

Original article

Is it me? The impact of patient–physician interactions on lupus patients’ psychological well-being, cognition and health-care-seeking behaviour

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Abstract

Objective. The aim was to explore the impact of patient–physician interactions, pre- and post-diagnosis, on lupus and UCTD patients’ psychological well-being, cognition and health-care-seeking behaviour.

Methods. Participants were purposively sampled from the 233 responses to a survey on patient experiences of medical support. Twenty-one semi-structured interviews were conducted and themes generated using thematic analysis.

Results. The study identified six principal themes: (i) the impact of the diagnostic journey; (ii) the influence of key physician(s) on patient trust and security, with most participants reporting at least one positive medical relationship; (iii) disparities in patient–physician priorities, with patients desiring more support with quality-of-life concerns; (iv) persisting insecurity and distrust, which was prevalent and largely influenced by previous and anticipated disproportionate (often perceived as dismissive) physician responses to symptoms and experiences of widespread inadequate physician knowledge of systemic autoimmune diseases; (v) changes to health-care-seeking behaviours, such as curtailing help-seeking or under-reporting symptoms; and (vi) empowerment, including shared medical decision-making and knowledge acquisition, which can mitigate insecurity and improve care.

Conclusion. Negative medical interactions pre- and post-diagnosis can cause a loss of self-confidence and a loss of confidence and trust in the medical profession. This insecurity can persist even in subsequent positive medical relationships and should be addressed. Key physicians implementing empowering and security-inducing strategies, including being available in times of health crises and validating patient-reported symptoms, might lead to more trusting medical relationships and positive health-care-seeking behaviour.

Key words: systemic lupus erythematosus, psychology, behaviour, quality of life, well-being, patient–physician interactions

CLINICAL
SCIENCE

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Key messages

- Difficult diagnostic journeys and negative medical interactions can cause persistent insecurity, health-care avoidance and symptom under-reporting in lupus patients.
- Empowerment, and physicians demonstrating availability, belief in symptom reporting and holistic care can mitigate patient insecurity.
- Psychosocial and quality-of-life difficulties are common and often undisclosed, requiring greater awareness and support.

Introduction

The generally protracted nature of the lupus diagnostic journey is well documented [1–4] and can contribute to the adverse physical [5] and psychological impacts [4, 6–8] of the disease. Multiple misdiagnoses can be experienced during this time, and early symptoms are often misattributed to psychological, mental health or medically unexplained symptom causes [1, 2, 4]. In our recent survey, >80% of participants who reported receiving a mental health/medically unexplained symptom misdiagnosis stated that it had reduced their trust in doctors and changed their health-care-seeking behaviour [4]. Price and Walker [9] documented that lupus patients' illness experiences are frequently delegitimized and that the diagnostic journey can be a distressing, 'damaging, iatrogenic experience'.

Expert commentary has also identified that, with improved life expectancy for SLE patients, a greater focus is required on quality of life and holistic care [10, 11]. In addition, a recent study found that the majority of respondents with SLE and other rheumatic diseases struggled to cope with their condition, yet only 16% had been offered psychological support from the UK National Health Service [2]; and Hale *et al.* [12] reported that lupus patients often feel misunderstood and isolated. There is limited research on UCTD patient experiences, but there are indications that patient satisfaction with medical care could be lower than with lupus [4].

Georgopoulou *et al.* [13] carried out a recent systematic review and concluded that more research was required to increase understanding of the patient–physician relationship in rheumatology. The physician–patient relationship is vital, because it has an impact on patient outcomes and satisfaction with treatment and care [13] and on various behaviours, although only medication adherence has been studied in any depth [13, 14].

A more in-depth understanding of patients' beliefs and behaviours based on their past experiences is important because they can be modified by clinicians using a patient-centred approach [15]. Greater understanding of patient experiences may also assist clinicians adapt their own behaviour to improve the medical relationship. Our study therefore aims to gain greater understanding of how past medical interactions influence SLE/UCTD patient cognition, well-being and health-care-seeking behaviour.

Methods

A questionnaire on diagnostic journeys, symptoms and perceptions of medical support was made available online on the LUPUS UK forum and lupus UK sufferers' Facebook page and completed by 233 participants [4]. Purposive sampling from those giving permission to be interviewed (>75% of respondents) was conducted, using the questionnaire responses to ensure a range of personal and disease characteristics, diagnostic experiences and perceptions of medical support. The interview schedule (Supplementary Data S1, available at *Rheumatology Advances in Practice* online) was semi-structured, with questions covering: the diagnostic journey, positive and negative relationships with physicians, emotional impact and health-care-seeking behaviour. Interviews were carried out by M.S., an experienced, qualitatively trained researcher. They continued until saturation (the number of interviews beyond which no novel insights were generated) was reached. Interviews lasted for ≈1 h and were transcribed verbatim. Thematic analysis [16] was used, with data coded by M.S., using NVivo11, after immersion in the transcripts. One-quarter of interviews were double coded by R.H. to ensure agreement and reliability. Common themes, preliminary assumptions and more abstract concepts emerging from the data were then discussed and agreed by the wider team. Validity of the findings was strengthened by considering cases that deviated from the more common responses [17], member checking by participants [18, 19] and comparing findings with responses on the questionnaires and analysis of the LUPUS UK forum. Detailed methods and the consolidated criteria for reporting qualitative research (COREQ) checklist for qualitative research [20] are included in Supplementary Data S2, available at *Rheumatology Advances in Practice* online.

