Systemic lupus erythematosus: what do Chinese patients and general practitioners know?

Xia Jun Wang
Peking Union Medical College Hospital https://orcid.org/0000-0002-9804-5287

Yue Sha
Chinese Academy of Medical Sciences and Peking Union Medical College

Dong Xu
Chinese Academy of Medical Sciences and Peking Union Medical College

lin Jia Chen (chenjl001001@sina.com)
https://orcid.org/0000-0003-4334-6119

Research article

Keywords: Systemic lupus erythematosus, Patients, General Practitioners, Questionnaire, Educational needs

Posted Date: May 7th, 2020

DOI: https://doi.org/10.21203/rs.3.rs-23287/v1

Abstract

Background: Systemic lupus erythematosus is a chronic autoimmune disease with multiple systems involved. Traditionally, the diagnosis and management of SLE is only limited at secondary and tertiary hospitals. In recent years, China has vigorously carried out the hierarchical medical system, which placed the emphasis on primary health care. It is said that general practitioner should provide recognition, monitoring, management and education for SLE patients, as well as coordinate closely with rheumatologist to optimize prognosis. However, little is known about GPs' knowledge and attitude towards SLE in China, as well as SLE patients.

Methods: Data were collected from 113 SLE patients and 225 community GPs. Patients were recruited from a rheumatology clinic, Peking Union Medical Hospital from October to December 2018. All the GPs involved in the study work in the community health centers in Beijing. Based on the self-designed questionnaire, a face-to-face questionnaire and internet-based questionnaire were conducted among SLE patients and GPs, respectively. Data was analyzed using SPSS 23.0 and knowledge level was reported as percent correct.

Results: The average score of patients' disease knowledge was 6.99±2.21. The results showed that higher levels of education were associated with higher levels of knowledge ($\chi 2$=4.231, P=0.04), as was being married ($\chi 2$=27.781, P<0.001), employed ($\chi 2$=63.865, P<0.001), follow-up duration ≥10 years ($\chi 2$=26.174, P<0.001), frequency of hospitalization ≥3 times ($\chi 2$=22.44, P<0.001), more organs and systems involved ($\chi 2$=90.36, P<0.001). Univariate linear regression analysis showed that patients with lower age, higher levels of education, being married and shorter follow-up duration had higher educational needs (P<0.05). Moreover, GPs answered 47% of the questions correctly. They showed poor awareness of SLE diagnostic classification, signs of recurrence, complications and follow-up management.

Conclusions: There are many gaps in SLE patients' and GPs' knowledge of the disease. And both of them have expressed the educational requirements of their expected aspects. Understanding the view of the SLE patients and GPs may help clinicians and policymakers focus their assessments and develop strategies to improve the management of SLE patients.

Background

Challenges in the management of SLE patients

Systemic lupus erythematosus (SLE) is an incurable and severe chronic autoimmune disease characterized by multiple organ involvement[1]. Despite the improvement of diagnosis and treatment, numerous challenges remain for the management of SLE. The challenges can include favouring disease remission, limiting the use of glucocorticoids, managing fertility and pregnancy, managing comorbidities and so on[2]. Besides, current evidence suggests that the percentage of nonadherent patients ranged from 37% to 75%, which have a remarkable correlation with depression, low education level and

polypharmacy[3-7]. Interventions to improve adherence and management of patients have become an urgent requirement. And there is no doubt that this requires a multidisciplinary approach to achieve better disease prognosis. American College of Rheumatology Ad Hoc Committee recommends that primary care physician(PCP) should be responsible for early diagnosis, appropriate referral, monitoring disease, and collaboration with a specialist[8, 9]. Since the low incidence and severity of SLE, most primary care physicians may not be exprienced in the management of SLE patients. In a cross-sectional survey in Mexican, Only 31% (n=32) of the PCP had a high or moderate level of competence for the evaluation of rheumatic disorders (included SLE)[10]. Overall, problems and challenges that the management of patients with SLE are facing come from several aspects, both patients and physicians.

