

Diagnostic overshadowing in systemic lupus erythematosus (SLE): A qualitative study

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Abstract

Objectives: SLE diagnostic journeys can be protracted, with negative impacts on long-term health. This study explored the role of diagnostic overshadowing (DOS) in delaying SLE diagnoses.

Methods: A qualitative analysis of 268 completed SLE patient surveys and 25 in-depth interviews purposively selected from the 2018–2021 Cambridge University Systemic Autoimmune Rheumatic Disease (SARD) studies.

Results: The majority of participants appear to have experienced DOS and there were indications that sustained DOS (S-DOS) may add years to some SLE diagnostic journeys. Symptom misattributions which contributed to S-DOS included: (1) “*Medical mystery*”, particularly when the clinician indicated that it was too expensive to keep investigating. (2) *Negative misattributions* (e.g. “nothing seriously wrong”), often due to a failure to connect multiple symptoms as possible indicators of an underlying condition. (3) *Diagnostic roadblocks*, including, in the case of some participants, a mental health, psychosomatic, ME/CFS or fibromyalgia (mis)diagnosis. (4) *Moral misattributions*, such as to “malingering”, which could undermine patient help-seeking and/or clinician help-giving.

Conclusion: Our data suggests that DOS may be an important factor in diagnostic delay in patients with SLE.

Keywords

Autoimmune, lupus, misdiagnosis, attribution, diagnostic overshadowing

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Introduction

Early diagnosis and treatment of Systemic Lupus Erythematosus (SLE) can slow disease progression and limit long-term damage.¹ Missteps in the medical system, however, can thwart opportunities for early intervention. Studies indicate a mean time to SLE diagnosis in the UK of between 6 and 7 years from first experiencing symptoms.^{2,3} Misdiagnoses and other symptom misattributions can contribute to these delays.⁴ SLE symptoms have been misattributed to a wide range of medical conditions,³ as well as to non-clinical characteristics, such as to “growing pains”.⁵ Nonetheless, early diagnosis does occur. Nightingale et al.,⁶ for instance, found a median time to SLE diagnosis (from first musculoskeletal symptoms) of 6 months among 10–19 year olds with mild to moderate disease in the UK, albeit using a different methodology to the studies^{2,3} cited above. With improvements, including rapid referrals,¹ timely diagnoses such as these could arguably become the norm.

Symptom misattributions and diagnostic delay

Piecing together findings from SLE studies,^{2–5,7,8} and case reports,^{9,10} symptom misattributions appear to contribute to diagnostic delay through two principal related processes.

First, a symptom of the undiagnosed disease (in this case SLE) is misattributed during a medical consultation to a previously not suspected patient characteristic or condition,

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and this reduces or removes the perceived need to continue seeking an explanation for the symptom. Fatigue arising from SLE might, for example, be taken to be a symptom of depression and contribute to a misdiagnosis of Major Depression. Second, the now established belief that the patient has or could have the characteristic/condition *overshadows* future clinical encounters. In particular, additional symptoms of the still undiagnosed disease may be misattributed to it. This could, for instance, entail the clinician misattributing SLE joint pains to the misdiagnosed Major Depression. The reasoning might be that the pains are a psychosomatic sequela of the depression.

The second described process is ‘diagnostic overshadowing’. Whilst there are a wide range of definitions of ‘diagnostic overshadowing’,^{11–13} the term is most often used to refer to the misattribution of the symptoms of an undiagnosed condition to a diagnosed one.¹³ A limitation of this usage/definition is that the more impactful forms of symptom misattribution can be to undiagnosed but suspected conditions¹²; non-clinical characteristics³; or assumed behaviours, such as feigning symptoms.¹⁴

Diagnostic overshadowing (DOS) in SLE

Where DOS has been investigated – principally among those taken to have intellectual disabilities or severe mental health conditions – it has been found to be a substantial problem.^{15,12} It also seems possible that DOS could be a major problem across a wide range of health conditions, including SLE. Our literature review indicated that there may be no published studies which address (with reference to “diagnostic overshadowing” and on the basis of empirical findings) DOS in SLE. There are, however, SLE studies^{3–5,16} that, whilst not referring to DOS, include a focus on phenomena entailing the misattribution of the symptoms of undiagnosed SLE. Neuro-psychiatric (NP) SLE symptoms are particularly susceptible to misattribution,³ and so also perhaps to DOS. This appears to arise in part from clinicians underestimating NP symptom prevalence in SLE.¹⁷

Whilst these SLE studies link misattribution to diagnostic delay,^{3–5,16} they leave largely unaddressed the question of how the misattributions survive multiple clinical encounters, often with senior consultants. With this in mind, and to address the DOS definitional limitations referred to above, we developed an operationalised definition of sustained DOS (S-DOS) (conceived as a DOS subtype) – with a set of requirements (Figure 1) and indicators (Table 5) – and applied it to the analysis of qualitative data from the Cambridge University SARD studies.

The study aims were:

- (1) Identify and categorise, from the qualitative survey and interview data, the principal types of misattribution of SLE symptoms.
- (2) Identify, from among these principal types, some of the more sustained and impactful forms of DOS, along with some of their causes and characteristics.

