

Understanding the impact of Systemic Lupus Erythematosus on work amongst South Asian people in the UK

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DOI:

[10.1177/09612033211022816](https://doi.org/10.1177/09612033211022816)

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Document Version

Publisher's PDF, also known as Version of record

Citation for published version (Harvard):

Ubhi, M, Dubey, S, Gordon, C, Adizie, T, Sheeran, T, Allen, K, Jordan, R, Sadhra, S, Adams, J, Daji, R, Reynolds, J & Kumar, K 2021, 'Understanding the impact of Systemic Lupus Erythematosus on work amongst South Asian people in the UK: an explorative qualitative study', *Lupus*, vol. 30, no. 9, pp. 1492-1501. <https://doi.org/10.1177/09612033211022816>

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Understanding the impact of systemic lupus erythematosus on work amongst South Asian people in the UK: An explorative qualitative study

Lupus

0(0) 1–10

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DOI: 10.1177/09612033211022816

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Abstract

SLE has a range of fluctuating symptoms affecting individuals and their ability to work. Although South Asian (SA) patients are at increased risk of developing SLE there is limited knowledge of the impact on employment for these patients in the UK. Understanding ethnicity and disease-specific issues are important to ensure patients are adequately supported at work. Semi-structured interviews were conducted with patients of SA origin to explore how SLE impacted on their employment. Thematic analysis was used to analyse the data which are reported following COREQ guidelines. Ten patients (8 female; 2 male) were recruited from three rheumatology centres in the UK and interviewed between November 2019 and March 2020. Patients were from Indian (n = 8) or Pakistani (n = 2) origin and worked in a range of employment sectors. Four themes emerged from the data: (1) Disease related factors; (2) Employment related factors; (3) Cultural and interpersonal factors impacting on work ability; (4) Recommendations for improvement. Patients' ability to work was affected by variable work-related support from their hospital clinicians, low awareness of SLE and variable support from their employers, and cultural barriers in their communities that could affect levels of family support received. These findings highlight the need for additional support for SA patients with SLE in the workplace.

Keywords

Systemic lupus erythematosus, lupus, South Asian, ethnicity, employment

Date received: 5 January 2021; accepted: 10 May 2021

Introduction

Systemic Lupus Erythematosus (SLE) is an autoimmune inflammatory disease that disproportionately affects young women (90% of patients are female) and has a broad range of presentations and clinical trajectories which can present challenges to diagnosis and treatment.¹ Pain, joint stiffness, fatigue, and cognitive dysfunction can fluctuate with flares, relapses, and remissions, and greatly affect quality of life despite advances in new therapies.^{1,2} Patients with SLE can become work disabled (unable to work due to illness) within the first few years of diagnosis as a result of their condition.^{3,4} Many patients are required to make adjustments at work or change their job type, and can struggle to fulfil their potential in terms of income

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generation, job satisfaction and career progression, leading to financial difficulties and loss of self-esteem.⁴⁻⁶

Ethnicity is a risk factor for both the development and impact of SLE. Women of African- Caribbean origin have the highest incidence and prevalence of SLE in the UK, followed by people of South Asian (SA) origin, a term which represents people with ancestry in the Indian subcontinent, who account for 5.3% of the UK population (Indian 2.5%, Pakistani 2% Bangladeshi 0.8%).⁷⁻¹⁰ The impact of SLE on SA patients is particularly marked as this group are likely to develop more severe disease compared to Caucasian patients.^{8,9,11,12} Work conducted in Manchester (UK) identified that 27% of SLE patients of SA origin developed lupus nephritis compared to 10% of patients of white British origin.¹¹ An inception cohort SLE study carried out in Birmingham (UK), of which 21% of patients were SA, showed that the mean age at recruitment was 36.3 (S.D 13.3) years, relevant as patients were of working age.¹³ Moreover, our previous work identified that SA patients had more concerns about SLE treatments than white British patients, considering them as overused and harmful, often depending on their beliefs about the causes of SLE.^{14,15} The language barrier between non-English speaking SA patients and their clinicians can create a barrier to providing culturally-sensitive information, resulting in distress, confusion, and disappointment with the health care provider.^{14,16} In terms of data on the impact of SLE on work in ethnicity, there is very limited evidence. There are a number of studies which have investigated the impact of SLE on work, predominantly from the USA.^{3,4,6,17,18} There are a smaller number of European studies. In a large European cohort survey 69.5% of respondents reported that SLE affected their careers; 27.7% changed careers within one year of diagnosis.⁵ A patient and carer survey in the UK (of which 39% patients were employed), highlighted that SLE affected patients' ability to work, and patients required financial support such as disability benefits.¹⁹ In a UK online survey all 393 patients reported a detrimental impact of SLE on their careers; 40.45% had become work disabled.² Importantly, none of these studies explored work-related issues in depth with patients of SA origin.

