South African Journal of Psychology 1–11 © The Author(s) 2021
Article reuse guidelines: sagepub.com/journals-permissions
DOI: 10.1177/00812463211048646 journals.sagepub.com/home/sap
SAGE

PsySSA
Psychological Society
of South Africa

Article

Emotional experiences and challenges faced by patients with systemic lupus erythematosus who attend a support group in Ghana

Norah Nkornu and Zulfawu Ibrahim

Abstract

Systemic lupus erythematosus is a disorder in which a person's immune system attacks the tissues and organs of the body, causing inflammation, damage, and dysfunction. Challenges associated with systemic lupus erythematosus include cognitive and behavioural changes as well as problems with perceived quality of life. It affects mainly women between the ages of 15 and 45 years. This study explored the lived experiences of adults living with systemic lupus erythematosus in Accra, Ghana. The study employed a qualitative research approach where 11 systemic lupus erythematosus patients were purposively recruited from Accra. Data were collected through one on one in-depth interviews using a semi-structured interview guide. Data collected were analysed using interpretative phenomenological analysis. The findings of the study revealed two main themes: Challenges living with systemic lupus erythematosus and Emotional experiences of systemic lupus erythematosus patients. Participants reported physical, financial, fertility challenges, struggles with medications, difficulty explaining the condition, and memory lapses as challenges. Emotional experiences reported include depressive feelings, sadness, fear, suicidal ideation, worry, dislike of the condition (systemic lupus erythematosus), and hope. These findings imply that participants are prone to psychological or psychiatric disorders if their emotions are not managed appropriately. The outcome of this study offers suggestions to policymakers and other organisations involved in the care and management of people with chronic conditions to adopt and effectively implement a multidisciplinary approach in health care by taking into consideration the mental health of persons living with systemic lupus erythematosus and other chronic conditions.

Keywords

Lived experiences, psychological well-being, quality of life, SLE

Department of Psychology, University of Ghana, Ghana

Corresponding author:
Norah Nkornu, Department of Psychology, University of Ghana, P.O. Box NT 771, Accra New Town, Accra, Ghana.
Email: nnkornu11@gmail.com

Systemic lupus erythematosus (SLE or lupus) is a chronic autoimmune condition known to be predominant in women than men and more commonly affects women in sub-Saharan Africa (Essouma et al., 2020). It is a disorder in which a person's immune system attacks the tissues and organs of the body, causing inflammation, damage, and dysfunction (Shiel, 2018). The causes and the medical course of the condition is unclear. A recent international study by the Lupus Foundation of America showed a low global understanding of the disease (Lupus Foundation of America, 2018). The true burden, while unknown in West Africa, is perceived to be or expected to be high but that proper epidemiological studies have not been done in this regard (Tiffin et al., 2014).

SLE was previously believed to be rare among Africans in the sub-Saharan regions, but studies have disputed this assumption. Several studies have reported SLE cases in South Africa, Senegal, and Nigeria (Adelowo et al., 2017; Diallo et al., 2017; Faller et al., 2005; Lewandowski et al., 2017; Tiffin et al., 2014). Furthermore, an audit of cases seen in a national referral hospital in Ghana revealed higher than expected rates in addition to high mortality, mostly among young women (Dey et al., 2015). A meta-analysis by Essouma et al. (2020) revealed high mortality in SLE in sub-Saharan Africa.

SLE patients live with symptoms on a continuous basis and only a few obtain symptom-free period (Lateef & Petri, 2012). A life with lupus usually has an unpredictable array of symptom dormancy and periods of relapse commonly referred to as 'flares' (Squance et al., 2014).

The condition has an impact on physical, psychological, and social well-being. Psychological well-being is a combination of having good feelings and functioning well in all areas of life according to Huppert (2009). Emotional uncertainties are evident among people with SLE as they live with pain from the condition, fears about treatment, difficulty with performing chores/housework, side effects of medications, and unexpected disease flares (Mathias et al., 2018). Studies have reported that chronic disease, such as SLE, has a negative impact on some people, causing them to become depressed or anxious, some get tired easily, and this affects their work. Waterloo et al. (2009) found emotional instabilities such as difficulties and uneasiness in social gatherings and depressive mood to be recurrent in people with SLE and these discomforts were linked to skin and joint abnormalities.