Sustained DOS was taken to occur when all of the following conditions were met:

- 1 One or more symptoms of an undiagnosed disease are misattributed to what the clinician suspects or believes is a characteristic of the patient or a condition that the patient has.
- 2 One or more of these misattributions are sustained (i.e. considered and not rejected) across multiple clinical encounters.
- 3 The misattribution in one clinical encounter contributes to the same or similar misattribution in a subsequent clinical encounter (e.g. through its appearance in the referral letter).
- 4 The misattributing has a significant adverse impact on the diagnostic process (including on the time to correct diagnosis).

Figure 1. Operationalised definition of Sustained DOS.

Materials and methods

Research strategy

Qualitative methods, drawing-upon constructivist grounded theory,¹⁸ were used to identify causal processes.¹⁹ Our approach was pragmatic, with a focus on informing practice rather than on building higher-level theories.

Data collection and analysis

We qualitatively analysed data purposively selected from the Cambridge University 2018–2021 SARD (CS) studies.^{3,20–24} We included all 268 completed lupus patient surveys and 25 of the 34 transcripts of interviews with SLE patients from the 3 CS studies^{3,21–23} described in section 1.1:a-c, Table 1. These studies included the diagnostic journey as a major focus. The 25 transcripts were selected on the grounds of providing the most diagnostic journey information and/or to maximise relevant variation, including a mix of timely and protracted journeys. We excluded two of the CS studies^{20,24} (reasons for omitting them are noted in section 1.2:a-b, Table 1). Taking a grounded theory method approach, the analysis moved iteratively between constructing concepts from, and testing these against, the data. Table 1 provides an example (section 2.1) and describes the study analysis stages (sections 2.1–2.7).

Ethical approval

The Cambridge University Psychology Research Ethics Committee approved the primary research studies (PRE 2018-84 and PRE 2019.099) and subsequent analyses of the data, including that in the current study. Participants gave

Table 1. Principal data collection and analysis stages.

Stages	Activities
I. Data collection for the 2018-2021 Cambridge University SARD (CS) Studies	
I.1 CS studies 2018-21 data used in the 2023 DOS study	
(a) Mixed methods survey study of SARD patient experiences ^{3,23}	(i) A pre-tested questionnaire (with quantitative and qualitative questions) was made available in December 2018 on the LUPUS UK online forum (>25 000 members) and facebook group (>7000 members). Inclusion criteria were: age ≥18 years; reporting a diagnosis of lupus (SLE or another type), undifferentiated connective tissue disease, mixed connective tissue disease, Sjögren's, or overlap condition, on their clinic letters; and listing symptoms supportive of these diagnoses. There were 233 eligible completed surveys. See Sloan et al. ³ for methodological details, including limitations; and for a copy of the questionnaire (in its supplemental material). (ii) All 181 completed surveys (from the 233) which reported a lupus/SLE diagnosis were included in the DOS study.
(b) Interview study exploring the impact of patient-physician interactions on lupus and UCTD patients. ^{21,23}	(i) Participants were purposively sampled from the 233 responses to the patient experiences survey (see I.1 (a) above), with the aim of ensuring a range of socio-demographic and disease characteristics, and diagnostic and medical support experiences. Twenty-one semi-structured interviews (of around an hour each) were conducted by MS in 2019. Interviews were in-person, or on the telephone/Skype; or the questions (and follow-up questions) were sent by email. Interviews were transcribed verbatim. For more details on the study, see Sloan et al., ²¹ with the interview schedule available in its supplemental material S1 . (ii) Transcripts of all 17 interviews with interviewees who reported an SLE diagnosis were included in the DOS study.
(c) Mixed methods study of the impact of the COVID-19 pandemic on SARD patients. ²²	(i) This was a sequential multi-phase mixed methods study of UK resident participants recruited through the LUPUS UK forum and lupus support UK facebook group. Inclusion criteria were: age ≥18, resident in the UK, and reporting a SARD diagnosis on their clinic letters. Pre-tested baseline surveys were distributed in March 2020, and follow-up surveys in June 2020 (n:111); and in-depth interviews (n:28) of around an hour were conducted by MS in July 2020 (mainly by phone). See Sloan et al. ²² for more details, including examples of survey questions and interview schemes (in its supplemental material). (ii) All the completed surveys reporting an SLE diagnosis (n:87), and 8 of the 17 transcripts of the interviews with interviewees reporting an SLE diagnosis, were included in the DOS study.
I.2 CS studies 2018-21 data NOT used in the 2023 DOS study	
(a) A qualitative analysis of the lupus UK forum. ²⁰	Data from this study was not used for the 2023 DOS study partly on the grounds that substantial numbers of posters did not indicate whether they had a diagnosis of SLE reported in a clinic letter. For more information on the forum study see Sloan et al. ²⁰
(b) Mixed methods study of telemedicine in rheumatology ²⁴	This 2021 study included a survey of rheumatology patients (n:1340) and clinicians (n:111) and in-depth interviews. It was decided to use (in the DOS study) the data from the studies described above (I.1 (a)-(c)), in preference to that from the telemedicine study, in part on account of the data from the former being more focussed on diagnostic journeys. For more information on the telemedicine study, see Sloan et al. ²⁴

(continued)

Table 1. (continued)

