EXTENDED REPORT

"Joining the dots" for patients with systemic lupus erythematosus: personal perspectives of health care from a qualitative study

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Objectives: To examine the perceptions of patients with systemic lupus erythematosus (SLE) about their health care provision in the United Kingdom.

Methods: Semistructured interviews were conducted with 10 women aged 26 to 68 years who were diagnosed with SLE one to 12 years earlier. Interviews were audio recorded, transcribed verbatim, and analysed using interpretative phenomenological analysis to organise the themes of importance to participants.

Results: Four themes emerged: diagnostic difficulties; understanding; communication; and integrated health care. Before diagnosis there was concern to appear legitimately ill and to have a label for the condition. After diagnosis participants still encountered health care professionals who were poorly informed about SLE. Family, friends, and employers did not understand the fluctuating nature of SLE, which often led to isolation. Participants felt that even health care professionals who specialised in SLE could not fully understand the psychosocial impact of the condition, and therefore did not provide information to meet those needs. Participants did not know which of the many health care professionals they had contact with to approach about their concerns. Lack of communication at an interdisciplinary level left them feeling that nobody was "joining the dots" for their health care.

Conclusions: Patients with SLE do not feel understood by health care providers or people close to them. Support from trained volunteers with SLE, as available at the open access lupus clinic in Dudley (West Midlands, UK), would ensure more adequate information from someone with personal experience. Such services may improve communication and help minimise SLE patients' isolation.

Patients with complex chronic diseases such as systemic lupus erythematosus (SLE) live with an uncertain future because their disease may fluctuate or progress in severity. The SLE patient's health care team needs to be aware of the continuing biopsychosocial impact of the condition.^{1–3}

Differing views on the required outcome and the appropriate treatment can affect patient satisfaction and their adherence to recommendations in the general practice setting^{4–5} and for patients with rheumatic diseases such as rheumatoid arthritis.^{6–8} This is probably because failure to provide appropriate information to rheumatology patients can result in distress, confusion, and disillusionment with the health care provider and the treatments offered.^{9–10} In the case of patients with SLE this may be compounded by receiving treatment from different health care specialties.¹¹

At present, specific evidence is limited but suggests that SLE patients need to develop a partnership with their health care providers to optimise communication and ongoing wellbeing.¹² Working within a biopsychosocial framework,¹³ considering internal (psychological) and external (social) features, we aimed to obtain personal accounts of SLE patients' experiences with a range of health care services within the NHS to provide localised evidence and stimulate international interest.

METHODS

Our study employed a qualitative approach using interpretative phenomenological analysis (IPA),^{14–16} which facilitates understanding of how patients perceive their illness and the

health care services.¹⁷ The study received ethical approval from Walsall local research ethics committee.

Patients with confirmed SLE¹⁸ were recruited from two sources within the Dudley Group of Hospitals NHS Trust (West Midlands, UK). Consecutive patients with SLE who attended the first two months of an open access lupus clinic (the Dudley Lupus UK Drop-In Clinic) were invited to take part in the study; five participants were recruited this way. Additionally, consecutive SLE patients were invited to participate during a routine outpatient appointment with their consultant rheumatologist. Another five participants were thus recruited. Study information sheets were provided to all potential participants, and all patients who were approached agreed to participate.

The 10 participants had been diagnosed with SLE for one to 12 years. Disease activity data are not presented because the participants discussed health care before and after diagnosis, so no uniformly representative set of data could be composed. Moreover, the level of disease activity should not add or subtract any value from the participants' views and experiences described.

All participants were white women aged 26 to 68 years. The population within the Dudley area is predominantly white (94%)¹⁹ and women are more likely than men to develop SLE.²⁰ SLE patients attending the Dudley Group of Hospitals reflect these statistics in the same way as our sample. Therefore, the present sample is broadly representative of

Abbreviations: IPA, interpretative phenomenological analysis; SLE, systemic lupus erythematosus

Table 1 Demographic information of the individual participants and summary statistics

Participant (pseudonym)	Age (years)	Marital status	Children (<18 years)	Employment status	SLE duration (years)
1 (Maud)	68	Widow	0	Not employed (retired)	12
2 (Brenda)	56	Widow	0	Employed (part time)	4
3 (Sally)	35	Single	0	Not employed (unable)	3
4 (Claire)	53	Married	0	Employed (part time)	1
5 (Grace)	54	Married	1	Not employed (unable)	7
6 (Alison)	32	Cohabiting	2	Not employed (unable)	1
7 (Katrin)	42	Married	2	Employed (part time)	4
8 (Stephanie)	26	Single	5	Not employed (homemaker)	7
9 (Jessica)	59	Widow	0	Not employed (retired)	6
10 (Sophie)	47	Married	0	Employed (part time)	9
Mean	47.20	–	1	–	5.40
Median	50	–	0	–	5
Mode	–	Married (50%)	0 (60%)	Not employed (60%)	1, 7 (20%)

SLE, systemic lupus erythematosus.

local people with SLE and is likely to highlight issues of importance within the local area. Further demographic information is summarised in table 1. In the table and in all quotes the participants have been given pseudonyms.