This study complies with the Declaration of Helsinki. The Cambridge Psychology Research Ethics Committee approved the research (no. PRE 2018-84), and informed consent was obtained from all respondents.

Results

Participants

Table 1 shows participant characteristics. The majority of participants were female, white and highly educated.

TABLE 1 Participant characteristics

Characteristic	Number	Percentage (rounded)
Age band, years		
18–29	3	14
30–39	1	5
40–49	7	33
50–59	5	24
60–69	5	24
Country of residence		
England	11	52
Scotland	3	14
Wales	4	19
USA	1	5
Australia	2	10
Ethnic group		
White	19	90
Mixed race	1	5
Asian	1	5
Gender		
Female	17	81
Male	4	19
Education		
GCSE/O level/equivalent	2	10
A level/equivalent	2	10
Degree	7	33
Postgraduate	10	48
Time delay to diagnosis, years		
<1	3	14
1–3	2	10
4–9	9	43
10+	7	33
Time since diagnosis, years		
<1	2	10
1–5	5	24
6–10	6	29
>10	8	38
Diagnosis on clinic letters		
SLE	17	81
Undifferentiated or unspecified CTD	4	19
Age at symptom onset/diagnosis, years		
Symptom onset <18, diagnosis <18	2	10
Symptom onset <18, diagnosis >18	5	24
Symptom onset and diagnosis >18	14	67

They included a range of disease severity and medical experiences.

Out of 32 survey respondents invited to participate, 21 were interviewed (66%) and the following six themes identified: (i) the impact of the diagnostic journey; (ii) the influence of key physicians on patient trust and security; (iii) disparities in patient–physician priorities; (iv) persisting insecurity; (v) changes to health-care-seeking behaviours; and (vi) empowerment.

Theme 1: the impact of the diagnostic journey

Interactions with physicians during the diagnostic journey were identified as vital in laying foundations for future medical relationships. Given that lengthy and difficult journeys to diagnosis were common, these foundations were often insecure. Repeated experiences of physicians' lacking knowledge of lupus/UCTD and medical disbelief in an organic cause for symptoms were frequent and reported as particularly damaging to future security and trust in physicians:

Nobody seemed to take me seriously... Doctors made me feel as if I was imagining things ... made me feel very anxious, nervous and somewhat depressed, being disbelieved, as if I wasn't important and didn't matter... Still get very anxious and upset when attending appointments. (Participant 21, female, 20s)

Diagnosis was often reported to be a relief, although some participants discussed also feeling shock and fear for their future. Descriptions of diagnostic appointments varied widely, in terms of empathy and the information and support offered. This was discussed as heavily influencing the future relationship with both the diagnosing physician and the disease.

Theme 2: the influence of key physicians on patient trust and security

The majority of participants reported currently having high levels of trust in key physician(s), predominantly their rheumatologist or general practitioner (GP):

I just felt he [rheumatologist] had my back, no matter what, he had my back. (Participant 3, female, 50s)

Factors contributing to trust and security included the following.

Availability

With a relapsing–remitting disease, rapid access to a trusted clinician was felt to be highly security inducing, even if rarely required.

Belief in patient accounts

Although some participants felt that their symptoms were believed, others discussed feeling relieved when test results were positive or when a visible symptom appeared. This provided objective 'proof' and validation of the often-invisible symptoms that many reported had been previously 'dismissed' and left untreated. This interviewee raised the difficulties experienced by patients and physicians:

You tend to get dismissed a lot, you know ... they say they want evidence ... he [rheumatologist] said very clearly 'I don't want to be found a couple of years down that I've misdiagnosed you or mistreated you or even ill-spent money off the Welsh budget'. (Participant 8, male, 60s)

Continuity and connection

Continuity and forming a trusting relationship with clinician(s), where the patient felt known personally and individual manifestations of the disease were understood,

often facilitated a great feeling of ‘safety’ with that physician.

My consultant has known me for years and just by looking at my face he can tell if something is wrong ... always supportive and shows that he cares. (Participant 13, female, 40s)

Theme 3: disparities in patient–physician priorities

There was a widely perceived disparity between physician and patient priorities, with physicians often reported to be focused on medication, joints and organ damage, whereas patients invariably also wanted, but reported rarely receiving, more holistic care and support with quality of life:

They're not really bothered about how my life's changed or things I can't do now ... They just want to be, like, 'Take this med ... have your bloods', and you're done, and that's it, don't talk about anything. (Participant 7, female, teenager)

It was discussed that specialist nurses might have more time to listen and focus on quality of life, but only a minority of participants reported having access to one. This participant articulated the potential inequality of access:

I said, 'I was diagnosed 3 years ago, why wasn't I referred to you?' ... She [rheumatology nurse] said, 'Well, to be honest, rheumatoid arthritis patients are referred to me straight away, but we don't do it with lupus'. (Participant 1, female, 40s)

Table 2 details examples of key physician behaviours influencing trust and security, identified as the ABC of availability, belief and continuity of holistic care.