Stages	Activities
2. Analysis for this 2023 DOS study of data from the CS studies described at 1.1 above	
2.1 General approach	The analysis moved between constructing concepts from, and testing these against, the survey and interview data. If, for instance, a concept generated from the first three interviews was discrepant with a phenomenon in the fourth, the concept would be developed (through adding “dimensional variation”) so that it was also consistent with that phenomena or excluded it from what it was indicated to help explain.
2.2 Initial analysis	(a) Segments of 10 interviews from study 1.1(b) were highlighted and memos (which included misattribution categories) added. This was done in the order in which the interviews had been conducted, on the grounds that the interviewer had developed and tested themes across the interview series. (b) Qualitative answers from 60 survey respondents from study 1.1(a) were highlighted and memos added. The selection of the 60 was in part on the basis of which completed surveys appeared from word searches (such as “pregnancy”) to have information relevant to the categories (such as “missed diagnostic opportunities in maternity care”) developed in the interview analysis described at 2.2(a) above. Choice of words to search with was based upon emerging concepts (as explained further in supplemental Material, section 5). In addition, answers from participants with a particular characteristic (e.g. being ANA negative) were analysed and then compared with answers from participants without that characteristic.
2.3 Categorisation	The categories, with category definitions, were arranged into a hierarchical framework. The subordinate categories (such as “novel disease” and “too expensive to solve”) were considered constitutive of, or contributing to the occurrence of, the superordinate categories (such as “medical mysteries”).
2.4 Amending the categories	This hierarchical framework was used to code the next 10 interviews (and go back over the first 10) and answers from another 60 survey respondents, with the categories amended to better reflect/explain the accumulating data (such as the subcategory “no explanation” being added to the “medical mysteries” subcategories).
2.5 Final coding	The resultant categories were used to code a final 5 interviews and 20 surveys; and to provide keywords with which to search all surveys from studies 1.1(a) and (c), with the results of these searches also coded.
2.6 Theoretical Saturation	Theoretical saturation was taken pragmatically to be the point at which the categories together addressed all the main research questions and additional interviews/survey responses did not provide major new relevant categories or insights.
2.7 Enhancing validity	Addressing threats to validity in the data analysis included: • The inductive-deductive process; • Triangulating findings from participants’ qualitative survey answers and their subsequent interviews; • Second-coder coding of final categories (with RH coding and MS second coding); • Searching for data which was discrepant with the emerging findings;¹⁹ • Feedback from participants, other patients, and clinicians.

electronic (for surveys) and audio-recorded oral (for interviews) informed consent.

Results

Interviewee characteristics are shown in [Table 2](#) (section 1). Survey respondent characteristics are reported elsewhere.^{3,22} The majority of survey respondents were female (>95%) and

white (>90%). We calculated the mean diagnostic journey length (time from first subjective symptoms of SLE to a formal diagnosis of SLE) for patients diagnosed in different decades ([Table 2](#), section 2). The findings did not indicate any major differences in diagnostic delay. However, we note that sustained diagnostic overshadowing (S-DOS) could have changed without significant changes in journey length. For limitations of our method, see [Supplemental Material, section 4](#).

Table 2. Interviewee characteristics and participant mean times to diagnosis.

I. Interviewee characteristic	Number of participants (% rounded)	
Age band		
18–29	4 (16)	
30–39	2 (8)	
40–49	9 (36)	
50–59	5 (20)	
60–69	5 (20)	
Gender		
Female	21 (84)	
Male	4 (16)	
Non-binary	0 (0)	
Ethnicity		
Asian/Asian British	3 (12)	
Black/Black British	1 (4)	
Mixed ethnicity	2 (8)	
White	19 (76)	
Diagnosis on clinic letter		
SLE	25 (100)	
Country of residence		
England	15 (60)	
Northern Ireland	0 (0)	
Scotland	4 (16)	
Wales	6 (24)	
2. Mean time to diagnosis for 148 UK resident ^a SLE participants in studies I.I a-b (Table 1) ^b		
Period diagnosed in	Number of participants ^c	Mean time to diagnosis (range)
Pre-1991	8	6 yrs, 8 mos (2 mos - 20 yrs)
1991-2000	24	6 yrs,10 mos (3 mos - 30 yrs)
2001-2010	38	8 years, 6 mos (2 mos - 32 yrs)
2011-2018	78	7 years, 4 months (1 mos - 40 yrs)

^aThis mean time to diagnosis data is from an analysis of SLE participants in survey study I.I(a) (Table 1). Study I.I(b) interviewees were recruited from study I.I(a) participants. Time to diagnosis data was not available for study I.I(c).

^bOnly the data from UK resident participants was used as: (i) There could be significant differences between experiences in different countries; (ii) The majority of participants in study I.I(a) (>90%) were UK resident; and (iii) There were not enough participants from any other single country to support meaningful other country-specific conclusions.

^c33 participants from the I81 SLE study I.I(a) participants were omitted from this time to diagnosis analysis on account of: (i) Being non-UK resident; (ii) It being unclear which year they were diagnosed in; and/or (iii) It being unclear how long they had had symptoms.