Informed consent was obtained from all participants before the interview. The interviews were conducted by one female researcher (EDH) and lasted between one and two hours. A semistructured interview schedule was employed to allow flexibility, individual contextualisation, and probing of issues that arose.²¹ Consistent with IPA research, the participants were the experts and researchers enable the process and seek to represent participants' views.²¹

Following established methodology, all interviews were transcribed verbatim and analysed using IPA.^{14–16} IPA proceeds on two levels of analysis—the descriptive (phenomenological) and the explanatory (interpretative). Each transcript was read and annotated for clarification. Following this, the first interview was analysed by noting any key words, language, explanations, or associations. This process was repeated with each transcript. This led to the development of four overarching themes or topic areas that seek to represent a cohesive interpretation of participants' experience of health care.

The main method by which a qualitative inquiry like IPA is validated is to report specific instantiations of the theme directly from transcripts.²² However, it is the issues and explanations themselves that are important, not the number of times a specific view is expressed.²³ To ensure interpretative reliability, the interviewer contacted participants after analysis and confirmed the themes. Two of the other authors (GJT and GDK) also read the transcripts, and the fourfold thematic analysis was discussed and corroborated.

RESULTS

In this section we present the four recurring themes that emerged from the analysis of all of the 10 women's experiences and perceptions of health care provision for their SLE.

“Searching for an answer”: theme 1 (diagnostic difficulties)

Owing to the nature of SLE, many of the women had seen several specialist health care providers from various disciplines, as well as their general practitioner (GP). The interactions leading up to a diagnosis of SLE had often been difficult. Participants felt they were treated as “malingering” because of their frequent visits to their GPs when no specific diagnosis could initially be found:

“... I kept going and they kept giving me blood test after blood test... he [a junior doctor in rheumatology] said ‘Well we just don’t know what’s the matter with her.’... he said ‘The trouble is, Sophie, if we keep sending you for tests like this we’ll end up having you put away.’...” (Sophie.)

Obtaining a diagnosis meant their illness was now legitimised by an official label:

“... I think it was just the relief of knowing they knew what it was...” (Sophie.)

“Nobody can understand”: theme 2 (understanding)

Once the diagnosis of SLE was established, there was a general feeling that GPs and health care providers not specialising in this disease lacked basic understanding. Sisters Jessica and Sophie (who both had SLE and were interviewed simultaneously) recalled a recent visit to the emergency department:

Jessica: “He [the treating doctor] said ‘Has she got impetigo?’”

Sophie: “And I said ‘No, she hasn’t, it’s discoid lupus’, [the treating doctor replied] ‘Well, is it catching?’”

Such interactions undermine patients' faith in the health care providers' knowledge. All of the participants also commented on how difficult it was for other people to understand what it was like to have SLE. As SLE is rare, participants found it difficult to explain to others. Lack of understanding about the fluctuation of symptoms and the impact this has on day to day functioning was a particular issue: there was an ongoing need to appear “legitimately” ill. Changes in the balance of relationships created tension as the women struggled to continue previous roles:

“... he’ll snap at me and say ‘Bloody hell you can go to work and you haven’t done anything [at home].’ and all the rest of it. It isn’t very often he does it, but you’ve got to sympathise with him in a way because it’s not only my life that’s changed, it’s his as well and probably to a greater degree...” (Claire.)

Concerns about the level of understanding contributed to participants' feelings of isolation. Sally, single and living

alone, relied on her parents for support when she was unwell. However, she felt her mother could not grasp the difficulties her SLE posed for her on a practical and emotional level. She had therefore resorted to taking her mother into consultations in the hope of forcing some understanding:

“... she [her mother] knows what lupus is all about and the symptoms but I don’t think she sort of puts it into like reality of having to live it... it’s as if she takes it in but she sort of doesn’t put it into practice, you know, of what it is I have to go through...” (Sally.)

It appears that patients like Sally have an unvoiced agenda that is a plea for understanding from both the family and health care provider.