Neuropsychiatric conditions such as psychotic episodes, mood changes, cognitive problems, headaches, seizures, and stroke have also been reported in SLE patients (Touma et al., 2020; West, 2013). Cognitive dysfunction in the various domains including memory, attention, executive function, visual-spatial processing, psychomotor speed, and verbal fluency have been highlighted as a key neuropsychiatric complaint in SLE sufferers (Huerta et al., 2015).

One's quality of life (QOL) may be affected by his /her perceptions, psychological state, physical health, social relationships, and environmental factors (Olesińska & Saletra, 2018). QOL of SLE patients is significantly reduced especially in patients showing neuropsychiatric symptoms (Monahan et al., 2017); this reduction was observed in all the various domains of QOL. A number of symptoms have been recounted in SLE; these might have diverse detrimental influence on the QOL of patients.

Given the lack of research on lived experiences of adults living with SLE in Ghana, we undertook a qualitative study by interviewing individuals with SLE to explore their 'lived experiences' of SLE as a chronic autoimmune condition. Our aim was to obtain the understanding of issues that may be under-explored in the clinical care of SLE.

Therefore this study sought to answer the following research questions: (1) What are the lived experiences of persons living with SLE? (2) What are the subjective feelings or emotions persons living with SLE have about the condition? (3) How has the condition affected or not affected persons living with SLE?

Method

This was a cross-sectional study which employed a qualitative approach specifically phenomenology. A phenomenological method offers exploration of the experiences of people with chronic conditions such as SLE and how that affects their QOL. It explores in detail how people make sense of their personal and social world and allowed detailed interpretation of these experiences. The study was conducted in Accra, Ghana.

Participants

Using purposive sampling technique, 11 participants were recruited from a support group in a national referral hospital in Accra. The study site was selected because all suspected Lupus cases are referred to this hospital. However, at the time of data collection, only 11 participants consented. Creswell (1998) suggested a sample size of 5–25 for qualitative studies, and Morse (1994) also proposed at least 6 participants. The majority of the participants interviewed were females.

Instrument

An individual in-depth, interview was conducted with 11 SLE patients using a semi-structured interview guide with open-ended questions exploring the experiences of people living with SLE. The interview guide comprised two sections: demographics with questions such as age, marital status, educational level, and occupation. Clinical information and disease duration were obtained from their folders with permission from participants. The second section explored the experiences with questions such as (1) Tell me about your life before you were diagnosed (probe: relationship with relatives, significant others, work, marriage), (2) How have things been different after your diagnosis? (probe: difficulties with everyday activities, work, dependency, relationship with relatives, and significant others; how they feel about it, stigma). Interviews were audio-recorded, transcribed, and analysed for themes.

Procedure

The SLE support group meets at the hospital once a month after their routine reviews. The leaders of the group informed the members about the intention of the researchers prior to the meeting date. On the day of the meeting, the researchers were introduced by the leaders as psychologists who were interested in exploring the lived experiences of SLE patients. There was one-on-one interaction between the researchers and the members at the end of the meeting; the purpose of the study was carefully explained to them with the intention of getting approval. Participants were assured that the finding would be shared with them if they are interested. Some participants gave approval immediately while others accepted to participate on the day of data collection. One-on-one interviews were conducted at the end of the next support group meeting in a room prepared for that purpose. Five participants were interviewed on the first day of data collection; the rest were interviewed on the second visit.

Ethical considerations

Ethical approval to conduct the research was obtained from the Ethical Committee for Humanities at the University of Ghana (Reference No. ECH 011/18-19) and the hospital administrators. The purpose of the study was explained to participants; they were also informed that their medical records would be reviewed. Participants were informed that they could withdraw at any point of the interview if they feel uncomfortable. Persons 18 years and above who were diagnosed of SLE, and consented to participate in the study were recruited. Furthermore, psychological assistance was provided for participants who might express emotional distress. Two participants accepted this offer.