The majority of participants reported multiple misattributions of their SLE symptoms pre-SLE diagnosis (Tables 3 and 4). Misattributions that contributed to S-DOS had a particularly detrimental impact on the diagnostic process. This was because these misattributions were repeated during multiple subsequent clinical encounters, and because more symptoms of the undiagnosed SLE tended to be misattributed to the assumed patient characteristic or condition. In addition, the misattributions – for reasons relating to cognitive error, ‘moral misattributions’, patient-clinician interactions, and/or organisational factors (such as restrictive referral policies) – were frequently resilient to countervailing evidence. Respondent-204 (female, 40s), for example, indicated that symptoms of her undiagnosed SLE

were misattributed to hypochondria over an 11 year period and that she was only then diagnosed with SLE when “a chest specialist” ordered an SLE relevant test “accidentally”. In other cases, it appeared to take the development of severe disease and/or hospitalisation to overcome S-DOS (Table 5/Row:3.2). Other scenarios which contributed to S-DOS are shown in Tables 3 and 4 below.

Not all reported instances of misattribution seem to have involved S-DOS. In particular, some attributions were taken to be provisional and investigations continued, and so the attribution did not have (as required in our S-DOS definition) “a significant adverse impact on the diagnostic process” (Figure 1). Respondent-86 (female, 30s), for example, reported:

Table 3. Patient reported misdiagnoses and other misattributions (other than 'moral misattributions') with the potential to constitute DOS.

Patient perceived/reported clinician attributions ^a	Illustrative patient quotes
<i>1. Negative misattributions</i>	
1.1 Nothing/nothing serious wrong	"Told to get on with your life, there's nothing wrong with you ...". (Respondent-14, female, 50s)
1.2. Not life threatening in Accident and Emergency (A&E)	"[A&E doctor said] 'You're showing no signs of shock... You don't need to be here.'"
1.3. Not SLE, nor another serious condition	(Interviewee-14, female, 30s) "Blood test for leukaemia, results came back negative, no further action taken." (Respondent-169, female, 20s)
<i>2. A different chronic disease</i>	
2.1 Another autoimmune disease	"A rheumatologist diagnosed rheumatoid arthritis and sent me home with a leaflet." (Respondent-74, female, 60s)
2.2 Another (non-autoimmune) chronic illness	"Never any investigations, simply the assumption that I'd got ME." (Interviewee-15, female, 60s)
<i>3. Semi-acute and acute conditions</i>	
3.1 Infections	"Was told the pain I was suffering in hands/feet/toes was due to the pneumonia." (Respondent-162, female, 50s)
3.2 Allergies	"Face swelling, due to kidney failure and fluid build-up, originally misdiagnosed as an allergic reaction." (Respondent-30, male, 20s)
3.3 Injuries	"Pulled muscles." (Respondent-58, female, 40s)
<i>4. Psychosomatic</i>	
4.1 Diagnosable/diagnosed	"Myriad of inaccurate patronising psychological assumptions including health fixation disorder." (Respondent-153, female, 50s)
4.2 Not diagnosable or ambiguous clinical status	"... apparently it was all in my mind!" (Respondent-92, female, 60s)
<i>5. Mental health condition</i>	
5.1 Diagnosed	"Postnatal depression." (Respondent-37, female, 50s)
5.2 Ambiguous clinical status	"GP said: 'Maybe there's an element of anxiety there'." (Interviewee-14, female, 30s)
5.3 Multiple mental health diagnoses/attributions	"GPs from 2003 to 2018 diagnosed stress, anxiety, post-natal depression, menopause and 'overdoing it'." (Respondent-37, female, 50s)
<i>6. Normal biological processes</i>	
6.1 Age-related	"Teenage laziness..., GP". (Respondent-78, female, 50s)
6.2 Hormonal	"GP... said symptoms were the menopause." (Respondent-242, female, 60s)
6.3 Normal for that patient	"Aches and pains in joints due to being 6 foot tall." (Interviewee-10, female, 60s)
<i>7. General health and fitness</i>	
7.1 Out of condition	"Rheumatologist saying there was nothing wrong with me apart from being obese." (Respondent-24, female, 40s)
7.2 Sleep	"need for more sleep" (Respondent-83, female, 50s)
<i>8. Situational factors</i>	
8.1 Stressful current life events	"being a busy person." (Respondent-73, female, 30s)
8.2 Environmental	"The heat..." (Respondent-109, female, 40s)
<i>9. Multiple symptoms not connected</i>	
9.1 Connections not made	"chronic sinusitis, balance issues, tinnitus, photosensitive epilepsy etc., all diagnosed in isolation with no reference to lupus." (Respondent-52, female, 40s)
9.2 Patient "complex" (without implied psychological link)	"They just tell me I am a complicated case and can not help or diagnose me with one thing, just multiple things." (Respondent-88, female, 50s)
9.3 "Polysymptomatic" (with implied psychological link)	"She said it was anxiety. She said I was polysymptomatic." (Interviewee-14, female, 30s)
<i>10. "Medical mystery"</i>	
10.1 No explanation	"Told there was no explanation." (Respondent-73, female, 30s)
10.2 Novel disease	"They decided I had a totally novel disease!" (Respondent-258, female, 40s)

(continued)

Table 3. (continued)

Patient perceived/reported clinician attributions ^a	Illustrative patient quotes
10.3 Too difficult/expensive to solve	"As soon as all the tests come back as negative, they just switch off and they put you in the too difficult box." (Interviewee-28, male, 70s)
10.4 Written-off	"[Patients] know when something isn't right with their body... don't write them off as a medical mystery because you're not sure". (Respondent-219, female, 40s)

^aIt was not possible to verify with clinicians whether they had made these patient reported attributions or whether for instance patients had misinterpreted their intended meanings.

