaction between HCQ and a GP-prescribed medication but my GP dismissed it as all in my head ... I found there is a potent interaction in some patients that can cause heart standstill ... won't be taking any medication on doctors' advice alone (Ppt G, Female, 50s)

Several patients discussed altering their dose themselves to improve QoL by balancing benefits with reducing side effects:

Well, if I'm going to only have another five years to go ... I need quality of life ... so I actually increased my steroids ... certainly made me a bit better ... I just do it (Ppt Q, Male, 70s)

More physician direction/information required at times

Many patients reported being given very little information, were often just handed leaflets, and felt anxious and confused about the lack of physician direction in medication decisions, often then seeking online advice from medically unqualified peers:

I find it really difficult that doctors do not give you their opinion any more. I appreciate the free choice but it is difficult to know what to do for the best ... It seems like a pretty heavy duty drug [AZA] to take if I don't really need it ... would I be better off waiting until things get worse? Am I doing myself harm by not taking it? (Forum post, Female)

Some participants preferred physicians taking a more decisive or directive approach at times, especially when severely unwell. This could increase security and was reported to improve adherence, especially within a trusting relationship. A very firm response from a trusted clinician to non-adherence was also felt by some participants to ensure future adherence:

She very clearly, concisely and firmly told me 'never ever again change any medication dosage without my approval' ... my consultant's mode of communicating her point acted as very effective 'aversion training'. I've never even been tempted to experiment with dosage since' (Ppt K, Female, 60s)

However, fear of physician displeasure was also a barrier to reporting non-adherence. Terminology included 'embarrassment' and 'guilt,' and there was concern that reporting non-adherence could lead to a withdrawal of support: 'they will give up on me'.

Theme 5: holistic care – beyond a purely medication-based focus

They're basically pill-centred ... they're missing a trick' (Ppt M, Female, 50s)

Rheumatologists were widely considered to be very focussed on medications, with limited/no time spent assisting patients with non-medication support to improve acceptance and self-management. Physiotherapy, psychological support, diet and pacing advice were only occasionally provided (Table 3). Fatigue was reported as the most life-changing symptom, yet only 12% felt they were receiving good/excellent support with fatigue and 41% reported no support at all.

Discussion

To our knowledge, this mixed-methods study is the first to explore the enduring impact of past medical interactions, particularly AMEs, on SLE/SARD patient behaviour. The potential comparison with some aspects of

TABLE 3 Patient quotes on receiving and/or the importance of non-medication support

Non-medication options to improve quality of life	Patient quotes
Pacing and exercise	<i>One of the most useful things from a Doctor was my rheumatologist giving me a 30 min consultation once just to tell me to slow down, to take rest, pace myself etc. I didn't listen at the time, but it sank in and I now do it and it is the best advice and time spent by a Doctor ever. He also told me to take up Tai Chi to aid in pain relief and relaxation ... massive positive impact on my lupus (Ppt R, Female, 40s)</i>
Psychological support	<i>I have become even more appalled at the lack of counselling support for patients of lupus and other chronic diseases. It would seem that you are expected 'to get on with it' (Ppt 159, Female, 70s)</i>
Alternatives offered to anti-depressants	<i>My GP has also always been very understanding and supportive ... suggested last week that instead of going back on antidepressants straight away that he wants me to try holistic therapy first and see how that goes. I am very lucky to have such a sympathetic GP and I can message him any time if I need to. (Ppt F, Female, 40s)</i>
Fatigue management support	<i>I appreciate that they're doing all the stuff to do with heart and lungs as a priority ... the fatigue is seen as a side effect, whereas I think it really is something that needs to be actually looked into ... There must be chemical changes. There must be biology going on, and I just find it incredible that nobody seems to be able to say what that biology is (Ppt M, Female, 50s)</i>
Physiotherapy	<i>I've been waiting like 2 years, every time I go on about physio, to me this is a big deal like losing ability in hands and knees and stuff, whereas for her [rheumatologist] it seems like nothing but that's on my mind quite a lot ... it's not on her agenda ... Even to get some exercises I can do at home because I'll do it. Just get some advice (Ppt A, Female, teens)</i>
Holistic care	<i>My wonderful local nurses got me into a local hospice for extra support in the form of advice on pain management, reiki, reflexology and some counselling. I am eternally grateful ... practical solutions, advice, reassurance and compassion (Ppt F, Female, 40s)</i>
Occupational therapy for cognitive dysfunction	<i>I didn't keep up with medication not because I chose not to, but often I would forget to take them, or I would forget to order new scripts in time. But now I have a monthly pill box, alarms, and working with OT for my dysfunction issues in general and that has made a big difference (Ppt J, Male, 20s)</i>
Diet advice	<i>Docs are terrible about issues of diet and lifestyle in the management of Lupus. I am on the autoimmune protocol and really notice a difference. When I eat something that doesn't agree with me I immediately fall into fatigue (Ppt 165, Female, 50s)</i>