Theme 4: persisting insecurity

Self-doubt was frequently expressed, probably initiated in the diagnostic uncertainty stage, when almost all participants stated that multiple symptoms with no initial explanation and the overwhelming fatigue made them feel ‘crazy’ and/or ‘lazy’. For many, this resulted in a continued loss of confidence in the medical profession and in their own ability to interpret their symptoms accurately, exacerbated by the unpredictability of when and how severely the disease would next flare. The psychological damage from previous and anticipated negative reactions from physicians was sometimes felt to be more damaging than the disease:

Managing a chronic disease is difficult; it involves acceptance and looking forward, appreciating small things rather than regretting what is lost ... The way the medical profession reacts to us is outside of our control [and] can be more damaging, psychologically and emotionally, than the chronic disease itself ... they are churning out a chronically ill collective of irreparably changed and damaged people. Singed souls who deserve better, much better. (Participant 16, female, 60s)

Despite many individual positive medical relationships, persisting insecurity usually remained in relationship to the wider medical profession. This was found to be most severe where one or more of the following had occurred.

Being repeatedly disbelieved, especially in childhood

The majority of all interviewees described being ‘dismissed’ or ‘disbelieved’; a minority feeling ‘gaslighted’, both pre- and post-diagnosis. This was particularly common in those patients with UCTD or with an atypical symptom, demographic and/or serological presentation, often leading to self-doubt:

When the bloods come back as well, there's nothing wrong ... you doubt yourself, you doubt your own body ... maybe I am losing it a bit, maybe I am just imagining it. (Participant 8, male, 40s)

Misattributing disease symptoms in children to growing pains, attention-seeking or hypochondria was common, and the damage was exacerbated when families accepted the physician's opinion. This was seen to result in a failure to continue seeking the correct diagnosis, damaged family relationships and a belief, often formed at a crucial period of development, that it was a character fault:

You get written off, and it affects your perception of your whole personality. (Participant 11, female, 40s)

Disproportionate clinician responses

Confidence in their own and physicians' ability to interpret symptoms correctly was discussed as also having been undermined by disproportionate responses, both pre- and post-diagnosis. Almost all patients had received dismissive responses or false reassurance, subsequently reported to be incorrect. Physician over-reactions were also discussed, especially in those patients with organ/life-threatening manifestations. Some GPs were reported to lack confidence in taking responsibility even for minor symptoms. Experience of disproportionate reactions is summarized by this participant:

I must have presented to five GPs and none would take me on with SLE and APS, too complex. Having said that, frequently I feel that problematic symptoms I present to the rheumatologist are often dismissed with a pat and a smile. (Participant 12, Female, 60s)

Inaccurate physician opinions on medical records or letters

These opinions, often reported as given with poor understanding of lupus/UCTD, and sometimes questioning personal and patient integrity, were felt to have caused discrimination and difficulty in accessing appropriate care in the future for several participants. It was also noted that physicians' use of words such as ‘complex’ or ‘complicated’ when used about the patient rather than the disease could feel judgemental, reduce self-worth and increase physician and self-blame.

Administrative failings

The frequency and reliability of appointments varied considerably between participants, seemingly more influenced by individual hospital/GP surgery organization than disease severity. Some participants felt they had ‘fallen through the cracks’.

TABLE 2 Examples of quotes describing key physician behaviours that influence patient trust, well-being and security

	Examples of positive experiences	Examples of negative experiences
The diagnostic appointment	<i>Everyone was so compassionate... I was sent away with a lot of information ... she [rheumatologist] made it as bearable as it's ever going to be... How it is handled at that moment, on that day, is so important ... I knew then I was in safe hands. (Participant 2, female, 50s)</i>	<i>She [rheumatologist] said you've got lupus and arthritis and that was it. So I went away and googled. I found out all about the bad stories... I was like, this is it, I'm going to die... I've never had it explained, even though it's been 4 years. I couldn't tell [school] anything because I didn't know what lupus is... I just think they [rheumatologists] don't care much. (Participant 7, female, teens)</i>
Availability in times of crises	<i>He [rheumatologist] said, 'If you need me, you just email'... It's priceless ... because you never know when a flare is going to strike. You could be doing cartwheels today. Tomorrow, you can't even move ... so to have that lifeline: 'Doc, I'm in trouble'. 'Right, get yourself to clinic', you know, and it's straight away. (Participant 3, female, 50s)</i>	<i>[Secretary] said, 'I refuse to take your phone calls anymore. If you've got anything to say, you will phone the rheumatology hotline'... [Hotline nurse] said, 'We can't keep replying to your phone calls. You're not the only patient we speak to in a week, and I'd urge you not to phone again'... And I was, like, 'Why are you being so obstructive? I'm really sick', and 10 days later I was admitted. (Participant 17, female, 30s)</i>
Belief and validation in patients' symptom reporting	<i>[Rheumatologist] sat there and listened ... there was no questioning my experience, it was accepting my experience. (Participant 8, male, 40s)</i> <i>He [rheumatologist] was so caring and gentle, and he would look at you as if you were the only person who existed for your entire appointment and what you were saying was totally valid ... I felt safe with [him]. (Participant 3, female, 50s)</i>	<i>[Rheumatologist] said, 'You walked in here unaided. Your hands aren't deformed. Appointments are allocated according to need'. Every symptom I have that isn't specifically to do with my joints he dismisses as being nothing to do with my autoimmune condition. Why won't he listen to what I am saying and why is he ignoring my neurological symptoms? ... It's because they don't look at the patient sitting in front of them ... they're looking at their computer screen ... he rarely looks at me. (Participant 16, female, 60s)</i>
Care: holistic care, continuity, communication and consideration for quality of life	<i>My rheumatologist has each patient fill out a questionnaire on symptoms... She wants to know how you really are doing ... discusses this and other concerns... She has the perfect combination of analysing clinical test results, factoring in symptoms and asking pertinent questions... She asks at every appointment about the fatigue, brain fog and quality of life ... gives practical advice. (Participant 14, female, 60s)</i>	<i>Quality of life is the problem that I want to address, get sorted. I'm not really interested in some of the things he's [rheumatologist] really interested in ... it's the fatigue that's ruining my life... He's not interested in the emotional or the practical side of living with the disease, he's purely interested in the disease. (Participant 4, male, 50s)</i> <i>The focus is always on what he [rheumatologist] wants to discuss; so frustrating! Fatigue and pain are unquantifiable. (Participant 12, female, 60s)</i>