Table 4. 'Moral misattributions'.^a

Patient perceived/reported clinician attributions ^b	Illustrative patient quotes
<i>1. Patient provides incorrect information</i>	
1.1 Unwittingly wrong	"I asked the same rheumatologist whether I could have lupus as I had some symptoms, he was completely dismissive." (Respondent-169, female, 20s)
1.2 Wilfully wrong	"Tell them that every fibre of your being hurts, they're like, 'really? You're 20 something... you're trying to pull a fast one'." (Interviewee-8, female, 50s)
1.3 Unclear if considered unwitting or wilful	"Every time I mentioned the butterfly rash that would appear across my face every night, but the doctors wouldn't believe me because it would be very faint by morning." (Respondent-129, female, 50s)
<i>2. Asserted/presumed motivations for being wilfully wrong</i>	
2.1 Seeking attention or support	"Treated like a liar or an attention-seeker by medics as a child." (Respondent-52, female, 40s)
2.2 Avoiding effort or anxieties	"without the diagnosis I was labelled a lazy student who just wanted to get out of doing homework." (Respondent-223, female, 60s)
2.3 Health anxiety conceptualised as moral weakness (e.g. patient could choose to pull themselves together)	"Too many Drs told me there was nothing wrong with me and 'go away and get on with my life'." (Respondent-16, female, 40s)
<i>3. Difficult patient</i>	
3.1 Time-wasting or demanding	"Left feeling like a neurotic, time-wasting moaner!" (Respondent-41, female, 50s)
3.2 Argumentative	"Argued with my GP for half an hour to get a blood test." (Respondent-92, female, 60s)
3.3 Being complex and hard to diagnose	"They just tell me I am a complicated case and can not help or diagnose." (Respondent-88, female, 50s)
<i>4. Patient to blame for illness</i>	
4.1 Contributed to causing the illness	"I was told I was just a busy working mum, and I should go and work part-time." (Interviewee-6, female 40s)
4.2 Imagining illness	"I was accused of having imaginary symptoms." (Respondent-92, female, 60s)
4.3 Failing to follow treatment advice for misdiagnosed illness	Reluctance to follow GP instruction "to go to the gym..." (Respondent-131, female, 20s)

^aMoral misattributions entail clinicians erroneously attributing disease symptoms, symptom reports, and/or other patient conduct, to presumed blameworthy patient motivations or behaviour.

^bAs with the attributions in Table 3, there was no opportunity to ask the referred to clinicians about the 'moral misattributions' which patients reported them as having made.

Initially I was diagnosed with juvenile arthritis, but only a couple of days later they diagnosed lupus.

To help assess the likelihood of there having been a misattribution, and of any misattribution having contributed

to S-DOS, a set of S-DOS indicators (Table 5) was developed. For instance, Respondent-96 (female, 40s) reported that a lupus expert had told her that she had had SLE at the time of the possible misattributions (matching Indicator:1.1, Table 5); her symptoms (such as joint

Table 5. Some of the principal indicators of possible sustained DOS.^a

Some principal indicators	Illustrative patient quotes
1. The symptom appears to have been a symptom of the undiagnosed SLE at the time of its attribution to something else	
1.1. The patient had SLE at the time of the attribution	"I got so ill and so overwhelmed... Paid to see Dr, who told me I had had SLE all along." (Respondent-96, female, 40s)
1.2. The symptom was a possible symptom of SLE.	"I had classic lupus symptoms, but they were never put together." (Respondent-57, female, 40s)
1.3. What the symptom was attributed to did not explain it	Symptoms attributed to "lack of vitamin D even when it was normal." (Respondent-38, female, teens)
2. Misattribution to the assumed characteristic was sustained across multiple clinical encounters	
2.1. Misattribution of an SLE symptom to the assumed characteristic was repeated	"Rheumatologist [said was] old age dermatologist [said was] old age." (Respondent-43, female, 70s)
2.2. Additional SLE symptoms were misattributed to the assumed characteristic	"GPs dismissed everything as 'growing pains' and 'being a teenager'." (Respondent-131, male, 20s)
3. The misattributing had a significant adverse impact on the diagnostic process	
3.1. There was a protracted diagnostic journey following the original misattribution	Mis/diagnoses of "Chronic fatigue/Glandular Fever/ME by GP in 1993" and diagnosed with SLE in 2018. (Respondent-10, female, 40s)
3.2. SLE was only diagnosed once the patient became seriously ill	"I had a build up of fluid around my heart that I saw the GP for, 3 weeks before it got so bad that I had to go to hospital to have this diagnosed." (Respondent-140, female, 50s)
3.3. The diagnostic delay was attributable in significant part to the misattributions	"GP noticed I'd had ongoing low neutrophil count for years, which is what the old GP thought signified a virus. Was referred straight to rheumatology." (Respondent-83, female, 50s)

^aAs with Tables 3 and 4, it was not possible to verify patient reports with the clinicians reported on.

inflammation) were possible SLE symptoms (Indicator: 1.2); and the dermatological condition, to which these symptoms had initially been attributed, did not explain them (Indicator:1.3). These indicators also assisted in the identification of factors that had contributed to S-DOS, such as the misinterpretation of blood results (Table 5/Indicator: 3.3), as well as highlighting some DOS impacts.