The main aim of this qualitative study was to understand the impact of SLE on the working lives of patients of SA origin and to explore ways to improve the situation.

Methods

Patient selection and recruitment

Inclusion criteria included: (1) a clinician diagnosis of SLE requiring medical treatment, (2) self-reported SA

origin, (3) currently in paid employment or stopped work due to SLE within the last 12 months, and (4) aged 18 years or over.²⁰ Patients were recruited between November 2019 and March 2020 from three SLE outpatient clinics in the West Midlands, UK, where British Asians (Indian, Pakistani, Bangladeshi) represent 8.9% of the general population yet account for over 20% of SLE patients.^{10,13} University Hospitals Coventry and Warwickshire NHS Trust, Royal Wolverhampton NHS Trust, and Sandwell and West Birmingham NHS Trust. Ethical approval was granted by The Yorkshire and The Humber – Leeds West Research Ethics Committee (19/YH/0259).

Data collection and analysis

Data are reported in line with the COnsolidated criteria for REporting Qualitative research (COREQ)²¹ (see Supplementary Material File 1). Semi-structured in-depth interviews guided by a pre-specified topic guide (see Supplementary Material File 2), were carried out by a bilingual research associate (MU). The topic guide was developed and agreed with a SA patient partner (RD) introduced by Lupus UK to promote patient and public involvement, prior to study recruitment. Topic areas explored the impact of SLE on work roles; discussions with employers and clinicians regarding SLE and work; the impact of SLE on work-life balance; and future information needs. Finally, patients were asked their opinions regarding the likely usefulness of an educational video on the Lupus UK website in the commonest SA language (Hindi), and the content they would find useful in this resource. Patients completed demographic and study questionnaires at the time of clinic visit. Physical activity was measured using the General Practice Physical Activity Questionnaire (GPPAQ) a short self-report measure where calculated scores are converted into a 4-level Physical Activity Index.²² HRQoL was measured using the 34 item LupusQoL questionnaire, designed for specific use in SLE.²³ Median scores were calculated for each of the eight domains where higher scores indicate better HRQoL with a range of 0 (worst) to 100 (best).

All interviews were audio-recorded and typed by an independent transcribing company. Transcripts were analysed using thematic analysis and QSR NVivo 12 software was used to organise and manage the data.²⁴ KK and MU undertook independent line by line coding of each of the 10 transcripts. Using data analysis guidelines, MU provided RD with training in qualitative data analysis.²⁵ Meetings were conducted within the research team, including RD, to discuss codes and develop themes. All authors were asked to verify agreement with themes and subthemes, and to ensure that none were missing following review of the transcripts.

Results

Patient recruitment and characteristics

Seventeen patients were approached to take part in the study, of whom 15 patients consented. Three patients changed their mind when contacted by telephone to arrange appointments, and two were not contactable. Ten patients participated in the interviews (Coventry $n = 3$, Wolverhampton $n = 5$, Birmingham $n = 2$). The target to interview 20 patients was not achieved due to the emergence of COVID-19. Patients were offered the opportunity to be interviewed in SA languages (Punjabi, Urdu, Hindi) but all patients chose to speak in English. Interviews lasted around 45 min, and took place either face-to-face at hospital clinics, or over the telephone.

Demographic characteristics of patients who took part are detailed in Table 1. The majority ($n = 8$) of patients were female, and from either Indian ($n = 8$) or Pakistani ($n = 2$) background. Half of all patients were educated to degree level ($n = 5$). The median age of patients was 43.5 (range 23–58) years and median duration of disease 12.5 (range 0.25–33) years. All patients were employed at time of interview; six in full-time and four in part-time employment. One patient rated their health as “very good”, two patients as “fair”, six patients as “good”, and one patient as “very bad”. Of those working part-time, three had reduced their full-time hours due to SLE. Patients worked in a range of public and private employment sectors such as medical, professional, administrative, manufacturing, and retail. Eight patients reported consulting a healthcare professional (GP, nurse, or pharmacist) in the 14 days prior to interview, and only one patient had been admitted to hospital due to infection in the previous year. Seven patients reported a median of 9 (range 1–60) sick days due to

SLE during the previous 12 months, and three patients reported consulting a healthcare professional regarding stress, anxiety or depression during the same time period.