Development of primary health care in China

In order to solve difficultly of getting medical service, China pays great attention to improving its' primary health care. And the Hierarchical Medical System played an important role in facilitating the goals[11, 12]. The core content of the System includes first visit in the community-level medical institutions, dual referral, acute and chronic disease treated separately, up and down linkage[13]. Traditionally, Chinese patients with SLE was diagnosed and managed at secondary and tertiary hospitals, having nothing to do with primary medical institutions. But because of the System, more and more SLE patients will come to visit primary care health institutions for disease management, which is guided by a community health service system named "Six in One". It refers to six kinds of community health service that includes community-level preventive, health care, medical treatment, rehabilitation, health education and family planning technical guidance [14]. However, it is an important yet a difficult task for GP to efficiently manage SLE patients in the way described above. In other words, the management of SLE patients while to face the opportunity also to face the huge challenge for GPs. For example, a recent study in China indicates that 56.9% of SLE patients were not adherent[15]. The responsibility of the GP is great, but study in GPs' knowledge and attitudes about SLE patient management is rare.

Previous studies have focused on SLE Disease Activity Index (SLEDAI), adherence, social support, health status and so on[16, 17], primary health care for SLE patients is relatively new and immature in China. This study aimed to know GPs' knowledge, attitudes and difficulty on SLE patient management, as well as patients' knowledge and educational demand to provide reference for future education.

Methods

From September to November 2017, 113 patients with SLE, who regularly visited Rheumatology clinic in Peking Union Medical College Hospital, were recruited into the study. At the same time, an internet-based survey among 225 GPs in a certain district of Beijing was conducted. All patients and GPs were invited to

complete a questionnaire, which was designed by several GPs and specialists in Rheumatology and General Internal Medicine. There were three parts to the questionnaire for patients. The first part included some biographical information of patients such as age, gender, marital status, educational level and so on. The second part was a disease knowledge scale which had 13 items in total. All questions needed to be answered with “Yes,” “No,” or “Unknown”. A correct answer was scored 1 and an incorrect answer or answer of “Unknown” was scored 0. The total score above 10 was “excellent”, 8~10 was “good”, and below 8 was “poor”. The third part was the educational needs scale, which consisted of nine areas, such as etiology of SLE, medication guidance, psychological support, preventive of infection. All items were rated on a four-point Likert scales with the descriptors: “absolutely needed”=1, “needed”=2, “partly needed”=3 and “not at all”=4. Cronbach’s α of the educational needs scale was 0.866. On the other hand, the questionnaire for GPs also included three parts: (1) basic demographic data; (2) Q & A about SLE; (3) opinions on continuing medical education(CME) for SLE. A total of 12 items were included in the second part. For each item, there were four choices with 1 to 4 correct answers, and answered correctly was scored 1, otherwise scored 0. In addition, semi-closed questions were used to understand the GPs' views on CME, such as methods. The reliability of questionnaires were tested by comparing the result of pre-investigation and formal investigation.

Statistical analysis

Datas were double-entered into and analyzed by SPSS23.0. Continuous variables were reported as means ± standard deviation. Categorical variables were expressed as absolute numbers and percentages. Pearson's Chi square test or the Fisher exact test was used to compare categorical variables between participants. Univariate linear regression and bivariate correlation were applied to evaluate variables associated with patients’ educational needs. All statistical tests were two-tailed, and p-value 0.05 was considered statistically significant.

Results

Patients’ characteristics

A total of 113 patients with SLE completed the questionnaire at the age range of 14 to 65 years old (mean age 36). The patients’ characteristics were shown in Table 1.

Patients’ knowledge of SLE and its influencing factors

The average score of patients' disease knowledge was 6.99±2.21, with the lowest score was 0 and the highest score was 13. The percentage of correct answers in each question was shown in table 2.

Obviously, patients have insufficient knowledge and misunderstandings about SLE, especially in the etiology of SLE, the treatment of drug side effects, and the factors that aggravate and alleviate the disease. More than two-thirds of patients believed that SLE was caused by immunosuppression, and about half of those patients had taken an immune booster. Moreover, most patients were extremely anxious because they deemed that SLE could be passed on to their offsprings.

In addition, the factors affecting patients' disease knowledge level were shown in table 3. The results showed that higher levels of education were associated with higher levels of knowledge (χ^2=4.231, P=0.04), as was being married (χ^2=27.781, P<0.001), employed (χ^2=63.865, P<0.001), follow-up duration ≥10 years (χ^2=26.174, P<0.001), frequency of hospitalization ≥3 times (χ^2=22.44, P<0.001), more organs and systems involved (χ^2=90.36, P<0.001). Age and sex did not make a difference on disease knowledge level (P>0.05).