Inadequate knowledge/care during health crises

Multiple interviewees felt 'unsafe' in the accident and emergency (A&E) department or as in-patients, on account of past experiences of inadequate clinician knowledge of systemic autoimmunity. Several interviewees who reported being discharged after life-threatening conditions, such as meningitis or a heart attack, were initially misdiagnosed and treated dismissively with 'diagnoses' such as anxiety or indigestion. Remaining vigilant was felt to place a large burden on patients, who were often very unwell:

I never feel safe or secure with any of them... Even in an emergency, I have to be well enough prepared to offer up anything I can to help even the most basic types of medics help me. (Participant 20, female, 60s)

Several participants discussed medical post-traumatic stress disorder (PTSD), usually from cumulative negative medical experiences, especially misdiagnoses, dismissal

of symptoms and feeling endangered from lack of physician knowledge. One likened the psychological state created to that of a 'rescue pet', constantly anticipating neglect and mistreatment. [Table 3](#) details further experiences of insecurity, demonstrating losses of both personal and medical confidence.

Theme 5: changes to health-care-seeking behaviours

Persisting insecurity and distrust were found potentially to be linked to multiple negative health-care behaviours, especially under-reporting and health-care avoidance. This included those with multiple organ involvement avoiding health care for potentially life-threatening symptoms:

Psychologically, it would be much better for me to never see another doctor... It makes me wonder how many of us have just walked away and died. (Participant 5, female, 50s)

TABLE 3 Insecurity and a loss of personal and medical confidence**A damaged sense of self, particularly in those disbelieved as children**

You're diagnosed as attention seeking and therefore everything you say is written off as fairy stories or exaggerated. Your character is a character of a liar... I actually internalized it as a character flaw at that age, that I was feeble... I don't know which bits of my personal weirdness could be attributed to lupus ... I am it, I don't want it to be me, but I am it, definitely. (Participant 11, female, 40s)

The damaging impact on care and self-esteem from inaccurate medical records

My medical record is like a deranged Twitter feed, with one idea about me feeding into another, creating a completely unrecognizable image of me as a patient and a person... My identity was badly messed with when I was young... For me, there's been a lot of victim blaming, not only from doctors but also me being convinced I must be somehow at fault... Over time, this just erodes what little self-esteem and confidence you have in yourself to dust... The only person who should be defining who I am is me. (Participant 5, female, 50s)

Increased self-doubt and reduced self-worth, especially in those with limited positive serology who have felt repeatedly disbelieved

I often say to [husband], 'Do you believe me?' I have actually sat and questioned my own sanity... I no longer trust my own judgement in relation to me, my symptoms, how I'm feeling and how I should expect to feel under these circumstances... It makes you worry about the very essence of your character... I have absolutely no value whatsoever as a person or as a human being. (Participant 16, female, 60s)

The catastrophic repercussions on multiple areas of an interviewee's life from the actions and written evidence of a disbelieving GP (despite highly positive dsDNA)

[GP] has created an alternate personality with my name, a fraudulent, socially excluded liar, based on no evidence whatsoever... He included depression and self-harm on secret DWP form [and] referrals, meaning I was openly mocked and regarded as a time-wasting malingeringer ... told me forcefully to see a psychologist... Confirmation of diagnosis for my employer stated, 'fairly vague symptoms' ... lost me my job... The worst thing is how this has permeated all aspects of my life... If he had set about destroying my life, he couldn't have done a better job... I feel very diminished as a person. (Participant 18, female, 50s)

Persisting medical insecurity from inaccurate medical opinions

[Hospital consultant] wrote to my GP that I was an argumentative and manipulative lady that was mis-taking her prescription medications ... completely unfounded... I've only just come across that letter and it's completely devastated me ... devastating and infuriating and also my confidence has been, my medical confidence that's what it is, has been affected no end. (Participant 17, female, 30s)

DWP: Department of Work and Pensions; GP: general practitioner.

Lack of active listening (especially looking at computer screens rather than patients) and failure to create a 'safe space' were also reported to have led to

non-disclosure of symptoms. Although this sometimes related to only one occasion and individual physician communication skills, a tendency to under-report symptoms was identified. This was also felt to be heavily influenced by time constraints of both primary care and rheumatology clinics, leading to patients having to prioritize which of their (usually multiple) symptoms to report.