Misattributions with the greatest impact

Certain types of misattribution, including those described below, appear to have quite often led to S-DOS with a substantial detrimental impact on the diagnostic process.

(a) "Medical mystery" and negative misattributions

Some participants reported that their clinicians had labelled symptoms as inexplicable or indicated that it was too expensive to keep investigating them (Table 3/Rows:10.1-10.4). It was, however, the assumed absence of a condition – "nothing seriously wrong" or not a specified disease (Table 3/Rows:1.1-1.3) – which could most powerfully overshadow the diagnostic process. For example, Respondent-89 (female, 30s) wrote:

Was being investigated for MS [multiple sclerosis]... and after confirming I didn't have it, was told by GP it must be stress.

In this and comparable instances, the ascertained absence of one serious condition seems to have been equated with there being no serious condition. In other cases, the investigation appears to have been used to reassure patients, rather than as part of a differential diagnostic process.

(b) Symptoms viewed in isolation

Conflating symptoms and conditions, such as diagnosing "rash" when presented with an SLE indicative "malar rash" (Respondent-113, female, 30s), and not connecting multiple symptoms as possible indicators of an underlying systemic disease, were among the principal problems across the different types of S-DOS. One participant's advice to clinicians was to "join the dots... if a patient is describing a set of symptoms on a number of visits" (Respondent-35, female, 60s). Patients reported that these unconnected "dots" were attributed to a wide range of clinical conditions and non-clinical characteristics, such as being "too active, not active enough" (Respondent-57, female, 40s). Patients reported having been correctly diagnosed with some of the conditions to which SLE symptoms had been attributed but that these conditions had left some "dots" unexplained. For example, one patient with cystic fibrosis (CF) had felt that some of her symptoms were "very odd for CF, which eventually led to a rheumatology screen revealing lupus specific markers" (Respondent-90, female, 40s).

(c) *Psychosomatic and mental health attributions*

As opposed to no connection being made between symptoms, they were quite often connected as the assumed manifestations of a psychosomatic or mental health condition (Table 3/Rows:4.1-5.3). These psychological misattributions could be resilient in the face of visible physical symptoms, as Respondent-212 (female, 30s) found:

GP told me I was suffering with anxiety... when I went with swollen legs.

In addition, what the clinician labelled as “an element of anxiety” (Interviewee-14, female, 30s) could in combination with patient-clinician interactions – such as the patient insisting that there is an undiagnosed illness – lead to a more formal diagnosis of health anxiety.

(d) *SLE ‘diagnostic roadblocks’*

Certain diagnoses had a particular tendency to stall the SLE diagnostic process. It is recognised that a substantial number of participants had, and believed that they had, some of these conditions (see [Supplemental Material on fibromyalgia](#)). Nonetheless, many participants indicated that the misattribution of SLE symptoms to these conditions (whether extant or not) had substantially delayed their diagnostic journey. Among these ‘diagnostic roadblocks’ were mental health (MH) and psychosomatic diagnoses, but also a number of conditions – including fibromyalgia and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) – which were said to have been conceptualised by some clinicians as comparable to MH and/or psychosomatic conditions. For example, Respondent-173 (female, 40s) reported that she was diagnosed with ME in 2005 and added:

nothing then looked at properly because of this ME diagnosis... Was not diagnosed [with SLE] until 2013.

In addition, diagnosis of these conditions appeared to quite often be problematic, such as diagnosing fibromyalgia “when no exam had been done...” (Respondent-103, female, 40s). Patients pointed to a number of factors (other than their symptom presentations) that may have contributed to these diagnoses. These included clinicians being confident to make them without a referral, and treatment for them being associated with limited perceived risk, such as “go to the gym” (Respondent-131, female, 20s). In addition, there appeared to be a willingness to proceed without a clear diagnosis. For example, Respondent-135 (female, 50s) reported:

GP diagnosed me as ‘nervous housewife’... Prescribed a sedative.

In contrast, clinicians were reported to be “reluctant to diagnose lupus” (Respondent-237, female, 40s), which several respondents suggested may have been because of the risks associated with autoimmune medications. It was also hard for patients to challenge some of these ‘roadblock’ diagnoses, including when there was no formal diagnosis to challenge, such as “anxiety issues” (Respondent-173, female, 40s).