Patients’ educational needs of SLE

The top four educational needs identified by patients were the knowledge of drug-use safety (92%), the etiology of SLE (86.7%), physical exercise guidance (86.7%) and preventive of infection (83.2%), which to some extent was consistent with the SLE knowledge gap. Univariate linear regression analysis showed that patients with lower age, higher levels of education, being married and shorter follow-up duration had higher educational needs (P<0.05) (Table 4). And, more remarkable, younger patients had higher educational needs within the domain‘Family care’ (β-est 0.02; 95% CI [0.004, 0.04]). Higher levels of education was associated with more psychology support (β-est -0.2; 95% CI [-0.3, -0.03]). Moreover, correlation analysis showed that patients with higher levels of SLE knowledge had lower scores on educational needs, in other words, suggesting significantly higher educational needs (Table 5, Figure 1).

Fig 1. Correlation analysis for scores on educational needs and SLE knowledge.

General practitioners’ characteristics

Two hundred and twenty-five general practitioners were recruited to the study. The average age was 39.08 ± 9.70 years, mainly female doctors. About 60% of them have intermediate professional titles and bachelor's degrees, and more than half of them had worked for more than 10 years. More details were given in Table 6.

General practitioners’ knowledge and attitudes toward SLE

Overall, general practitioners answered 47% of the questions correctly. The commonest errors laied in misunderstanding the diagnostic basis of SLE and underestimating the signs of SLE recurrence. Personally, GPs known little about the diagnosis and treatment of SLE as the average level, self-rated on a ten-point Likert scales with the descriptors: “not know at all”=1, “completely understand”=10, were 3 and 3.5. Furthermore, GPs had difficulty in identifying complications of SLE. For example, approximately four-fifths of them did not consider coronary atherosclerosis to be a complication of SLE.

On the other hand, most GPs considered SLE as a chronic disease and agreed that the management of SLE patients in community-level medical institutions was important and necessary. However, it was rare to see SLE patients visiting primary medical institutions, which lead to insufficient treatment and management experience for GPs. To change that, 76% of GPs believed that training courses were a good choice to acquire knowledge of SLE.

Discussion

This is the first study to assess, at the same time, knowledge in Chinese GPs and SLE patients about SLE. We found that most GPs have positive attitudes toward SLE management but did not feel that they performed it effectively. They showed poor awareness of its diagnostic classification, recurrence, complications and follow-up management. Several obstacles may explain this phenomenon. Few patients visited the primary care institutions because of lacking certain examinations and distrust of GPs’ ability, as well as the convenience to see a specialist without referral in China. This, in turn, will make GPs less and less experienced with SLE. Organizing training courses and going to general hospital for further study is a relatively recognized way to improve the ability of SLE diagnosis and treatment, but will be limited by the current work according to current medical situation in China. Our results also suggest, although, that guidelines may instruct GPs’ clinical practice on SLE, participants were less likely to search literatures, especially in foreign language, perhaps because they were not skilled at using English database due to educational level. According to our findings, we developed evidence-based recommendations which can inform the design of GP education programs on SLE.

Additionally, we found that SLE patients have many knowledge gaps and misconceptions, as well as education needs. For example, the majority believed that SLE was caused by immune-suppression, and it could be transmitted to their offspring, as well as lifelong glucocorticoid therapy was required. Deficiency of associated knowledge was common among patients regardless of different education levels, marital status, and disease duration or conditions. This may be related to the complexity, severity and relatively low incidence of SLE. Specially, the knowledge level was lower when subjects were unmarried or divorced, with lower education levels, had fewer hospitalizations and organs involved. This difference may be speculated to be due to insufficient family support and personal attention, which emphasize on the importance of family members on further education. Besides, someone mentioned that their knowledge of SLE came from the process of recurrence, which suggested that education in the early stages of the disease was crucial. Also, we summarize the unmet education needs of patients, and the first one is about medications. As we all know, adherence to steroids and Immunosuppressant is a high priority for

SLE patients. But associated drug side-effects might cause treatment discontinuity, which in some way could be ascribed to lack of knowledge. Obviously, patients did not acquire as much knowledge as we think they do. Besides the biological aspects, patients' psychological issues is also conspicuous. Some patients needed psychological counseling and psychotherapy because of psychological burden of the disease, especially those with higher education levels. The more medical needs patients have, the more difficult the current medical model is to meet. Along with the in-depth reform of the medical care system, a more holistic disease management, coordinated with general practitioner, might be an effective method to cope with the unmet need and manage patients better. General practitioners play an important role in the management of SLE patients which includes education, counselling, psychological support, monitoring and referral[18]. Yet, many primary medical institutions remain unaware of it, and efforts are still needed to spread high-quality patient education and standardise GPs' daily practice on SLE.