Data analysis

Interpretative phenomenological analysis (IPA) was used to analyse the data. To ensure credibility, all interviews were audio-recorded with consent from participants and transcribed. Interviews were conducted in a consulting room and the names and identifying information of participants were not taken to ensure privacy and confidentiality. The audio recordings were kept on a hard drive after the transcription and only the principal investigator has access to it. The study was analysed following Smith and Osborn (2007) recommended guide for Phenomenological Analysis to ensure trustworthiness. The steps are as follows: (1) gaining an understanding of the transcribed interview by reading and re-reading of the data and identifying point of interest; (2) transformation of initial notes into emerging themes; and (3) connecting the themes. This method allowed for systematic analysis of the data to extract emerging patterns and ideas. The first author familiarised herself with the data by transcribing the interviews, repeatedly reading through the transcripts, and writing short notes. These short notes were developed into initial codes. Initial codes with similar connections were put together and classified as themes, on the bases of their association with experiences living with SLE. The process of peer checking was introduced at this stage and throughout the rest of the data analysis process as a way of ensuring the credibility of the data. There was back and forth engagement between the two authors as well as refinement of the codes and generated themes until agreement was reached.

Results

As stated earlier, there were more female than male participants. Respondents were between 18–35 years and all of the participants had tertiary education. More than half of the participants (8) were employed, and 6 were married.

The findings are presented based on the central research question that was raised. The analysis answered the question of the lived experiences of SLE patients. This fundamental research question guided the presentation of the findings.

Research Question: What are the lived experiences of SLE patients?

The presentations of findings is grouped under two superordinate themes: Challenges living with SLE and Emotional experiences of SLE patients. These themes are presented below.

Challenges living with SLE

People go through diverse challenges when they are diagnosed with chronic ailments which they have to live with for the rest of their lives. This theme explored the views and perceptions of the participants concerning the difficulties they encounter. Six sub-themes emerged concerning the challenges of living with SLE: physical challenges, financial challenges, struggles with medication, difficulty explaining the condition, fertility challenges, and memory lapses. Each of these themes are described below.

Physical challenges. The respondents reported facing several challenges as a result of their condition. According to them, they were very active and going about their normal businesses before the condition settled in. This was reported by all the 11 participants. One of the quotes from a respondent is as follows:

> Ohh me, my life was normal. I used to work normal, no pain, no difficulties, I was able to go about my normal day to day activities with no difficulty. I could do my house chores by myself, scrub my bathroom, my hall, in fact I could do everything. (Respondent 5)

From the excerpt above, normal life meant being able to execute daily activities without challenges. Within the African context, women take pride in being able to manage their home. However after diagnosis, Participant 5 reported having difficulties with usual daily activities. This challenge is perceived as a threat to her womanhood since she is not able to manage affairs in her home by herself. Also the utterance 'Hmm' is a connotation of worry or burden in the Ghanaian context which expresses how apprehensive she feels. This is confirmed by the extract below:

> The other challenges has got to do with myself. The things I used to do which am no longer able to. Hmm. . . For a long time now, I am not able to wash because of the pains in my fingers. Now my hands feel stiff, I can't grind pepper in the earthenware bowl. I can't do these petit, petit stuff so sometimes emm . . . (paused) it's quite emm . . . hurtful. (Respondent 3)

Financial challenges. Some of the respondent expressed worry about the cost of medications. They indicated that the drugs are expensive, and they spend more than a half of their income on medications. However, this was not the case when they were not sick. Another worry expressed had to do with inability to take on extra jobs due to decline in health:

> . . . The toll on my money, that's my major challenge. Like I said, at first I had the other source of income and that was enough for me so I could just save my main salary and use it for other things but now it's only my salary and the drugs you come in to buy is almost taking about a third, almost a half of your salary, and you can't use the other half for anything because there are other budgetary allocations. (Respondent 9)

From the quote above, Participant 9 values financial freedom; he used to take on many jobs to make more money however, due to the weakness and pain associated with SLE, he is unable to work extra jobs. This may be a challenge to him because, in the Ghanaian context, young men are supposed to take care of their parents, siblings and their nuclear family if they are married, however, Participant 9 has to rely on his family for financial assistance 'When it come to the money as well, of course they(family) will quickly do some contributions'. This could possibly affect his ego as a man.

Struggles with medication. Respondents expressed issues about the SLE medications they take due to its side effects. They also had issues with being on medications and the challenge of swallowing many pills every day:

> My life, really my life is destroyed 'basa'. The medicine has made me gain weight and also it has affected my hips. I was told the medication has cause a deformity in my hip bone so I have to undergo surgery in my hips. I have been on the medication for close to three years now. (Respondent 2)

The medications supposed to manage the condition is also causing other side effects. This is distressing to participant 2; taking medication every day and knowing very well that it is going to cause you other problems but you have no choice is distressing. The utterance ‘basa’ means ‘in a messy situation that is difficult to fix’ in the Ghanaian local language. The participant used this word to explain how her life has been affected. This may have affected her QOL negatively.