Moral misattributions

For the purposes of our study, ‘moral misattributions’ entail clinicians erroneously attributing symptoms and/or patient conduct to presumed blameworthy patient motivations and/or behaviour. A number of principal categories of moral misattributions were identified, including:

- *Dishonesty* (Table 4/Row:1.2). Patients quite often felt that they were being accused of exaggerating symptoms or even “faking it to some degree” (Interviewee-17, female, 50s). Motivations clinicians were said to have ascribed to these presumed behaviours (Table 4/Rows:2.1-2.2) included attention seeking or avoiding anxieties or effort, such as being “school-shy” (Respondent-52, female, 40s). Patients with neurological symptoms, such as “vertigo” (Respondent-169, female, 20s), appeared to be particularly vulnerable to clinician disbelief.
- *Mental illness conceptualised as moral weakness* (Table 4/Row:2.3). This included clinicians being reported to have implied that patients should get a grip and be less depressed.
- *Being difficult* (Table 4/Rows:3.1-3.3). Patient behaviour that clinicians were reported to have taken to be “difficult” included pushing for tests/referrals, disagreeing with the clinician, and/or in-putting their own diagnostic suggestions. Being “difficult” appears, however, to have often led towards the correct SLE diagnosis.
- *Being to blame for the illness* (Table 4/Rows:4.1-4.3). This included patients being blamed for contributing to the illness, such as through an unhealthy lifestyle (Respondent-142, female, 50s), or through not treating it, such as not taking antidepressants for SLE symptoms misattributed to depression.

Moral misattributions could have a negative impact on the diagnostic process through providing incorrect explanations for symptoms that might otherwise have led to the SLE diagnosis. Moral misattributions could also undermine

patient help-seeking and/or clinician help-giving. This included the impact of articulated moral misattributions on patient self-concept, and/or on patient-clinician relationships, reducing patient engagement with clinicians or its forcefulness. In addition, moral misattributions, such as taking the patient to be in part to blame for their illness, could reduce the help that clinicians were prepared to provide. Clinicians could also be less willing to engage with patients taken to be difficult, whilst being difficult could in itself be interpreted as evidence of a MH disorder. However, whether being ‘difficult’ – as in pushing for answers – slowed-down or speeded-up the diagnostic process seemed to depend in part upon the patient’s social position. For example, Respondent-245 (female, 50s) reported:

a friend of a friend who’s a GP had a long chat with my GP who then agreed my symptoms were serious and I was referred to a neurologist.

Moral misattributions could also influence social status and reinforce power imbalances. For example, with several (at the time) children (Respondent-52, female, 40s; Interviewee-27, male, 20s), the misattribution of SLE symptoms to “laziness” seems to have reduced their social standing with, and support from, the medical system and/or family. This slowed down their diagnostic journeys and rendered them more distressing.

Discussion

As far as we are aware, this is the first published *empirical* study which addresses “diagnostic overshadowing” (DOS) in SLE. We applied an operationalised definition of sustained DOS (S-DOS) to the qualitative answers from 268 completed patient surveys and the transcripts of 25 in-depth interviews. Experiences of S-DOS were common among study participants. Misattributions which contributed to S-DOS appear to have had a particularly detrimental impact on the diagnostic process, principally because the misattributions influenced multiple subsequent clinical encounters (in some cases for over a decade). For instance, once the early symptoms of some participants’ undiagnosed SLE had been misattributed to fibromyalgia, the consequent fibromyalgia diagnosis provided an explanation for some of their later SLE symptoms. This could help explain Cornet et al.’s finding that an initial mis/diagnosis of fibromyalgia was associated with a 5 year increase in the median SLE diagnostic delay.¹⁶ We acknowledge that early childhood trauma may be a shared risk factor for fibromyalgia²⁵ and SLE.²⁶ Hence, there exists the possibility of developing fibromyalgia many years prior to developing SLE.

Whilst the literature focuses on DOS among individuals with a serious mental illness,²⁷ or with intellectual disabilities,²⁸ our study indicates that DOS could be an equally

powerful force among patients without these conditions/ characteristics. Furthermore, whereas much of the literature frames DOS as something which happens in one location at one time, and in particular during a visit to the emergency department,¹² our findings suggest that DOS tends to be a process over time and across settings. This is why the perspective of the patient – who is in general the only one ‘there’ across the whole diagnostic journey – can be critical. With a few exceptions,^{28,29} this perspective has been neglected in DOS studies. Our findings also suggest that one form of DOS (such as attributing joint pains to anxiety) can morph into a more durable form (such as a diagnosis of health anxiety) if the patient fails to accept the clinician’s misattribution as a sufficient explanation for their symptoms.

Typology of S-DOS

We identified circumstances and types of misattribution which appear to have quite often led to S-DOS with a substantial detrimental impact on the diagnostic process. These include:

- (1) *Negative misattributions, unconnected symptoms, and medical mysteries.* A principal facilitator of negative misattributions, such as “nothing seriously wrong”, was a failure to connect multiple symptoms as possible indicators of an underlying systemic condition, a failure also noted in other studies.³⁰ Even when the symptoms were connected, it was often as the assumed manifestations of a psychological illness. In other cases, clinicians were reported to have been content to leave the symptoms and/or the patients as an insoluble “medical mystery”.
- (2) *Diagnostic roadblocks.* Mental health, psychosomatic, ME/CFS and fibromyalgia diagnoses – sometimes based upon the misattribution of the symptoms of undiagnosed SLE – had a particular tendency to stall the SLE diagnostic process. That these diagnoses were difficult to challenge, but relatively easy to make, contributed to their power to overshadow. For example, consistent with the literature,³¹ fibromyalgia was frequently diagnosed without a full history or exam.
- (3) *Moral misattributions.* These entail clinicians erroneously attributing symptoms or patient conduct to presumed blameworthy patient motivations and/or behaviour (such as being “difficult” or “faking” symptoms).