Strengths and limitations

Finally, a number of limitations need to be considered. First, the questionnaires were developed by authors and specialists from Peking Union Medical College Hospital(PUMCH). This could have caused less comparability with others. Secondly, GPs were recruited from one region in Beijing. This might limit the generalizability of these results to all GPs in China. The same is true for patients. Finally, the questionnaires of the investigation itself unintentionally influenced the participants' answers.

Conclusions

In conclusion, the study revealed significant gaps in GPs' knowledge required for the early identification and management of patients with SLE. Patients' views towards SLE suggests that health care providers have failed to educate patients about the disease self-management. Our findings highlight the need for better education of both GPs and patients about SLE to ultimately improve the care of all patients with SLE.

Declarations

Abbreviations

GP, General Practitioner; SLE, Systemic lupus erythematosus; PUMCH, Peking Union Medical College Hospital.

Ethics approval and consent to participate

The study received ethical approval from the Peking Union Medical College Hospital (no. S-K353). And written informed consent to use the data was obtained from all participants including parents for

participants under 16 years old.

Consent for publication

Consent for publication was gained from all participants as part of consenting to participate in the study.

Availability of data and materials

The data that support the findings of this study are available from the corresponding author on request.

Competing interests

The authors declare that they have no competing interests.

Funding

There are no funds in this article.

Authors' contributions

Wang JX designed the study and the questionnaires, collected and analysed all data, wrote the manuscript. Sha Y contributed to data-collection and critically edited the manuscript. Xu D co-designed the questionnaire and contributed to data-collection. Chen JL developed the idea for the study and critically edited the manuscript. All authors read and approved the final manuscript.

Acknowledgments

To all the SLE patients and GPs who voluntarily participated in this study. We would also like to thank Yan Long, Li Nie and Fumin Huang for their assistance with conducting the research and analyzing data.

Authors' information

Wang JX, Department of General Practice (General Internal Medicine), Peking Union Medical College Hospital, Chinese Academy of Medical Science Peking Union Medical College, Beijing 100730, China (Currently working in Yuetan Community Health Service Center, Fu Xing Hospital, Capital Medical University). Sha Y and Chen JL, Department of General Practice (General Internal Medicine), Peking Union Medical College Hospital, Chinese Academy of Medical Science Peking Union Medical College, Beijing 100730, China. Xu D, Department of Rheumatology, Peking Union Medical College Hospital, Chinese Academy of Medical Science Peking Union Medical College, Beijing 100730, China.

References

1. Fava A, Petri M: **Systemic lupus erythematosus: Diagnosis and clinical management**. *J Autoimmun* 2019, **96**:1-13. doi: 10.1016 / j.jaut.2018.11.001.
2. Felten R, Sagez F, Gavand P-E, Martin T, Korganow A-S, Sordet C, Javier R-M, Soulas-Sprauel P, Rivière M, Scher F *et al*: **10 most important contemporary challenges in the management of SLE**. *Lupus Sci Med* 2019, **6**(1):1-31. doi: 10.1136 / lupus-2018-000303.
3. Alsowaida N, Alrasheed M, Mayet A, Alsuwaida A, Omair MA: **Medication adherence, depression and disease activity among patients with systemic lupus erythematosus**. *Lupus* 2018, **27**(2):327-332. doi: 10.1177 / 0961203317725585.
4. Chehab G, Sauer GM, Richter JG, Brinks R, Willers R, Fischer-Betz R, Winkler-Rohlfing B, Schneider M: **Medical adherence in patients with systemic lupus erythematosus in Germany: predictors and reasons for non-adherence - a cross-sectional analysis of the LuLa-cohort**. *Lupus* 2018, **27**(10):1652-1660. doi: 10.1177 / 0961203318785245.
5. Marengo MF, Waimann CA, de Achaval S, Zhang H, Garcia-Gonzalez A, Richardson MN, Reveille JD, Suarez-Almazor ME: **Measuring therapeutic adherence in systemic lupus erythematosus with electronic monitoring**. *Lupus* 2012, **21**(11):1158-1165. doi: 10.1177 / 0961203312447868.
6. Mehat P, Atiquzzaman M, Esdaile JM, AviÑa-Zubieta A, De Vera MA: **Medication Nonadherence in Systemic Lupus Erythematosus: A Systematic Review**. *Arthritis Care Res (Hoboken)* 2017, **69**(11):1706-1713. doi: 10.1002/acr.23191.
7. Prados-Moreno S, Sabio JM, Pérez-Mármol JM, Navarrete-Navarrete N, Peralta-Ramírez MI: **Adherence to treatment in patients with systemic lupus erythematosus**. *Med Clin (Barc)* 2018, **150**(1):8-15. doi: 10.1016/j.medcli.2017.05.035.
8. Lam N-CV, Ghetu MV, Bieniek ML: **Systemic Lupus Erythematosus: Primary Care Approach to Diagnosis and Management**. *American family physician* 2016, **94**(4):284-294.
9. Mok CC: **Systemic lupus erythematosus: what should family physicians know in 2018?** *Hong Kong Med J* 2018, **24**(5):501-511. doi: 10.12809 / hkmj187319.
10. Cabrera Pivaral CE, Gutiérrez González TY, Gámez Nava JI, Nava A, Villa Manzano AI, Luce González E: **Clinical competence for autoimmune and non-autoimmune rheumatic disorders in primary care**. *Rev Alerg Mex* 2009, **56**(1):18-22.