Difficulty explaining the condition. Explaining the condition to people was a challenge to some participants. One respondent explained that she has difficulties explaining to people that she is not well because physically she seems to be fine. Her major challenge is convincing people that she is not well. Stated below is her quote:

> The only challenge I think I have is making people understand what really is wrong with me. I find it difficult explaining it, so it’s very difficult making people understand. (Respondent 4)

In Ghana, little is known about SLE, finding terms to explain the condition in the local language is difficult. Participant 4 continues to explain:

> As I was coming here (clinic) this morning, I had to ask permission from my bosses, they may not understand because they see me at work every day and yet I always ask permission to come for medical review at least every 3 or 6 months. That has been my challenge, convincing people that yes really something is happening inward. (Respondent 4)

This participant does not have the overt symptoms of the condition therefore she appears physically healthy. Her colleagues at work may not believe that she is sick; she may be perceived to be lazy for asking time off work regularly. This might affect her chances of pursuing higher positions at her work place.

Fertility challenges. SLE is a condition where fertility challenges can arise following treatment. A participant expressed the following concerns:

> It is still a challenge for us conceiving, that’s one major challenge with all this health issues. We didn’t have any children before the condition started. Early 2013, this whole thing started and it’s been drugs, drugs, drugs. When I was getting a little bit well, my [family] sat me down and told me that the doctor said the medication I’m taking has a possible side effect of infertility. (Respondent 9)

From the excerpt above, Respondent 9 is highly likely to experience poor emotional well-being because in the Ghanaian context, being able to have a child makes you a complete adult. In the Ghanaian culture, marriage is for procreation, even during the marriage ceremony prayers are offered for the couple to be fertile and productive. Pressures from the extended family starts to mount after some years of childlessness and mostly women are the main target. A feeling of guilt can be a likely consequence for a person in such a context.

Memory lapses. Difficulties in remembering things was expressed by some participants. According to one of the participants, she used to be very smart and could remember everything but after diagnosis and being on treatment for some time; she has noticed that she is forgetful:

> . . . I forget things. I am very forgetful lately, sometimes I leave important things undone for days and also forget appointments. I didn’t use to be like this. (Respondent 5)

Being forgetful can have a negative impact on daily lives. It could be frustrating not remembering simple and important things. This can be observed from the narrative of Participant 5.

Emotional experiences of persons living with SLE

Participants expressed a range of emotions and these were influenced by the perceptions they hold about the condition and challenges related to the condition. Based on the narratives, the majority of participants expressed negative emotions.

Negative emotions. The majority of respondents' expressed negative emotions about their condition. These emotions can be detrimental to their well-being and QOL. The negative emotions include depressive feelings, fear, suicidal thoughts, dislike of SLE and worry.

Below are some quotes:

> I get depressed by coming to clinic because I see people who are in worse conditions and then you ask yourself, is this the end. (Respondent 6)

Furthermore, participants indicated that they have fear about the condition because they are uncertain about the future:

> Emmm . . . the challenges they are quite a few. You know the fear aspect, you know this condition even though you are taking medication anything can happen at any time. You have fear that what if one day I should fall ill, will I go back to how I was, am I going to suffer the same fate like I did before, the money you are going to spend and other things. There is also the fear of like getting married, having children, will I be able to bear children, will I be able to take care of them, my family, that one is also there. (Respondent 11)

Suicidal ideation was reported by one participant as a result of her inability to function well after diagnosis:

> . . . Hmm . . . I feel bad and sad. Sometimes I feel like taking my own life, ooh its true oo when you see how you were first and now you are not like that its very painful . . . (Respondent 2)

From the quotes above, it can be deduced that participants are experiencing psychological distress which could lead to severe mental health challenges. Furthermore, it could be observed that participants are engaged in social comparison where they compare themselves to others in similar situations whose conditions have deteriorated. This act of negative social comparison could be fueling the negative emotions.

Despite the negative emotions expressed by the majority of participants, they expressed some form of hope that things will get better. This is a positive emotion which may have given them the strength to keep going '. . . Hmm what will I do? The sickness has come already and there is nothing I can do. I have hope. I believe that God will heal me. So far as there is life, there is hope' (Respondent 5).