All domains of the LupusQoL were classified as “impaired”, as shown in Table 2. Fatigue was the most affected domain with the lowest median score of 37.5, followed by intimate relationships with a median score of 43.8, and body image with a median score of 45.8, indicating poorer quality of life in these areas, although all domains can be considered low. Pain was the highest scoring domain with a median score of 70.8 suggesting that pain was not driving the other low scores. Only 40% of patients achieved the Government recommended levels of physical activity (GPPAQ).²²

Interview data

The four main themes and subthemes emerging from the data are presented in Table 3 below, with reference to patient quotations provided in Table 4.

Table 2. LupusQoL scores.

Domains	Median (range)
Physical health	54.69 (25, 90.63)
Pain	70.83 (16.67, 100)
Planning	50 (0, 100)
Intimate relationship	43.75 (0, 100)
Burden to others	50 (0, 91.67)
Emotional health	56.25 (4.17, 87.5)
Body image	45.83 (5, 100)
Fatigue	37.5 (12.5, 93.75)

Higher scores indicate better HRQoL with a range of 0 (worst) to 100 (best).

Table 1. Demographic information of patients interviewed.

Patient ID	Gender	Level of education	Age (years)	Country of birth	Ethnicity	SLE duration (years)	Employment sector	Years in employment	Working pattern
P1	F	GCSE	55–59	Kenya	Indian	33	Retail	15+	Part time
P2	M	Other – Class 10	40–44	Pakistan	Pakistani	13	Catering	6–10	Part time
P3	F	Degree	45–49	UK	Indian	12	Local Government	3–5	Full time
P4	F	Degree	30–34	UK	Indian	17	Administrative	6–10	Full time
P5	M	A Level	50–54	UK	Indian	12	Manufacturing	3–5	Full time
P6	F	A Level	50–54	UK	Indian	26	Catering	6–10	Full time
P7	F	Degree	40–44	UK	Indian	13	Customer service	15+	Full time
P8	F	A Level	20–24	UK	Indian	0.25	Customer service	1–2	Part time
P9	F	Degree	30–34	UK	Indian	10	Skilled	6–10	Full time
P10	F	Degree	44–49	UK	Pakistani	5	Medical	<1	Full time

Table 3. Themes and subthemes that emerged from the data.

Themes	Subthemes
Theme 1: Disease related factors affecting work ability	1.1 Fluctuating symptomology 1.2 Clinician support 1.3 Lack of disease specific work information at diagnosis
Theme 2: Employment related factors affecting work ability	2.1 Employer support 2.2 Workplace adjustments 2.3 Occupational health 2.4 Future career plans
Theme 3: Cultural and interpersonal related factors affecting work ability	3.1 Lack of awareness 3.2 Fear of stigma in the wider community 3.3 Family support
Theme 4: Recommendations for improvement	4.1 Clinician discussion 4.2 Employer campaign 4.3 Video resource

Table 4. Patient quotes throughout the text.

Quote reference in text	Patient quote
Quote 1	I can't just keep bringing just lupus into to it, they think that's an excuse. If I need some time off work because I'm aching, they consider it as fake. (Patient 1, female, 55–59 years)
Quote 2	I am very wary about the hospital appointments. Now, I just take that as annual leave because I am scared what employers will do. (Patient 10, female, 44–49 years)
Quote 3	My joints were all swelling up and I can't stand for long. I can't sit for long time. Then the doctor told me that you have to quit that job. So I did that at the time. Two years I didn't work at all. (Patient 2, male, 40–44 years)
Quote 4	When I was first diagnosed. . .there was very little information on how this affects your body and work. (Patient 9, female, 30–34 years)
Quote 5	I didn't know it would mean I'd need to take time off work. I didn't know what the symptoms were or how the medication would affect me. (Patient 8, female, 20–24 years)
Quote 6	It was just one page with very little information– you can't really take that to an employer. They would still ask me what I needed, and I didn't have a clue. (Patient 8, female, 20–24 years)
Quote 7	I did take information in, to ask them to read it, but they haven't got time, they just put them in the folder, I don't know. I do keep mentioning to them about lupus, but either they aren't interested or what, they just say "yes we do know". (Patient 1, female, 55–59 years)
Quote 8	I have got really good managers. Say if I came into work not feeling well, I tend to go back home and work from home rest of the day. (Patient 4, female, 30–34 years)
Quote 9	I mean obviously you struggle financially (to go part-time). But it's either that, or struggling with lupus and full-time work, and being ill all the time. (Patient 6, female, 50–54 years)
Quote 10	I even suggested at one point "can I juggle my hours so that I'm not that stressed in the morning to get to work", and that was denied. . . I found them to be so unsupportive. So I just had to hand in my notice because I couldn't put up with it any more. (Patient 10, female, 44–49 years)
Quote 11	Yes, a phased return. I had to increase by an hour a day, that was excellent. There was no way I was going to start on an eight hour per day. (Patient 5, male, 50–54 years)
Quote 12	I think "what will happen if I am not able to work?" I have very young kids you know. . . I don't have experience to do anything else, plus with my problems, I can't go to another trade now. . . if they sack me from here it will be very difficult. (Patient 2, male, 40–44 years)
Quote 13	It gives you that confidence and you look forward to getting out rather being stuck in the house. It gives a purpose doing something that you enjoy, and it takes your mind off your own health. (Patient 6, female, 50–54 years)
Quote 14	I think the Asian British can understand more, they can be more open minded and have computers to look things up. My parents or in-laws didn't look things up on the computer. It's like telling my parents about diabetes, I think it's difficult for them to understand, than the English speaking patients. (Patient 6, female, 50–54 years)