11. Liu X, Hou Z, Towne SD, Jr., He M, Tan A, Jiang D, Mohammed ASH, Mao Z: **Knowledge, attitudes, and practices related to the establishment of the National Hierarchical Medical System (NHMS) among outpatients in Chinese tertiary hospitals**. *Medicine (Baltimore)* 2018, **97**(35):e11836-e11836. doi: 10.1097 / MD.0000000000011836.
12. Wang Y, Sun L, Hou J: **Hierarchical Medical System Based on Big Data and Mobile Internet: A New Strategic Choice in Health Care**. *JMIR Med Inform* 2017, **5**(3):1-15. doi: 10.2196 / medinform.6799.
13. Fang P, Jiang S, Yang X, Su M: **Discussion on key problems and countermeasures of the implementation of hierarchical medical system in China**. *Chinese Hospital Management* 2016, **36**(11):1-3.
14. Xue W: **Observation and reflection on the operation mode and effect of community health service.** *Medical Information* 2009, **01**(7):33-34.
15. Du X, Chen H, Zhuang Y, Zhao Q, Shen B: **Medication Adherence in Chinese Patients With Systemic Lupus Erythematosus**. *J Clin Rheumatol* 2018, **00**(00):1-5. doi: 10.1097 / RHU.0000000000000952.
16. Elera-Fitzcarrald C, Fuentes A, González LA, Burgos PI, Alarcón GS, Ugarte-Gil MF: **Factors affecting quality of life in patients with systemic lupus erythematosus: important considerations and potential interventions**. *Expert Rev Clin Immunol* 2018, **14**(11):915-931. doi: 10.1080/1744666X.2018.1529566.
17. Xu Q, Liu D, Zeng F, Luo H, Zuo X, Li Y: **Social support and management strategies for chronic disease in patients with systemic lupus erythematosus**. *Zhong Nan Da Xue Xue Bao Yi Xue Ban* 2019, **44**(1):67-73. doi:CNKI:SUN:HNYD.0.2019-01-012.
18. Mok CC: **Systemic lupus erythematosus: what should family physicians know in 2018?** *Hong Kong Med J* 2018, **24**(5):501-511. doi: 10.12809/hkmj187319.

Tables

Table1. Patients Characteristics (N=113)

Variables	Mean (SD) / median (IQR)
Age(y)	60.1 (12.0)
Sex, M/F(N)	61/52
Height (cm)	164.0 (7.5)
Weight (cm)	66.1 (10.8)
BMI (kg/m^2)	24.5 (3.3)
ASA, 1/2/3 (N)	7/96/10
SPO_2(%)	90.0 (89.0, 91.0)
Duration of mechanical ventilation (min)	220.0 (162.5, 285.0)
Total infusion (mL)	1500.0 (1000.0, 1500.0)
Duration of PACU stay (min)	105.0 (85.0, 137.5)
LUS score	13.0 (11.0,16.0)
Smoking status, N (%)	
Current	10 (8.8)
Previous	11 (9.7)
Never	92 (81.4)
Type of surgery, N (%)	
Neurosurgery	10 (8.8)
Thoracoscopic surgery	31 (27.4)
Abdominal surgery	45 (39.8)
Major orthopedics surgery	17 (15.0)
Others	10 (8.8)

Data were described as mean ± standard deviation or median and inter-quartile range as appropriate.