Under-reporting of mental health and cognitive concerns was particularly common, with the reasons including embarrassment, fear of stigma and/or that physical symptoms would then be misattributed to mental illness. Participants discussed: anxiety, seizures, psychosis, mood changes, cognitive dysfunction and varying levels of depression, with a significant minority having felt suicidal. Some participants had not reported these symptoms. Those who had 'plucked up the courage', or whose key physician had noticed or explicitly asked, were often those with the most trusting medical relationships. They generally reported empathetic and very supportive responses:

I became really stressed and depressed... He [rheumatologist] was worried about my stress levels and the effect it would have on my immune system ... referred me to a charity ... supports people with life-threatening and life-limiting diseases. (Participant 13, female, 40s)

Table 4 gives examples of physician impact on patient health-care-seeking behaviour. Negative reactions from patients included: avoidance, withdrawal and difficulty in making trusting relationships. Positive reports centred largely on joint decision-making, medication adherence and openness in reporting difficulties.

Theme 6: empowerment

Diagnosis was often reported as the first step towards empowerment, because it provided validation, an explanation for the reduction in previous abilities and improved knowledge to assist self-management. Some participants described regaining the dignity and self-respect that was often lost on the journey to diagnosis.

Participants gave many examples of physician-led empowerment, including: active listening, shared decision-making, physician belief in patient reports and result/knowledge-sharing. Teaching self-management and discussing methods to improve quality of life were not commonly reported, but much appreciated when they occurred:

She [rheumatologist] didn't just treat you and listen ... she definitely, very cleverly and carefully, through how she spoke, taught you to live the best life you could with the illness. (Participant 2, female, 50s)

In contrast, test results not being automatically disseminated to all patients was felt to be disempowering and identified by many as a systemic failing, with wide-ranging consequences. Multiple participants reported belatedly discovering abnormal results, previously not reported or reported as normal, adding to insecurity and distrust. Most patients consulted multiple clinicians, who were sometimes perceived not to communicate fully

TABLE 4 Examples of cumulative and individual physician influence on patient health-care behaviour

Negative health-care behaviours		Positive health-care behaviours				
Avoiding seeking medical help	Not reporting symptoms	Difficulties in building trusting medical relationship	Withdrawal from communication	Engagement	Following physician instructions	Openness in reporting medication difficulties
<p>Self-treat to avoid 'fight' to access care <i>To get taken seriously and to get them to treat you holistically, you really have to fight... It's exhausting. You feel defeated before you start really... Discomfort or the symptoms have to be above a certain threshold before I will put myself through the aggro. If it's below a certain threshold, I will put up with it or self-medicate.</i> (Participant 11, female, 40s)</p>	<p>Fear of reporting mental health symptoms <i>I've been feeling depressed but I'd never tell the doctors. I know it's from the disease and what it does to my brain... but if they had that on notes then everything, every symptom, they'd just say it was the depression... so my husband, he's actually offered me some of his [depression medication].</i> (Participant 17, female, 30s)</p>	<p>Long-term impact of a negative interaction <i>He's [rheumatologist] used his position of power to belittle me, humiliate me... I'm irrevocably changed by that relationship with him because I can no longer unself-consciously go to any doctor... so he may well have damaged me in a way that prevents me getting the best medical care in the future.</i> (Participant 16, female, 60s)</p>	<p>Physician failure to establish rapport <i>When I was trying to talk, she [rheumatology registrar] was tapping on her computer... I shut down because she didn't make any attempt to establish any sort of rapport... she'd lost me... You need someone to open warmly to get you feeling comfortable and to find a way to express what you need to say, because it's normally complicated.</i> (Participant 2, female, 50s)</p>	<p>Joint decision-making <i>I have confidence in her [rheumatologist] expertise, but she doesn't use it to talk down to me... good balance between it being her expertise and it being my body and my life.</i> (Participant 19, female, 50s)</p>	<p>A mutually trusting relationship leading to adherence <i>He [SLE specialist] believes you, I've never once felt that he doesn't believe me... With every other rheumatologist I'd argue [about medication]... question it... but I won't with him: 'Okay, you're the boss'. (Participant 17, female, 30s)</i></p>	<p>Teamwork and support leading to honesty in reporting non-adherence <i>We work together to find what's best for me... I am very honest with my GP and rheumatologist about what I've taken and what I haven't, what is working for me and what isn't... they're quite supportive of this.</i> (Participant 10, male, 20s)</p>

GP: general practitioner.

TABLE 5 Examples of empowerment, disempowerment and navigating the medical relationship as an 'expert' patient