(continued)

Table 4. Continued.

Quote reference in text	Patient quote
Quote 15	But this is something I have to live with . . . I can't not tell anybody anything, and I wouldn't want to hide this from my in-laws. (Patient 8, female, 20–24 years)
Quote 16	I was born and bred this this country. I don't see that "oh I have to keep things in", like we have in our culture, where you can't tell anybody anything, I don't have that stigma. (Patient 10, female, 44–49 years)
Quote 17	I did have a very difficult time at the start of my marriage because I was living with my in-laws . . . that generation will never understand . . . they thought "oh you go to the doctors to have medication and then it's okay". It is a bit frustrating because they still want to you to go to places, and visit, and behave in a certain way. (Patient 6, female, 50–54 years)
Quote 18	So more guidance on what to tell the work people would be useful. It just said that I can carry on working with lupus, but I didn't know what I needed to change. If it did, I could have given that to my manager and said, "this is what I need." (Patient 8, female, 20–24 years)
Quote 19	I think most of the people in companies should understand what certain people suffer with, and what the symptoms are, and how it affects them at work. (Patient 1, female, 55–59 years)
Quote 20	I can read English, and even for me it was overwhelming. But it can also help our family members, like in my family, my mum can't write or read English. She can't speak in English. I can't speak Punjabi very well, so I can't relay that message of the condition to her. (Patient 8, female, 20–24 years)

Theme 1: Disease related factors affecting work ability

This theme collates patient views relating to SLE symptoms and their impact on work; the nature of discussions with clinicians; and the information received at diagnosis.

Fluctuating symptomology

Patients reported that symptoms such as fatigue and joint pain, both with fluctuating severity, caused difficulties for them at work. Due to the invisibility of these symptoms, some patients felt they would not be believed by their employers if they took frequent sick leave. These patients would go to work when unwell to avoid further sickness review meetings when absence parameters had been reached. Patients also reported taking frequent time off work for hospital appointments. They worried that employers and colleagues would question their ability to continue working, and were fearful of losing their jobs (Table 4, quotes 1 and 2).

Clinician support

Patients discussed work to varying degrees with their clinicians during routine appointments; ranging from no discussion, to attending a specific SLE clinic to discuss work issues with an occupational therapist (OT) and specialist nurse. Conversations that took place about work were mainly initiated by patients after requesting written support for workplace adjustments,

though occasionally by clinicians who asked patients to consider role changes or to stop working when the nature of the job exacerbated their symptoms (Table 4, quote 3).

Lack of disease-specific work information at diagnosis

Patients felt they were not given enough information about the impact that SLE could have on their employment (Table 4, quotes 4 and 5). Some were not made aware of the side-effects of new medication (such as drowsiness) which resulted in taking additional time off work, and sought further information from the internet. Furthermore, patients felt they did not receive sufficient information for their employers regarding how they could be supported in the workplace (Table 4, quote 6).

Theme 2: Employment related factors impacting work ability

This theme collates patients' views on support received from employers and occupational health (OH) departments at work; adjustments required to continue working; and future career plans.

Employer support

There was low awareness of SLE in the workplace, and patients felt it was their responsibility to educate employers using information from hospital clinics and the internet. Despite this, support still varied, and some

felt that employers did not engage with them adequately about how to accommodate SLE at work (Table 4, quote 7). Some patients who took additional breaks to manage their symptoms worked extra time to compensate, either for their “own peace of mind” or as they were asked to do so by their line manager. Patients who reported positive work experiences had sympathetic managers who made the effort to understand SLE and provide support where necessary such as instigating OH involvement for ergonomic office support, or appreciating that tasks may be carried out at a slow pace (Table 4, quote 8).