LUS score was described in patients without pneumothorax(N=85).

Abbreviations: SD, standard deviation; IQR, inter-quartile range; M, male; F, female; BMI, Body Mass Index; ASA, American Society of Anesthesiologists classification; SPO_2, oxygen saturation measured by pulse oximetry; PACU, postanesthesia care unit; LUS, lung ultrasound

Table 2a. Agreement between LUS and CT for atelectasis diagnosis

	LUS		
CT	+	-	Total
+	305	22	327
-	6	651	657
Total	311	673	984

Table 2b. Agreement between LUS and CT for pneumothorax diagnosis

	LUS		
CT	+	-	Total
+	72	3	75
-	8	253	261
Total	80	256	336

Table 2c. Agreement between LUS and CT for pleural effusion diagnosis

	LUS		
CT	+	-	Total
+	131	13	144
-	10	314	324
Total	141	327	468

Table2. Agreement between LUS and CT of pulmonary complications for accumulated quadrants

Table 3. Correlation between possible factors and lung ultrasound scores (N=85)

Variables	Correlation Coefficient (r)	*P*
Sex (M/F)	0.229	0.035
Age (y)	-0.041	0.707
BMI (kg/m^2)	-0.127	0.246
SPO_2 (%)	-0.244	0.024
Smoking	-0.039	0.725
Duration of mechanical ventilation (min)	-0.127	0.245
Type of surgery	0.075	0.494
Sufentanil dose (ug/kg/h)	0.125	0.253
Total infusion (mL)	0.046	0.677
Transfusion (Y/N)	-0.156	0.155

Lung ultrasound score was recorded and analyzed in patients without pneumothorax.

Abbreviations: LUS, lung ultrasound; M, male; F, female; BMI, Body Mass Index; SPO_2, oxygen saturation measured by pulse oximetry.

Figures

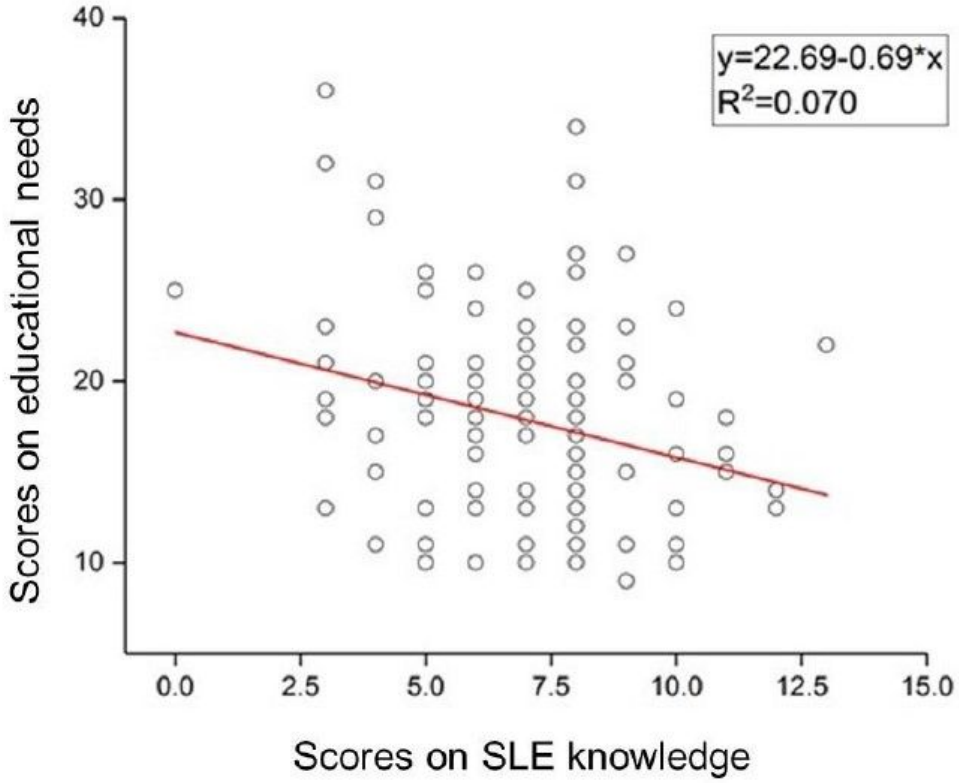

Figure 1

Correlation analysis for scores on educational needs and SLE knowledge.