Empowerment	
A diagnosis was often the first step in empowering these patients	<i>My initial reaction was of profound relief. After all those years of strange symptoms and accusations of mental weakness, everything fell into place. Far from it being my fault in some way or evidence of lack of true grit, I could see that I had actually overcome much... Knowing what I was facing felt more empowering than facing a mystery opponent. (Participant 19, female, 50s)</i>
From physicians, by involving patient in decisions and in clinic letters	<i>He [respiratory consultant] is very thoughtful... He does the letter... in front of me. He dictates it and will pause and look at me like, 'Is that the right thing to say? Are you happy with that?'. Yeah, and then I can say, 'Oh no, you missed a bit', or 'I don't quite understand that decision'. So I really like that. I feel like I've had a sort of summary [and] I can question it there and then, rather than get a letter 8 weeks later where you're copied in and you think, 'Really?'. (Participant 6, female, 40s)</i>
Self-advocacy	<i>Most of them [A&E clinicians] don't have much knowledge about lupus... They say, 'your ESR's not raised'... 'You haven't got an infection'... I educate them... I say I am fully diagnosed with systemic lupus... They all listen. On more than one occasion, senior doctors have sent in junior doctors to speak to me so they can learn. (Participant 2 female, 50s)</i>
From being listened to and given some control by physicians	<i>She [psychiatrist] is just a terribly good counselling person, listening person... made you feel in control... really helpful to have, yeah, just time to talk the whole thing through. She said, 'I don't think I need to see you again, but you can any time... I don't think you need pills for this but you could'... You felt like that put you in the driving seat. (Participant 6, female, 40s)</i>
Disempowerment	
By withholding test results	<i>It's part of that whole being invisible in the process again... when they don't think the results of the tests, they somehow aren't anything to do with me... The tenor of the interaction is that the patient is the supplicant asking the person with power for their grace and favour... We've got so many specialists involved... I'm the one who can do it [coordinate sharing of results] but they're withholding information from me. (Participant 4, male, 50s)</i>
By physicians restricting access to specialists	<i>[Rheumatologist] said, 'A neurologist's time is like gold dust. If I refer you to a neurologist and he thinks I'm wasting his time it'll reflect badly on me professionally, and I'm not willing to do it'. (Participant 1, female, 40s)</i>
Sharing disease and research information with physicians	
<i>They say, 'You've been seeing Dr Google again'. You think, you know, all I'm trying to do is make things better for myself. I'm not trying to make you look like a clown or anything... They haven't got the time to sit down and spend hours and hours on the Internet, whereas I have. (Participant 9, male, 60s)</i>	
Tactfully negotiating the patient-physician relationship as an 'expert' patient	
<i>I try my best not to let encounters with medics disempower me... Basically, I try to avoid going in as the disempowered, emotionally conflicted supplicant I was until 2010... On the other hand, I avoid going in so arrogantly I risk precipitously alienating whichever medic I'm seeing... willingness to negotiate respectfully and diplomatically. (Participant 20, female, 60s)</i>	

A&E: accident and emergency.

with each other and/or not to understand individual serological results as well as the patient. Therefore, receiving all results was felt to improve security and the ability to self-manage and to facilitate communication between specialists.

Requesting records and test results was often part of increasing assertiveness and self-advocacy, largely involving either reaching a 'tipping point' of frustration or feeling empowered by positive medical relationships or support from LUPUS UK and peers. Becoming increasingly knowledgeable and appropriately assertive was widely perceived to improve quality of care:

Things have changed dramatically though, with the help of the [LUPUS UK] forum... and after asking [rheumatologist] to follow the [BSR] guidelines. I've learnt so much from the group about rehearsing appointments, having a script, demanding a clear outcome... feel so much more confident than the frightened patient diagnosed... in a flippan 5-minute conversation. (Participant 18, female, 50s)

Participants indicated that physician receptiveness to mutual knowledge sharing was empowering, and referred to strategies such as 'sowing a little seed' for sharing their knowledge without threatening their doctor's professional pride. Although many physicians were amenable to this patient input, others were reported to react defensively. Several participants suggested that younger physicians seemed more amenable to considering patient-sourced information.

Table 5 details further examples of empowerment and disempowerment, including: the power of a diagnosis, the feeling of being in control and self-advocacy. Fig. 1 gives examples from five participants of physician/patient methods of mitigating common areas of persisting medical insecurity and negative health-care behaviours. Listening, belief, time, knowledge and teamwork were all identified as important.

Fig. 1 Patient quotes highlighting key physician and/or patient methods of mitigating the frequent areas of persisting insecurity

	CAUSES/AREAS OF PERSISTING INSECURITY AND NEGATIVE IMPACT ON PATIENT COGNITIONS, WELLBEING and/or HEALTHCARE BEHAVIOUR	KEY PHYSICIAN AND PATIENT METHODS OF MITIGATING INSECURITY
Ppt 13, F, 40s	<i>I am actually quite wary now if I have to attend A&E after my negative and disappointing experiences...I only go if I have no choice... constantly dismissed...if they have not heard of lupus, then how can they possibly decide the best possible course of treatment...how are you supposed to feel safe or secure?</i>	<i>He [rheumatologist] wants me to get better physically and emotionally too...always made an effort to listen and take me seriously...he has never fobbed me off or dismissed anything I have said to him...he sees me as an actual person and not as a bunch of symptoms</i>
Ppt 7, F, Teens	<i>They [rheumatologist] go, 'are you sure you're not exaggerating your symptoms'...I was like that's it I'm not even listening now, I need to leave...Next time I was like... 'you shouldn't have said that to me. I was going a step forward and you've put me 10 steps back'...I don't want to see them ...if they don't care why should I care</i>	<i>She [GP] actually cares...she just understands, she listens to me, she's quite happy to give me a longer appointment if I need it, like she overruns she's not worried about 10 minutes in and out and we can cover loads of things and she just listens</i>
Ppt 10, M, 20s	<i>I have long lasting trauma from some of the experiences I've had...a neurologist [who] immediately decided my problems were psychological...to this day I am wary of chasing up neurological issues although now I have set diagnosis and small fibre neuropathy. The thought of returning to the battleground of my years pre-diagnosis is a very anxious thought</i>	<i>I get on well with my current rheumatologist and we chat about my issues very comfortably. Again, she is not patronising about my knowledge...realistic about my symptoms but accordingly sympathetic.</i>
Ppt 15, F, 40s	<i>I feel I wasted decades of my life not being at my optimum health and am both frustrated and angry at the system for this...points to an institutional lack of knowledge and information. I don't blame any of the individuals [but] because I have experienced this lack of knowledge so often, I now automatically presume the person will not have enough knowledge of my condition unless they have proved otherwise to me</i>	<i>I keep up to date with research and developments. I manage my own lupus now with just trusted advice from my rheumatologist, but through research I found my own way to manage the disease with the correct diet and regular exercise being the key</i>
Ppt 5, F, 50s	<i>I never feel medically safe or secure...Apart from the grinding uncertainty of what part of me the SLE will be interested in attacking next, I'm incapable of trusting doctors or the fragmented system they work in due to the cumulative trauma of past and present performance...utterly powerless and helpless when I see [doctors]...leaves me in a constant state of hypervigilance and sometimes terror</i>	<i>My GP understands he has to provide me with a lot of context to every answer he provides me with in order to trust what he says. For this to work I have to have a fair amount of knowledge about SLE myself. Even then I rarely feel safe.</i>