adverse childhood experiences (ACEs) [21] and other adverse life experiences [22] remains tentative, but highlights the severity of damage, and longer-term sequelae. Many participants reported repeated AMEs, particularly dismissal, psychosomatic misdiagnoses and lack of physician knowledge, often on their arduous diagnostic journeys [15, 16, 23], but also post-diagnosis. An unexpected finding in our study was that, although participants with AMEs had significantly lower satisfaction with many aspects of medical care, the non-adherence rate for the AME group as a whole was not significantly greater than the rate for the non-AME group. One theory, identified through interviews, is that AMEs contributed to both extremes of adherence, thus balancing each other out when combined quantitatively. In

particular, some interviewees reported greater avoidance of physicians, while others stated they were completely adherent due to the lengthy time undiagnosed and untreated.

Our findings are also in agreement with previous research identifying discordance between SLE/SARD patient and physician priorities [24–27] and the importance of medical relationships in medication adherence [8, 28]. Satisfaction with medical care was significantly lower for non-adherers and those not reporting non-adherence to their physicians, particularly in relation to support, information and listening skills. A key, previously unexplored, finding was that half of participants who reported not telling their clinicians about non-adherence gave an un-supportive/unavailable medical relationship as a reason.

Supportiveness of the current medical relationship was directly cited by a quarter of participants as a reason for adhering, often with the use of the words ‘trust’ and ‘respect’ when describing their current physician(s), particularly their rheumatologist. However, many participants reported adhering to improve their QoL, regardless of the quality of their medical relationships.

Improving QoL was the most frequently cited reason for medication adherence whereas preventing organ damage and/or death—which physicians were felt to be focussed on—was only cited by <10% of participants. Physicians have guidelines to follow [29] and clearly a responsibility for ensuring medication choices prevent organ damage and reduce mortality. However, our findings suggest that medication discussions may promote greater adherence if the physician elicits each patient’s priorities and presents the more immediate as well as long-term benefits. Although this study has focussed on intentional non-adherence, we found that clinicians could also influence the frequent non-intentional non-adherence caused by the cognitive dysfunction common in many SARDs patients. Participants’ discussions of embarrassment and reticence to admit forgetting medication suggests that non-judgemental raising of the topic and advice on memory aids such as using Dosette boxes, reminder apps and family support could be helpful.