Workplace adjustments

All patients had asked for adjustments to manage their SLE, with most requesting home working, or changes to working hours. This was to accommodate their fluctuating symptoms or the sometimes long and frequent hospital appointments, though there were financial implications of reducing to part-time hours (Table 4, quote 9). Others had to change job roles as they could no longer carry out their usual tasks. Adjustments were not always granted, which patients attributed to low awareness of SLE. One patient’s request to adjust early morning start times was repeatedly refused as the manager did not want to be seen making exceptions in the workplace. This eventually led to the patient resigning (Table 4, quote 10).

Occupational health

OH was available in the workplaces of 9/10 patients and most received support when newly diagnosed, returning after absence, or starting a new job (Table 4, quote 11). However, patients were disappointed when OH could not assist in the way expected, for example being unable to suggest more suitable roles to accommodate SLE symptoms or resolve disputes with managers regarding reasonable adjustments.

Future career plans

Patients were concerned about their ability to continue working due to SLE symptoms and were afraid that repeated absences would lead to losing their jobs. Younger patients and those with family responsibilities worried about their future financial security (Table 4, quote 12). Despite concerns, patients wanted to continue working and discussed the benefits of work for their physical and mental wellbeing (Table 4, quote 13). Those who had disclosed their condition to colleagues received emotional and practical support, making it easier to remain at work.

Theme 3: Cultural and interpersonal factors

In this theme, patients discussed: the lack of awareness of SLE in the SA community; the stigma of having a health condition; and the importance of family support.

Lack of awareness

Patients discussed the lack of awareness in their families and SA communities. SLE was “new” and “unheard of,” making it difficult for others to appreciate. Generational differences were highlighted, with an assumption that the older generation would be unable to understand how symptoms of SLE could affect daily life, mainly due to the language barrier and limited access to the internet or other forms of information about SLE (Table 4, quote 14).

Fear of stigma in the wider community

There was reluctance in disclosing SLE to others outside of the immediate family. After learning that SLE can cause problems with conception and pregnancy, parents encouraged non-disclosure to future in-laws due to concerns that it might adversely affect their daughters’ likelihood of getting married. Patients recognised these concerns as coming from older family members and did not necessarily share those views themselves (Table 4, quotes 15 and 16).

Family support

Support from family members was instrumental in achieving a work–life balance and often came in the form of assistance with household chores. In most cases, patients who were able to remain in full time employment attributed this to the practical support received from their family, highlighting that without their assistance they would be unable to go work. Patients with limited support, particularly where SLE was not understood by parents or in-laws, struggled to manage their various responsibilities, and were unable to maintain full time work. Cultural norms within the SA community were cited, particularly the expectations of a daughter-in-law, and problems with meeting these expectations in addition to work responsibilities (Table 4, quote 17).

Theme 4: Recommendations for improvement

In this theme, patients highlighted the need for more SLE and work-related discussions with clinicians and employers, and reported a need for wider awareness,

noting that SLE-specific information was only available in the clinical environment.

Clinician discussion

Patients felt they would benefit from regular discussion with their consultants about work. Although leaflets were received at diagnosis to give to employers, many could not recall exactly what information was contained within. Some patients wanted more detailed information to explain the potential impact of SLE on their work, both for themselves and their employers (Table 4, quote 18).

Employer campaign

Patients felt that employers were well-placed to raise the profile of SLE amongst managers and colleagues. Suggestions included emails, leaflets, presentations, and an annual “road show” by Lupus UK to workplaces. It was important to patients that their condition was recognised in the workplace so that they could be supported appropriately (Table 4, quote 19).

Video resource

Patients were asked their opinion about the potential value of an educational video resource available in Hindi, on the Lupus UK website, to help raise awareness in the SA community. Patients were strongly supportive of this and felt it was a necessary resource due to the reported language barrier within multigenerational households. The benefit of this resource was especially recognised for non-English speaking family members to help understand the overall impact of SLE (Table 4, quote 20).