Discussion

Although trusting relationships with specific physicians were commonly reported amongst these SLE and UCTD patients, many participants demonstrated persisting psychological damage and insecurity, usually initiated in the period of diagnostic uncertainty. This accords with previous studies that found that these diseases create uncertainty for both patients and physicians [9, 21] and that arduous diagnostic journeys challenged patients' self-worth [7, 9]. We found this particularly apparent if symptoms were perceived as being disbelieved or dismissed, especially during childhood/adolescence. Difficulties were experienced in developing an identity that was not defined by the disease, its limitations and disbelief from the medical profession and their families in an organic cause for their symptoms. Although behavioural interventions in juvenile SLE have shown positive results [22], our participants mostly remained misdiagnosed until adulthood. As DeQuattro *et al.* [23] also suggested, targeted interventions among those with adverse childhood experiences should be a priority.

Clinical judgement and blood test results are often inaccurate in SLE/UCTD patients, especially during infections. This can be the result of dysfunctional immune systems, atypical presentations and the effects of immunosuppressants. Combined with experiences of a lack of physician knowledge of these diseases, especially in A&E, patient trust in the accuracy of clinical judgement

and existing testing was often low. This frequently led to persisting insecurity, even post-diagnosis, that life-threatening symptoms would be missed/misdiagnosed, and there were multiple reports where this had occurred. For less severe, although still life-changing, symptoms, such as fatigue and pain, the insecurity was largely that these symptoms would be dismissed and disbelieved. Listening and taking a patient's self-reported symptoms seriously were therefore identified as of key importance, in agreement with several other studies [4, 24, 25].

Although it has been found that lupus patients often under-report flares [26] and minimize symptoms [27] and that the majority of physicians are unaware of this tendency [27], there has been little research to ascertain the causes of under-reporting. Our study identifies that previous and anticipated disproportionate responses to symptoms, usually dismissal and over-reassurance, are perceived as a major contributor to health-care avoidance and symptom under-reporting. This is in agreement with recent cancer research showing reporting delays amongst those previously 'reassured', owing to not wanting to appear hypochondriacal [28]. Consultation time constraints and patients' embarrassment in reporting multiple symptoms also led to under-reporting and prioritizing which symptoms to report.

Many participants reported a lessening of self-doubt and increased self-efficacy over time and discussed how an informed, assertive, mutually respectful method

of working with physicians improved communication and care. Knowledge was generally acquired from supportive key physicians, online, LUPUS UK and peers. Previous studies have also found that this can lead to empowerment [29] and can enhance active participation and improve the medical relationship [30]. However, there were frequent concerns expressed over how to share extensive knowledge tactfully, the lack of automatic provision of all test results, and reports of inaccurate, sometimes offensive and/or damaging, written information from physicians. These concerns demonstrated remaining power differentials that could impact optimal treatment, trust and self-management. Although shared decision-making was almost unanimously preferred in routine appointments, trusted key physicians adopting a more directive approach at times of health crises could enhance medical security.

Several participants in our study expressed great trust in key physicians who demonstrated excellent patient-centred care, in accordance with Hashim's [31] suggestions of eliciting the patient's agenda, active listening and expressing empathy. However, many lupus patients report less favourable communication experiences with doctors [32], and almost all our participants also described medical interactions where they had felt dismissed and their priorities/concerns had not been elicited or addressed. This is in line with research showing that clinicians elicited the patient's agenda in only 36% of encounters [33]. Failure always to elicit the patient's agenda might explain, in part, our finding of a widespread perception of a disparity in patient-physician priorities, with psychosocial and quality of life concerns (especially fatigue, pain, mental health and cognitive impairment) often felt to be neglected. Previous studies record similar disparities and suggest the need for more comprehensive, holistic assessments and approaches towards well-being [10, 11]. The preference of some physicians for directly addressable issues if time is limited [34] might need to be revised, because our participants clearly articulated a priority for listening and empathy as opposed to purely solution- or medication-focused discussions. Further research into the patient-nurse relationship is required, but it seems likely that greater use of specialist nurses and provision of psychosocial in addition to medication-focused support could help to meet this need and lead to earlier detection of (often undisclosed) mental health concerns.