We identified a ‘hierarchy of evidence’ in both diagnosis and treatment decisions, perceived to be dominated by a limited range of blood tests (especially with GPs and less experienced rheumatologists) and clinician judgement. These were felt by patients to not always be reflective of their actual condition, or in line with their often extensive knowledge of current research, thus further reducing medical security. While ANA is helpful (although not essential) in diagnosis, the titre can vary over time independently of disease activity [30–32], and is therefore not recommended for monitoring/medication decisions [29]. Although dsDNA and/or complement are accurate biomarkers in some patients, that is not the case for all patients [33]. This research builds on previous reports [26] that greater prioritization should be given to patient-reported symptoms. Patient self-reported symptoms are often the least susceptible to external verification, yet can be the most life-changing (fatigue, pain, neurological and cognitive difficulties) [15]. Currently, most studies only use patient-reported outcomes (PROs) as secondary endpoints, if at all. This limited evidence-based data likely influences many clinicians’ preference (as perceived by these patients) for clinical or laboratory evidence over PROs. However, with such a heterogeneous disease and highly individual responses/reactions to medications, our study participants expressed strong feelings that the ‘evidence-based data’ should also include evidence gained from actively listening to their symptoms. Failure to listen to patients was commonly discussed as one of the main contributors to misdiagnoses, damaging to the clinical relationship and potentially leading to sub-optimal

medication decisions. The key importance of listening in adherence was verified quantitatively by ratings for clinicians’ listening skills being significantly lower in non-adherers and non-reporters of non-adherence. Rheumatologists were also viewed as medication-focussed while patients wanted greater support with non-pharmacological measures, such as physiotherapy and psychotherapy, which have been found to improve QoL in previous studies [34–36].

This study has a number of limitations, particularly in the self-reporting and self-selecting nature of respondents to online surveys. Due to the exploratory nature of this study, reasons for adherence were extracted from open-ended answers, which can reduce reliability. In introducing the concept of AMEs for these patients, we used proxy measures that were enlightening for initial exploration of the concept yet cannot be assumed to be reliable. We will further explore the concept of AMEs, and their enduring impact, in future studies. There was a low proportion of males and respondents from minority ethnic groups leading to lower generalizability, although interviewees were selected purposively to ensure more of a balance. Interviewees had a slightly longer than average [15] length of diagnostic journey, and we did not elicit quantitative measures of severity of physical and mental health, both of which may have impacted views of care. Further details of the mixed methodology used, including strengths and limitations, are reported in the [supplementary material](#), available at *Rheumatology* online.

We have extended the work of Náfrádi *et al.* who identified the need for a flexible physician–patient balance of control in medication decisions [37] with our findings that level of control desired differed for each patient and varied over the disease course. We have also built on Smith’s discussions of ‘institutional betrayal’ [38] and how improved physician–patient concordance in decision making can ameliorate distrust from adverse medical events. Collaboration and concordance were invariably preferred, although a more directive physician approach may be required/wanted more in the early stages of diagnosis, when severely unwell or cognitively impaired. Although fear of physician displeasure motivated adherence in some, it was also reported as a barrier to reporting any non-adherence. Intelligent or creative non-adherence [39] [40], whereby knowledgeable patients made rational decisions to self-adjust dosage or to not adhere was not infrequent, often underpinned by distrust or inadequate access to support. As it was reported to have preferable outcomes at times, patient blaming [41] and always viewing non-adherence as a negative patient behaviour is not appropriate, especially in the context of many physicians being widely perceived as lacking basic knowledge of SLE. This contributed to patient insecurity in the appropriateness and safety of diagnostic, medication or monitoring decisions. With no clear treatment pathways, and undiscovered or unclear biomarkers in some SARD patients, there is an even greater requirement for

improved physician–patient communication and shared decision making, in addition to targeted, individualized tests and medication [42].

More physicians actively listening to patients, both in terms of symptom-reporting and ascertaining individual treatment goals, would improve medical relationships, satisfaction and potentially medication adherence. Optimal medication prescribing and adherence, enabled by positive medical relationships, not only improves disease outcomes but can also reduce the significant psychosocial impact of SLE. Despite the many positive current medical relationships cited by most interviewees, this study highlights the importance of clinicians being aware of the persisting impact on patient wellbeing, behaviour and medical relationships of past adverse medical experiences (AMEs).

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Data availability statement

Additional anonymised data may be made available on request.

Supplementary data

[Supplementary data](#) are available at *Rheumatology* online.

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