Discussion

Data from this pilot study demonstrate that SLE has negatively affected SA patients’ working lives. Work absences were evident and HRQoL was impaired across all SLE-specific domains, similar to that reported by SLE patients previously.²⁶ The most affected LupusQoL domain was fatigue, which was also emphasised by patients in the interviews as a problem that affected their ability to work. Scores for intimate relationships and body image indicated problems in these domains though did not feature in the interviews, possibly as these areas did not affect work-related issues for this group. Pain was the least affected domain at the time of the interview. This score, along with good self-reported physical and mental health, may explain the reason that these patients are currently in employment. The study design included patients who were employed or had recently stopped working within

the last 12 months (though we did not capture any patients in the latter), and so we were unable to explore the views of those who had stopped working, or have never been able to work due to SLE, or have had lack of educational progression from developing SLE at an early age.

This study highlights the lack of SLE awareness and support in the workplace. Due to fears about job security some patients continued working when unwell, or did not disclose hospital appointments to employers, instead choosing to use their annual leave. Attending work without adequate support or adjustments could lead to job dissatisfaction, low psychological well-being and exacerbation of symptoms, subsequently reducing patients’ capacity to remain employed.²⁷ Our results concur with other studies that showed further consideration is required in the workplace to ensure that correct procedures are adhered to with regards to supporting individuals working with chronic illness and disabilities.^{2,19}

Stigma regarding illness in general is common within the SA community, often acting as a barrier to appropriately managing health conditions and seeking support.^{28–31} This could create additional barriers to open discussions on health issues. The language barrier reported in multigenerational households could also contribute to this issue, which may explain why the idea of a culturally sensitive video resource was strongly supported and deemed necessary by patients. The educational video “Yeh Hai Lupus” (This is Lupus) has now been developed to provide lasting support for SA patients and their families in the UK and abroad. This was the first step in raising awareness in the SA community which will enable patients to maintain their employment and prevent work disability.

The lack of opportunity to discuss work related issues with clinicians needs further consideration. Within the National Health Service (NHS), appointment duration is often too short to discuss work issues in the detail required. This work highlights the need for more involvement of specialist nurses with appropriate training and social care personnel, which has also been suggested for patients with rheumatoid arthritis.^{32,33} Moreover, the employer perspective is routinely missing in the wider rheumatology literature, possibly due to lack of focus and support for the relationship between health and the workplace. Despite the existence of OH departments, patients in this study reported a need for educating their managers/employers themselves with information about SLE. With this regard, Lupus UK have published two specific information booklets on working with SLE, one for the employer and one for the patient.^{34,35} However, not all patients recalled being given these resources, and some patients felt that employers did not act on

information from clinicians and/or the Lupus UK leaflets. Employer support is likely to vary according to organisation size and sector, and further work is needed to explore the provision of better information for employers and their needs for supporting people with SLE in the workplace.

Our study had a number of limitations, including a small sample. Initial R&D delays with commencing the study were further impacted when recruitment ended abruptly in March 2020 as COVID-19 prevented patients attending regular clinic appointments. However, as data saturation was achieved in the thematic analysis of the patients' interviews, it was reasonable to report these results. Our sample included only two male patients and it is possible that we may have missed specific problems relevant to men who may suffer from more severe disease.³⁶ We did not cover the full spectrum of SLE disease, the impact of disease severity on employment nor the full range of employment types. For example, we did not recruit people who have never worked, or who are currently unemployed, so have missed those likely to be the most severely affected. As with the profiles of many other patients participating in health research, we recruited participants with higher education levels, half of all our participants were educated to degree level, which is not representative of the SA population nor SLE patients in general.³⁷ A different study is needed to explore the impact of SLE on education and subsequent employment opportunities for patients where SLE starts in school years.³⁷ Furthermore, as all patients chose to speak in English, we recognise that our sample is not representative of the SA population in the UK. It is likely that our participants represent those who have achieved higher levels of sociocultural adaptation. We were unable to recruit a more representative sample with a wider range of cultural and social issues that may exist for immigrants who do not speak English, who may be more likely to experience a higher burden and job stability, aggravated by disease factors and access to care barriers. Whilst we followed sound procedures for involving a patient partner in this pilot study, we have been careful not to over interpret these results in view of our sample's limited diversity. It is evident that our recruitment strategies did not reach nor appeal to a wide range of target population and the accessibility of our study documentation could be further expanded in line with Sacristan et al.'s commentary.³⁷ We are also cognisant that our previous work has highlighted the challenges of ethnicity in healthcare and identified language as a barrier to accessing healthcare.³⁸ Despite making considerable effort to recruit a larger and more diverse sample, there could be a range of perspectives and experiences that we have been unable to capture. For these reasons,

it may be difficult to fully generalise these results to all SA patients.