SLE is associated with an increased risk of mental health symptoms [35–37], with estimates of $\approx 70\%$ of patients having neuropsychiatric manifestations [36]. Prevalence of depression in SLE is estimated at 30–50% [35, 37], and one study found that $\approx 20\text{--}50\%$ of rheumatological patients have psychosocial problems attributable to their disease, which were frequently not discussed with their physician [38]. Failure to elicit mental health symptoms is therefore of concern, particularly given that many of our participants also felt their mental health was directly damaged by difficult diagnostic journeys and/or negative medical interactions. Thus, clinicians

might need to discuss these symptoms sensitively (and signpost patients to relevant services if necessary), taking into account that patient reticence in disclosing symptoms might be a protective mechanism from having had their symptoms dismissed or misdiagnosed previously.

Many of these SLE/UCTD patients had high levels of medical knowledge and might present as competent and prepared, with an outward appearance of confidence. Nevertheless, the majority of participants reported high anxiety during medical encounters and persisting insecurity. Trauma and PTSD in response to misdiagnosis and/or the impact of chronic illness have been reported in other studies [39, 40], but we believe that this is the first study to consider the potential of medical PTSD from negative medical experiences pre- and post-diagnosis in some SLE/UCTD patients. Further research is needed to investigate how widespread this problem might be and to inform measures to prevent and ameliorate medical PTSD among these patients. We hypothesize, from the detailed stories shared, that it might take many positive experiences for medical trust slowly to be rebuilt, whereas one negative experience can potentially have the effect of precipitating an immediate return to an earlier position of fear and insecurity, particularly in the most traumatized. A positive first step would be for key physicians to acknowledge difficult diagnostic journeys and discuss the (often persisting) impact on patient well-being and behaviour.

Although purposively selected to ensure a wide range of demographic and disease characteristics, the participants were not representative of the wider lupus/UCTD population in terms of education and ethnicity. Owing to a very low proportion of non-white respondents to the survey, it was not possible to ensure a representative range of ethnic groups for the interviews. This under-representation is, unfortunately, common in rheumatological research [41] and might have influenced the results owing to differences in symptoms [42] and disease severity between ethnic groups, indicating the potential for a disproportionate adverse impact of delayed diagnosis [43]. Ethnicity might also differentially impact patients' experience of both lupus [7] and interactions with physicians [44].

Survey participants agreeing to be interviewed generally had a high level of education, which could have influenced our results, particularly in relationship to level of knowledge acquired and trust in physicians. For example, Berrios-Rivera *et al.* [45] found that higher educational attainment was associated with decreased trust in physicians among lupus patients, although Jolly *et al.* [46] detailed that educational level was not associated with differences in satisfaction with care. Given that recruitment was through online support groups, participants might not be representative in terms of medical experiences and level of disease knowledge. However, despite these identified sampling limitations, the persisting medical insecurity and the subsequent effect on medical relationships and health-care behaviour are likely to be replicated among many SLE/UCTD patients

(and other, even less well-understood CTDs, such as SS), owing to the diagnostic delays and frequency of psychological misdiagnoses identified in these patient populations as a whole [1–4]. The consistency of these patients' experiences with previously reported research and triangulation from the survey results [4] and forum discussions enhances validity. Our follow-up research will also elicit the physician viewpoint and examine these findings quantitatively to assess whether they are replicated in patients with a more generalizable range of education and ethnicity by stratified sampling from hospital clinics. Our research team also plans to explore the acceptability and feasibility of various methods of patient-directed training and peer support.

Conclusion

In conclusion, we found, in agreement with previous studies, that trust in specific physicians is often very high [47] but that persisting insecurity and distrust in the wider medical profession often remain. The need for greater awareness (and action) amongst physicians on this widespread persisting medical insecurity is the key message from this research. These patients and the research team have together identified several simple actions from physicians that do not require any additional time or cost but could vastly improve SLE/UCTD patient medical experiences. These include: physicians assuring patients that they will be available in times of crisis, believing and validating patient symptoms, providing compassionate, holistic care and acknowledging the ongoing impact from often traumatic diagnostic journeys. Empowerment, and all physicians being more aware of the need to promote trust and security frequently and actively, would help to combat the unpredictability of the disease and ameliorate some of the psychological and behavioural impacts from previous negative medical experiences.

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A potential methodological limitation of medical research is that it is usually designed and carried out by clinicians and/or researchers on, rather than with or by patients. We believe that a great strength of this study is that patients were equal co-contributors from design to write-up and that the patient members of the research team communicated regularly as a group, discussing the emerging themes and helping to ensure that the patient perspective remained centre stage (while being subject to the same tests of validity as other perspectives). LUPUS UK staff and rheumatologists were also involved in every stage of the research, providing regular input throughout every stage of the study, including review of the draft manuscript. Particular thanks and acknowledgement to all the participants and to the expert patient representative members of the study team: Michael Bosley, Moira Blane, Lynn Holloway and Colette Barrere.

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NOTE: Medication adherence and reporting of adherence will be combined with quantitative measures and published at a later date.

Supplementary data

Supplementary data are available at *Rheumatology Advances in Practice* online.

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