Participant 2 reported suicidal ideation, however she explained that she derives some form of hope to keep living for the sake of her daughter because she feels she has a responsibility to take care of her daughter and protect her. Another reason could be that despite the challenges, she has someone by her side. 'I get tired of fighting and I feel like giving up but my daughter motivates me to keep living. If not for my daughter, I would have taken some medicine and ended it long ago' (Respondent 2).

Discussion

The findings show that SLE patients face various challenges in their lives as a result of the condition. Participants reported noticing significant changes in their lives after diagnosis which is distressing and has a negative impact on their QOL. They reported physical challenges, financial challenges, struggles with medication, difficulties explaining the condition, memory lapses, and fertility challenges. The dominant word participants used to describe their lives before the condition started was ‘Normal’. According to them they had normal lives before the symptoms started. Terms like ‘work well’, ‘do everything’, ‘do anything’, and ‘go about normal daily activities’ were used by the participants to mean ‘normal’ lives. Their explanation meant that having a normal life is going about your daily duties without difficulties, problems, or any health challenges. However, participants reported changes in their lives after diagnosis. They explained that they have difficulties going about their daily activities due to the decline in physical and mental health. These associated challenges have affected the ability to work leading to financial struggles. The side effects of medications affects fertility which may have socio-cultural implications. One of the main threats to marriages in Ghana is infertility (Evens, 2004). Findings of this study are consistent with previous studies that have reported physical challenges such as fatigue, which makes them dependent on others, low emotional states, financial challenges, difficulties with fertility and childbearing, side effects of medications, the lack of knowledge about the disease, difficulties in working, and changes in their interpersonal relationships (Barros et al., 2012; Lynch, 2017; McElhone et al., 2010; Phuti et al., 2019).

The participants further reported emotional experiences living with SLE; negative emotions such as depressive feeling, sadness, fear, suicidal ideations, and worry were expressed by the participants which were as a result of the challenges caused by the condition. The findings are in line with a study conducted among persons with scleroderma or systemic sclerosis which is also an autoimmune diseases (Milette et al., 2018); Participants reported negative emotions such as fear, anxiety, anger, and frustration. One of the main sources of stress for these patients was the inability to predict the progression of the disease and impact of the symptoms. Beckerman et al. (2011) argued there may be a bidirectional relationship such that activities of chronic disease within the individual influences emotional well-being or feelings of depression and anxiety triggering more disease activity. The negative emotions could impact one’s QOL negatively.

Furthermore, participants’ comparing themselves to other SLE patients whose conditions have worsened with time lead to the feeling of worry and anxiety. It can be inferred that the negative social-comparisons increased their feelings of distress.

Despite the negative feelings experienced, all participants had some form of hope to keep striving. One of the participant’s positive emotion was inspired by a sense of spirituality as stated ‘I have hope. I believe that God will heal me. So far as there is life, there is hope’. In line with this, findings from a study conducted by Stamm et al. (2008) among patients with rheumatoid arthritis shed a different light on living with autoimmune disease. Participants in their study described their experience as ‘mastering with the disease’ instead of ‘suffering with the disease’. They perceived the disease as a new challenge which required them to engage in meaningful activities to master the challenge. These positive aspects of living with the disease are supported by Weitzner et al. (2011) who also reported positive perceptions and experiences among patients living with spinal cord injury.

Findings of the current study suggest that, the physical symptoms and their associated challenges are likely to affect the physical and mental health of persons living with SLE which could have a negative effect on their QOL. To improve the QOL of people living with SLE, it is not enough to address the physical symptoms. It is therefore necessary to address the cognitive and emotional impact of the disease process as well.

The main focus of the current study was to understand the lived experiences of persons living with SLE in Ghana. However, it was observed that all participants expressed some sense of hope living with the condition. Since this study did not explore resilience and social support among the participants, it is recommended that future studies explore resilience and coping mechanisms employed by persons living with chronic conditions. Furthermore, we found negative social comparison as a cause of distress and future studies should explore this area.

The main findings from this study reveal the difficulties that SLE patients' encounter which have negative impact on their QOL. The outcome of this study offers suggestions to institutions and organisations to adopt and effectively implement a multidisciplinary approach to the management of chronic illness by working with mental health professionals to assist in the psychological care and management of SLE patients.

Among the study limitations is the reliance on a convenience sample, meaning that only those attending the support group and who were available were engaged. As a result, the study failed to explore the experiences of patients who, for various reasons, did not join a social support group. Finally, the sample size does not allow the generalisation of findings.