Conclusion

This study provides useful and novel insight into SA patients' beliefs and information needs regarding SLE and employment. Although low awareness of SLE in the workplace may be a problem for patients of all ethnicities, SA patients can have additional cultural barriers within their families and households which affect their ability to work. The video resource we have developed is the first step in addressing some of these issues, though there are a number of important employer and clinician barriers to providing support that need to be addressed.

Acknowledgements

We thank all participants who took part in this project which supports Lupus UK's mission to support patients from all backgrounds and to understand their needs so that they can be better addressed in the future. We thank our patient partner (RD).

Declaration of conflicting interests

The author(s) declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: All other authors report no relevant conflicts of interest except REJ reports grants from NIHR, outside the submitted work and membership of Boehringer Ingelheim primary care advisory board.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: this work was funded by Lupus UK on an academic grant (1000018).

Supplementary material

Supplementary Material Files 1 and 2 can be found online with this article.

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References

1. Dörner T and Furie R. Novel paradigms in systemic lupus erythematosus. *The Lancet* 2019; 393: 2344–2358.
2. Booth S, Price E and Walker E. Fluctuation, invisibility, fatigue – the barriers to maintaining employment with systemic lupus erythematosus: results of an online survey. *Lupus* 2018; 27: 2284–2291.
3. Baker K, Pope J, Fortin P, Silverman E and Peschken C. 1000 Faces of Lupus Investigators and CaNIOS (Canadian Network for Improved Outcomes in SLE)

- work disability in systemic lupus erythematosus is prevalent and associated with socio-demographic and disease related factors. *Lupus* 2009; 18: 1281–1288.
4. Baker K and Pope J. Employment and work disability in systemic lupus erythematosus: a systematic review. *Rheumatology (Oxford)* 2009; 48: 281–284.
 5. Gordon C, Isenberg D, Lerstrom K, et al. The substantial burden of systemic lupus erythematosus on the productivity and careers of patients: a European patient-driven online survey. *Rheumatology* 2013; 52: 2292–2301.
 6. Yelin E, Trupin L, Katz P, et al. Work dynamics among persons with systemic lupus erythematosus. *Arthritis Rheum* 2007; 57: 56–63.
 7. Rees F, Doherty M, Grainge M, Davenport G, Lanyon P and Zhang W. The incidence and prevalence of systemic lupus erythematosus in the UK, 1999–2012. *Ann Rheum Dis* 2016; 75: 136–141.
 8. Samanta A, Roy S, Feehally J and Symmons DPM. The prevalence of diagnosed systemic lupus erythematosus in Whites and Indian Asian immigrants in Leicester City, UK. *Br J Rheumatol* 1992; 31: 679–682.
 9. Johnson AE, Gordon C, Palmer RG and Bacon PA. The prevalence and incidence of systemic lupus erythematosus in Birmingham, England. *Arthritis Rheum* 1995; 38: 551–558.
 10. Office for National Statistics (ONS). Census KS201EW - Ethnic group, <https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/ethnicity> (2011, accessed 31 July 2020).
 11. Patel M, Clarke AM, Bruce IN and Symmons DPM. The prevalence and incidence of biopsy-proven lupus nephritis in the UK: evidence of an ethnic gradient. *Arthritis Rheum* 2006; 54: 2963–2969.
 12. Levy DM, Peschken CA, Tucker LB, Canadian Network for Improved Outcomes in SLE 1000 Faces Investigators, et al. Influence of ethnicity on childhood-onset systemic lupus erythematosus: results from a multiethnic multicenter Canadian cohort. *Arthritis Care Res (Hoboken)* 2013; 65: 152–160.
 13. Yee C-S, Su L, Toescu V, et al. Birmingham SLE cohort: outcomes of a large inception cohort followed for up to 21 years. *Rheumatology (Oxford)* 2015; 54: 836–843.
 14. Kumar K, Gordon C, Barry R, Shaw K, Horne R and Raza K. ‘It’s like taking poison to kill poison but I have to get better’: a qualitative study of beliefs about medicines in rheumatoid arthritis and systemic lupus erythematosus patients of South Asian origin. *Lupus* 2011; 20: 837–844.
 15. Kumar K, Gordon C, Toescu V, et al. Beliefs about medicines in patients with rheumatoid arthritis and systemic lupus erythematosus: a comparison between patients of South Asian and White British origin. *Rheumatology (Oxford)* 2008; 47: 690–697.
 16. Rutter SJ and Kiemle G. Exploring the social and interpersonal experiences of South Asian women with a diagnosis of systemic lupus erythematosus. *Psychol Health* 2015; 30: 318–335.
 17. Hale ED. “Joining the dots” for patients with systemic lupus erythematosus: personal perspectives of health care from a qualitative study. *Ann Rheum Dis* 2006; 65: 585–589.
 18. Utset TO, Baskaran A, Segal BM, et al. Work disability, lost productivity and associated risk factors in patients diagnosed with systemic lupus erythematosus. *Lupus Sci Med* 2015; 2: e000058.
 19. Kent T, Davidson A, Newman D, Buck G and D’Cruz D. Burden of illness in systemic lupus erythematosus: results from a UK patient and carer online survey. *Lupus* 2017; 26: 1095–1100.
 20. Gordon C, Amisssah-Arthur M-B, Gayed M, British Society for Rheumatology Standards, Audit and Guidelines Working Group, et al. The British Society for Rheumatology guideline for the management of systemic lupus erythematosus in adults. *Rheumatology (Oxford)* 2018; 57: e1–e45.
 21. Tong A, Sainsbury P and Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007; 19: 349–357.
 22. Department of Health. The General Practice Physical Activity Questionnaire 2009. A screening tool to assess adult physical activity levels within primary care, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/192453/GPPAQ_-_guidance.pdf (accessed 10 October 2019).
 23. McElhone K, Abbott J, Shelmerdine J, et al. Development and validation of a disease-specific health-related quality of life measure, the LupusQoL, for adults with systemic lupus erythematosus. *Arthritis Rheum* 2007; 57: 972–979.
 24. QSR International. NVivo Qualitative Data Analysis Software [version 12], <https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home> (1999).
 25. Stack RJ, Stoffer M, Englbrecht M, et al. Perceptions of risk and predictive testing held by the first-degree relatives of patients with rheumatoid arthritis in England, Austria and Germany: a qualitative study. *BMJ Open* 2016; 6: e010555.
 26. McElhone K, Castelino M, Abbott J, et al. The LupusQoL and associations with demographics and clinical measurements in patients with systemic lupus erythematosus. *J Rheumatol* 2010; 37: 2273–2279.
 27. Munir F, Yarker J and Haslam C. Sickness absence management: encouraging attendance or ‘risk-taking’ presenteeism in employees with chronic illness? *Disabil Rehabil* 2008; 30: 1461–1472.
 28. Singh H, Cinnirella M and Bradley C. Support systems for and barriers to diabetes management in South Asians and Whites in the UK: qualitative study of patients’ perspectives. *BMJ Open* 2012; 2: e001459.
 29. Rooney LK, Bhopal R, Halani L, et al. Promoting recruitment of minority ethnic groups into research: qualitative study exploring the views of South Asian people with asthma. *J Public Health (Oxf)* 2011; 33: 604–615.
 30. Bedi M and Devins GM. Cultural considerations for South Asian women with breast cancer. *J Cancer Surviv* 2016; 10: 31–50.