Moral misattributions can disrupt the diagnostic process through undermining patient help-seeking and/or clinician help-giving. Some patients, for instance, reported being

treated as less deserving of help on account of being regarded by clinicians as in part to blame for their symptoms. This seems consistent with Weiner's attribution-emotion-action model.³² In addition, consistent with studies of self-stigma,³³ some patients appear to have internalised moral misattributions (such as thinking that maybe they were "malingering"), which left them feeling less able to push for further investigations. Moral misattributions could also draw on or add to power imbalances. For example, with several (at the time) children, the misattribution of SLE symptoms to "laziness" seems to have reduced their social standing with and support from the medical system and family.

These findings highlight the negative impact of DOS on quality of care and outcomes, as well as providing examples of DOS entailing "epistemic injustice".³⁴

Participant insights and the literature suggest some possibilities for addressing S-DOS. For instance, the reported clinician reluctance to make an SLE diagnosis, for fear of autoimmune medication related risks, seems consistent with an omission/inaction bias,³⁵ and so may be amenable to "cognitive debiasing".³⁶ Other problems and related solutions – such as improving clinician autoimmune knowledge³ and longer consultations³⁷ – could also be pertinent. In addition, there appeared to be important medical system issues. Of particular note, whilst GPs as gatekeepers can be critical in reaching a correct diagnosis,³⁸ patient reports indicated that GPs may not in general actively plan, coordinate or drive forward the diagnostic process. This may, for instance, help explain why momentum tended to stall with a negative Multiple Sclerosis test, rather than it leading to the next step in the differential diagnosis. It may also be why patients were often left to advance their own diagnostic journeys, which could lead to clinician perceptions of them as difficult and/or to a health anxiety diagnosis.

Strengths and limitations

Whilst qualitative methods were well suited to identifying S-DOS processes,¹⁹ it would be useful if future research could explore their frequency across a more representative sample of SLE patients. Purposive sampling of participants to interview (from survey respondents) helped to ensure a reasonable range of interviewee characteristics, including length of diagnostic journey. Nonetheless, shortfalls in survey representativeness could (even from a qualitative perspective) limit the "transferability"³⁹ of our findings. These shortfalls included sampling biases arising from having recruited through online support groups and there being a considerable under-representation of survey respondents who were male or non-white. This is of particular importance, as SLE symptomology and healthcare experiences can vary with gender and ethnicity.⁴⁰ In addition, whilst participants reporting an SLE diagnosis on their

clinic letter was an inclusion criteria, there was in most cases insufficient symptom information to verify the SLE diagnoses. There may also have been significant recall bias.

A major limitation of our S-DOS analysis was that it was based on patient perceptions alone. Some participants may have misinterpreted clinician attributions and some reported misattributions of SLE symptoms could have been correct attributions of non-SLE symptoms. Further, no one can be an entirely neutral observer of their own diagnostic journey. This, however, appears to have been more of an issue with broader patient judgements than with event specific information (such as whether fibromyalgia was diagnosed without a physical exam), and it was the latter type of information that our analysis focussed on. It is also important to acknowledge the potential for bias arising from researcher "positionality".⁴¹ This was mitigated by the study team having a broad mix of characteristics (e.g. clinicians, academics and autoimmune patients), and through reflexivity practices.⁴¹ Nonetheless, other groups of authors may have interpreted the data differently. Another limitation is that we did not explore in any detail whether the experiences of participants diagnosed more than a decade ago differed from those with a more recent diagnosis. In addition, we had limited data on comorbidities. More details on the data collection limitations are reported elsewhere^{3,21,22} and more on the analysis limitations are provided in [Supplemental Material \(section 3\)](#).

Our study provided valuable patient-data derived insights into some of the principal causes and consequences of SLE symptom misattributions across our study cohort. However, further research – including with clinician interviews and more representative samples – is needed before our findings can be regarded as other than provisional if generalised/transferred to different and larger groups of SLE patients.

Conclusions

Our study suggests that diagnostic delay and sustained DOS (S-DOS), which appear to be common in SLE, need to be understood as in part the result of patient-clinician attitudes, motivations and interactions, and that misattributions can contribute to and arise from all of these. In addition, the factors that seem to contribute to S-DOS in SLE, such as the prevalence of neuro-psychiatric symptoms, also occur in other autoimmune diseases. Therefore, whilst the literature tends to focus on DOS in mental illness, our study suggests that it could be an equally powerful force across a wide range of autoimmune diseases.

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Author contributions

MS conceived and planned the 2018–2021 Cambridge University SARD studies (with contributions from DC, RH, CW and others); MS obtained funding and ethics approval; MS conducted the interviews and distributed/administered the surveys; MS, RH, DC, CW and others designed the surveys; RH conceived the diagnostic overshadowing study; RH, MS, DC, and CW developed the study aims; RH and MS sampled the data; RH analysed the data, with MS second-coding a sample; DC and CW contributed clinical advice on the analysis; RH wrote the first and subsequent drafts of the manuscript; MS, DC and CW reviewed and edited the manuscript; and all authors approved the final version.

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Data Availability Statement

Additional anonymised data, including that showing the development of concepts, is available on request.

Supplemental Material

Supplemental material for this article is available online.

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