Conclusion

SLE (lupus) is a complex inflammatory disease with diverse clinical presentations, which is known to pose many physical, behavioural, and QOL challenges. Although the impact of SLE is known, not much research has been done in Ghana. Additional research on experiences and psychological well-being will boost the care of SLE patients in Ghana and elsewhere on the African continent.

Acknowledgements

The authors wish to express gratitude to the research participants for taking time off their schedules and giving us the opportunity to understand their experiences better and also share with others.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

ORCID iDs

Norah Nkornu https://orcid.org/0000-0002-2470-450X
Zulfawu Ibrahim https://orcid.org/0000-0003-3233-987X

References

Adelowo, O. O., Olaosebikan, B. H., Animashaun, B. A., & Akintayo, R. O. (2017). Juvenile systemic lupus erythematosus in Nigeria. *Lupus*, *26*(3), 329–333. https://doi.org/10.1177/0961203316672927

Barros, B. P., Souza, C. B., & Kirsztajn, G. M. (2012). The structure of the 'lived-experience': Analysis of reports from women with systemic lupus erythematosus. *Journal of Nursing Education and Practice*, *2*(3), 120. https://doi.org/10.5430/jnep.v2n3p120

Beckerman, N. L., Auerbach, C., & Blanco, I. (2011). Psychosocial dimensions of SLE: Implications for the health care team. *Journal of Multidisciplinary Healthcare*, *4*, 63–72. https://doi.org/10.2147/JMDH.S19303

Creswell, J. W. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. Sage Publications, Inc.

Dey, I. D., Boima, V., Atiase, Y., Yorke, E., Ganu, V., & Mate-Kole, C. C. (2015). Rheumatology in Ghana – A paradigm change. In M. Lartey, T. Archampong, & M. O. Mate-Kole (Eds.), Internal medicine practice in Ghana: Challenges, innovations and future directions. *University of Ghana readers* (pp. 7–21). DigiBooks Ghana Ltd.

Diallo, M., Diatta, B. A., Diop, A., Ndiaye, M. T., Ndiaye, M., Seck, B., & Niang, S. O. (2017). Lupus erythematosus in Senegal: Study of 340 cases. *Dermatology Case Reports*, *2*, 135. https://doi.org/10.35248/2684-124X.17.2.135

Essouma, M., Nkeck, J. R., Endomba, F. T., Bigna, J. J., Singwe-Ngandeu, M., & Hachulla, E. (2020). Systemic lupus erythematosus in native sub-Saharan Africans: A systematic review and meta-analysis. *Journal of Autoimmunity, 106, 102348*. https://doi.org/10.1016/j.jaut.2019.102348

Evens, E. M. (2004). *A global perspective on infertility: On under recognized public health issue*. North Carolina Central University.

Faller, G., Thomson, P. D., Kala, U. K., & Hahn, D. (2005). Demographics and presenting clinical features of childhood systemic lupus erythematosus. *Journal of Endocrinology, Metabolism and Diabetes of South Africa*, *10*(2), 64–68. https://www.ajol.info/index.php/jemdsa/article/view/34684

Huerta, P. T., Gibson, E. L., Rey, C., Huerta, T. S., & Huerta, P. T. (2015). Integrative neuroscience approach to neuropsychiatric lupus. *Journal of Immunology Research*, *63*(1–3), 11–17. https://doi.org/10.1007/s12026-015-8713-6

Huppert, F. A. (2009). Psychological well-being: Evidence regarding its causes and consequences. *Applied Psychological: Health and Well-Being*, *1*(2), 137–164. https://doi.org/10.1111/j.17780854.2009.01008.x

Lateef, A., & Petri, M. (2012). Unmet medical needs in systemic lupus erythematosus. *Arthritis Research and Therapy*, *14*(4), S4. https://doi.org/10.1186/ar3919

Lewandowski, L. B., Watt, M. H., Schanberg, L. E., Thielman, N. M., & Scott, C. (2017). Missed opportunities for timely diagnosis of pediatric lupus in South Africa: A qualitative study. *Pediatric Rheumatology Online Journal*, *15*, 14. https://doi.org/10.1186/s12969-017-0144-6

Lupus Foundation of America. (2018). *International survey shows low global understanding about lupus*. https://www.lupus.org/

Lynch, K. A. V. (2017). *Narratives of men living with systemic lupus erythematosus*. https://scholarworks.waldenu.edu/dissertations