31. Palmer CK, Thomas MC, McGregor LM, von Wagner C and Raine R. Understanding low colorectal cancer screening uptake in South Asian faith communities in England – a qualitative study. *BMC Public Health* 2015; 15: 998.
32. Prior Y, Amanna EA, Bodell SJ and Hammond A. A qualitative evaluation of occupational therapy-led work rehabilitation for people with inflammatory arthritis: perspectives of therapists and their line managers. *Br J Occup Ther* 2015; 78: 467–474.
33. O'Brien R, Woodbridge S, Hammond A, Adkin J and Culley J. The development and evaluation of a vocational rehabilitation training programme for rheumatology occupational therapists. *Musculoskelet Care* 2013; 11: 99–105.
34. When an employee has lupus - an employer's guide (Lupus UK 2015). <https://www.lupusuk.org.uk/wp-content/uploads/2015/10/When-An-Employee-Has-Lupus-V2.0.pdf> (accessed 5 November 2019).
35. I want to work - a self help guide for people with lupus (Lupus UK 2015). <https://www.lupusuk.org.uk/wp-content/uploads/2015/10/I-Want-to-Work-V2.0.pdf> (accessed 5 November 2019).
36. Murphy G and Isenberg D. Effect of gender on clinical presentation in systemic lupus erythematosus. *Rheumatology (Oxford)* 2013; 52: 2108–2115.
37. Sacristán JA, Aguarón A, Avendaño-Solá C, et al. Patient involvement in clinical research: why, when, and how. *Patient Prefer Adherence* 2016; 10: 631–640.
38. Kumar K, Chambers S and Gordon C. Challenges of ethnicity in SLE. *Best Pract Res Clin Rheumatol* 2009; 23: 549–561.