“Are they really listening?”: theme 3 (communication)

Communication was a major issue within health care interactions, particularly concerning the flow of information from health care provider to patient. All participants expressed disappointment with the information received from their GPs and their specialist health care providers. Reflecting this, many of the women found it difficult to give the exact name of SLE:

“... I don’t know I just can’t pronounce it...” (Grace.)

The participants felt they needed a health care provider to sit down with them to explain their condition and answer questions about causality, treatment, and progression:

“I think when they first tell you you’ve got it, it’s no use somebody telling you you’ve got it and giving you a leaflet, I think you need to be taken somewhere and sat down and really talked to about it... I mean they deal with it every day and I think sometimes they forget the impact it has on somebody...” (Claire.)

Dissatisfaction was expressed about the information contained in the leaflets that were available:

“... every information leaflet I’ve picked up says mainly the same... but they can’t experience it’s hard to live with...” (Alison.)

Generally, more information was required about self help strategies and points of contact. In clinical settings, participants said they found that their lupus specialists were too time pressured to be interested in their problems and doubted that they really listened to them or understood the psychological and social consequences of their condition:

“... you tell them all what’s been happening, what’s on your mind then half the time you think ‘Have they listened to that, have they took in what I’ve just said?’ or, you know, ‘Are they really listening?’” (Sally.)

Poor communication with their health care providers and lack of adequate, tailored information, meant that many of the women were ill informed about their SLE and had many underlying fears that had not been addressed. Several of the participants expressed concern that their SLE would prove fatal but were unsure how likely this was or how much time they had ‘left to live’.

“Joining the dots”: theme 4 (integrated health care)

The women felt that there was a lack of cohesion in their health care. Often, the women said that because so many people were involved in their health care, they did not feel that anyone got to know them sufficiently well. The women felt that they had no specific point of contact with whom they felt comfortable enough to discuss issues in any depth. Often they were seen by a registrar rather than the consultant, which is common practise within the British NHS.²⁴ However, the registrar was referred to as the “understudy” by one participant (Sophie), which underlines the women’s feeling that they were not seen as important. Several of the participants noted that no-one seemed to be joining the dots and integrating their health care:

“... it’s not as if you can talk to one person [health care provider], you’ve got all these different people and somehow along the line they never all link up.” (Sally.)

Participants felt that specialists with different health care disciplines did not always communicate effectively with each other, and often no-one would commit themselves to confirming that a new symptom was part of their systemic disease or not:

“... if somebody had told me that was part of it I could have put it on a back burner instead of pushing my doctor to send me somewhere to sort it out... nobody would actually commit themselves to say it. I’ve read it in a book now...” (Katrin.)

Participants also admitted to experimenting by ceasing drug treatment or not seeking help when needed because the health care providers “... wouldn’t do anything...” (Sally.) Only one participant described concordance²⁵ where she discussed her condition with her consultant “... and we take it from there.” (Stephanie.)

DISCUSSION

We explored British SLE patients’ personal perceptions of their health care provision using an interview based qualitative approach. We discovered the difficulties that SLE patients might experience in obtaining health care services appropriate to their needs, including the personal perception that they had not received enough information about psychosocial issues or potential future disease progression. This may arise from a lack of cohesive health care for SLE, poor communication between health care providers and patients, or a lack of understanding of the nature of SLE and its biopsychosocial impact by health care providers as well as patients’ family, friends, and colleagues.

Unvoiced (and therefore unmet) patient agendas are problematic, although patients will explain these to health researchers.⁴ Commonly unvoiced concerns include worries about symptoms, tests, drugs, and prognosis. Unless patients are explicit, health care providers have trouble recognising their need for information and support. Unmet expectations can lead to a defeating circle of negative expectations for each future encounter.⁹ When patients feel they are given enough written and verbal information their satisfaction with services is higher.²⁴ This is likely to be a universal phenomenon, irrespective of the rheumatic disease or exact health care system.²⁶

Other qualitative studies indicate that information on SLE from leaflets and the internet can initially frighten new patients.¹⁰ Seeing patients as partners in health care decision making is essential in order to redress the unequal balance of power between patient and health care provider and hence

allow them to reach concordance.²⁵ Our participants did not generally describe such interaction, in contrast to findings of frequent concordance among rheumatoid arthritis patients in a larger British interview study,⁷ although that study focused on health care specifically provided by rheumatology health care professionals and may have been influenced by being carried out by an integral member of the patients' health care team. Our participants often felt inappropriately informed by health care providers (particularly the GP), who were unsure about SLE. This is unlikely to be particular to the UK, because mixed health care for SLE provided by generalists and specialists is certainly a feature in many European and North American countries.^{27–28}