Mathias, S. D., Berry, P., De Vries, J., Pascoe, K., Colwell1, H. H., Chang, D. J., & Askanase, A. D. (2018). Patient experience in systemic lupus erythematosus: Development of novel patient-reported symptom and patient-reported impact measures. *Journal of Patient-Reported Outcomes*, *2*, 11. https://doi.org/10.1186/s41687-018-0028-7

McElhone, K., Abbott, J., Gray, J., Williams, A., & Teh, L. S. (2010). Patient perspective of systemic lupus erythematosus in relation to health-related quality of life concepts: A qualitative study. *Lupus*, *19*(14), 1640–1647. https://doi.org/10.1177/0961203310378668

Milette, K., Thombs, B. D., Maiorino, K., Nielson, W. R., Körner, A., & Peláez, S. (2018). Challenges and strategies for coping with scleroderma: Implications for a scleroderma-specific self-management program. *Disability and Rehabilitation*, *41*(21), 2506–2515. https://doi.org/10.1080/09638288.2018.1470263

Monahan, R. C., Beaart-van de Voorde, L. J. J., Steup-Beekman, G. M., Magro-Checa, C., Huizinga, T. W. J., Hoekman, J., & Kaptein, A. A. (2017). Neuropsychiatric symptoms in systemic lupus erythematosus: Impact on quality of life. *Lupus*, *26*(12), 1252–1259. https://doi.org/10.1177/0961203317694262

Morse, J. M. (1994). Designing funded qualitative research. In N. K. Denizin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed.). Sage

Olesińska, M., & Saletra, A. (2018). Quality of life in systemic lupus erythematosus and its measurement. *Reumatologia*, *56*(1), 45–54. https://doi.org/10.5114/reum.74750

Phuti, A., Schneider, M., Makan, K., Tikly, M., & Hodkinson, B. (2019). Living with systemic lupus erythematosus in South Africa: A bitter pill to swallow. *Health and Quality of Life Outcomes*, *17*, Article 65. https://doi.org/10.1186/s12955-019-1132-y

Shiel, W. C., Jr. (2018). *Lupus (systemic lupus erythematosus)*. https://www.emedicinehealth.com

Smith, A. J., & Osborn, M. (2007). *Interpretative phenomenological analysis*. http://research.sites.olt.ubc.ca/files/2012/03/IPA_Smith_Osborne21632.pdf

Squance, M. L., Glenn, E. M., Reeves, G. E. M., & Howard Bridgman, H. (2014). The lived experience of lupus flares: Features, triggers, and management in an Australian female cohort. *International Journal of Chronic Diseases*, *2014*, 816729. https://dx.doi.org/10.1155/2014/816729

Stamm, T., Lovelock, L., Stew, G., Nell, V., Smolen, J., Jonsson, H., & Machold, K. (2008). I have mastered the challenge of living with a chronic disease: Life stories of people with rheumatoid arthritis. *Qualitative Health Research*, *18*(5), 658–669. https://dx.doi.org/10.1177/1049732308316348

Tiffin, N., Hodkinson, B., & Okpechi, I. (2014). Lupus in Africa: Can we dispel the myths and face the challenges? *Lupus*, *23*(1), 102–111. https://doi.org/10.1177/0961203313509296

Touma, Z., Moghaddam, B., Su, J., & Katz, P. (2020). Cognitive function trajectories in association with the depressive symptoms trajectories in systemic lupus erythematosus over time. *Arthritis Care Research (Hoboken)*. Advance online publication. https://dx.doi.org/10.1002/acr.24349

Waterloo, K., Omdal, R., Husby, G., & Mellgren, S. I. (2009). Emotional status in systemic lupus erythematosus. *Scandinavian Journal of Rheumatology*, *27*(6), 410–414. https://doi.org/10.1080/030097498442226

Weitzner, E., Surca, S., Wiese, S., Dion, A., Roussos, Z., Renwick, R., & Yoshida, K. (2011). Getting on with life: Positive experiences of living with a spinal cord injury. *Qualitative Health Research*, *21*(11), 1455–1468. https://dx.doi.org/10.1177/1049732311417726

West, S. G. (2013). Clinical aspects of nervous system. In D. J. Wallace & B. H. Hahn (Eds.), *Dubois' lupus erythematosus and related syndromes* (8th ed., pp. 368–381). Elsevier.