A particular difficulty noted by our participants, and apparent in complex chronic diseases like SLE, is the number of health care providers with whom they come into contact. Participants also disliked seeing different health care providers within a specific discipline, a common complaint within the British NHS.²⁴ Moreover, participants felt there was a lack of communication at an interdisciplinary level, which compounded problems with understanding. Often participants felt that no one was joining the dots to provide cohesive health care. Like many European and North American hospitals, British NHS units have generally good systems of interdisciplinary communication, including formal letters from specialist to specialist and the GP and specialised combined clinics. However, feelings that health care is not coordinated may be an even bigger problem in countries with less developed health care services, and is likely to be more related to how effective any communication is with the patient rather than between the health care professionals. Further research on interdisciplinary health care and how this can be implemented effectively would be informative for all rheumatic diseases.

In the present study we focused on women with SLE, who form the majority of patients.²⁰ Although the issues raised by the women are likely to extend to men with SLE, there may be sex specific concerns—for example, related to seeking health care, employment, and masculinity. These should be considered in future sex specific studies.

The present sample of SLE patients was purposefully small and geographically localised. This is common in qualitative research, where the objective is to explore in detail the experiences of a defined group.¹⁵ When larger sized samples are interviewed the data can become unwieldy and the level of the resulting qualitative analysis is often more descriptive than explanatory. While this can provide useful enumeration of content^{7–10} it was not the objective of the present study, which sought to obtain understanding of the experience of health care for patients with SLE. The 10 women interviewed brought a variety of experiences, which, when analysed in depth, indicated four overarching themes. We did not seek data saturation—this can never be truly achieved because every patient has individual experiences. The purpose and value of qualitative research lies in the potential conceptual generalisation.²⁹ Specific findings may not generalise, particularly in countries with different health care systems to the British NHS, and even across regions of Britain. However, the themes that arose in the present interviews may be found to generalise more broadly if the study is replicated internationally. The main reason for this is because the themes arise from how patients perceive their health care and as such may be generic, irrespective of the exact health care system. We would encourage international replication of the methodology we used to examine this.

The present study is a first step towards understanding issues involving health care interactions that are important to women with SLE, and concurs with other recent research; Sawyer's audit of an SLE clinic in Southampton (UK) also

found that patients require support, education, and the opportunity to ask questions.³⁰ Findings from one health care setting may be used more widely, even in the international arena. For example, we would suggest that one potential way in which to resolve some of the issues identified in the present study would be to learn from and extend an interdisciplinary approach for SLE patients carried out in the USA by Crane and colleagues.¹¹ Their rheumatology nurse coordinates assessments of SLE patients and ensures that findings gathered by team members are discussed and explained to the patient at case conferences. A similar model is now being advocated by the UK Department of Health through a new post called the community matron, who will act as case manager for patients with chronic illnesses.³¹ We suggest that it may be difficult for these nurses to have expertise in all chronic conditions—exactly the problem participants expressed about GPs in the present study. Clinical nurse specialists in rheumatology may be better placed to act as the case manager for SLE patients in the following ways: first, by providing referral to appropriate medical specialists and allied services; second, by centralising all test findings and actively coordinating treatment recommendations from these specialists (to facilitate concordance and directly provide prescriptions); third, by disseminating and reinforcing only pertinent and understandable information required by patients (as well as all involved health care providers); and fourth, by monitoring patients' ongoing well-being, satisfaction, and understanding (feeding back to the first three points) through regular contact. This could be face to face or over the telephone, and either initiated by the case manager at set intervals or by the patient when a query arises. Clinical nurse specialists in rheumatology may already take on this case management role,³⁰ but formal recognition, funding, and international guidelines are required to facilitate the ongoing development of health care services for SLE patients.¹¹

Previous research has established internationally that self management education which provides SLE patients with information about coping with their condition is of benefit.^{1–3–32–36} On the basis of our findings, we propose that one possible approach to optimise outpatient care for people with SLE would be the combination of coordinated interdisciplinary health care with an open access hospital based service that is available monthly for SLE patients in Dudley (UK). The Dudley Lupus UK Drop-In Clinic offers information and talks on patient selected topics. Signposting and support for SLE patients (and their carers) are provided by trained volunteers (who have SLE themselves) and allied health care providers, including psychologists. This service is in addition to our standard lupus clinic, led by one rheumatology consultant and nurse with combined discipline appointments available. Specific care pathways are being developed to integrate these services and link them back and forth with primary and tertiary care. Such an overall concept could be adapted to the particular conditions of other health care systems, with its success evaluated in that context.

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