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Awareness and Misconceptions of Female Students in King Saud University on Systemic Lupus Erythematosus

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Abstract

Objectives: To determine the level of awareness of systemic lupus erythematosus (SLE) among preparatory year program female students enrolling in King Saud University.

Methods: The authors developed a self-administered questionnaire to estimate the level of awareness on SLE. According to their scores, respondents are classified as knowledge adequate if they could answer 11 (35.5%) of the question. Descriptive statistics were calculated in terms of mean and standard. Chi-square and T tests were used to compare different subgroups for nominal and continuous variables respectively.

Results: Six hundred thirty participants completed the questionnaire. Mean age ± (SD) was 18.6 ± (1.17), 591(93.8%) were of Saudi nationality, and 607(96.3%) were single. The number of respondents in each university section was as follows: Humanity 228(36.2%), Health 201(31.9%), and Science 201(31.9%). One participant (0.02%) reported the diagnosis of SLE. Seventy-nine (12.5%) knew someone diagnosed with SLE. Two hundred fifty two (40%) have previously heard the term SLE. Of those, 73(29%) had adequate knowledge on SLE with a superior knowledge in participants who knew someone with SLE (p=0.018). In regards to the etiology of SLE, 71 (28.2%) identified it as an autoimmune disease. While 39(15.5%) thought it is infectious, 56(22.2%) attributed it to evil eye and 12(4.8%) believed it is the result of an act of sorcery or witch crafting. When asked about the preferred future source of knowledge, 476(75.6%) have chosen to obtain it directly from health care providers, while 183(29%) preferred social media.

Conclusion: The awareness on SLE among university participants is low. Future educational campaigns are needed to increase awareness and rectify misconceptions.

Keywords: Systemic Lupus Erythematosus; Female students; Awareness; Questionnaire

Background

Systemic lupus erythematosus (SLE) is a multisystem autoimmune disease of unknown etiology resulting in widely variable presentations. The effect of SLE on females is serious as its onset and diagnosis occur during reproductive age. One of the most important unmet needs in SLE is early detection and management. Initial nonspecific symptoms can substantially lead to diagnostic delay. The revised American College of Rheumatology (ACR) criteria originally designed for classification purposes [1] have been widely used as a diagnostic tool. This has led to a diagnosis delay of 2 years in the Euro-Lupus cohort in which the average age of symptom onset was 29 years, while the confirmed diagnosis (made by fulfillment of 4 criteria) was at age 31 years [2]. Public awareness is another vital factor that precedes clinical evaluation and has been shown to be an important step in reducing diagnosis delay of inflammatory arthritis [3]. Awareness on SLE is generally poor. In the period 1997-2001, Moriarty et al. studied the level of awareness among the Portuguese population and found that only 34.2% of the population was aware of the condition [4]. Another study performed in Ireland which aimed to evaluate SLE patients' satisfaction with the available health support services found that before being diagnosed, only 19% of the patients were aware of the existence of SLE [5]. Upon suspicion of the development of the condition, potential patients may seek medical advice more promptly. Early detection and management of SLE may aid in the control of the condition and avoidance of irreversible damage observed in unmanaged cases [6]. The effect of awareness in shortening diagnosis delays was also reported by the Portuguese study, as a shortening in the delay was observed after awareness campaigns [4]. The aim of this study was to evaluate the level of awareness in a selected population using a self-administered questionnaire consisting of selected ACR classification criteria as components of awareness testing.

Methods

This is a quantitative observational cross-sectional study. Preparatory year participants from the science, humanity and health sections in King Saud University in the year of 2013/2014 were included.

Because of few background studies this project could rely on to calculate an adequate sample size, a pilot study was conducted on 14 participants, which revealed an awareness level of 7%. The accuracy of the estimate desired is 2% with a 95% confidence interval (C.I.). The sample size was therefore estimated to be 625. An extra 75 study

subjects were added in case of incomplete questionnaires or participants who are unwilling to participate or do not give their consent. This gives a total sample size of 700. A stratified sampling technique was chosen for its feasibility. To achieve this, investigators asked for the number of classes in each preparatory year section (humanity, health, and science) then divided the sample size (700) among these sections. After that, the investigators randomly chose equal number of classes from each section to match the sample size. The data collection tool in our study was a self-administered questionnaire in Arabic, which was designed according to our requirements. Questionnaires were distributed among participants during class hours. The investigators divided the chosen classes from each section among them. The questionnaire consists of 3 sections: Socio-demographic data, participant's existing knowledge about SLE, and source of future knowledge. Participants' existing knowledge about SLE was evaluated through a scoring system with a maximum value of 31 answers. Participants were grouped into 2 categories according to their level of knowledge: Adequate (a score of 11 or more out of 31) and Inadequate (a score of less than 11 out of 31). This categorization is determined based on the participants' ability to respond correctly to 35.5% of the scored questions. The developed questionnaire took into consideration religion/beliefs as an important background in the Muslim version (since prayer/Roqiua was considered as a right answer in the management of SLE section) and was taken out in the suggested non-Muslim version. This modified scoring system for non-Muslims is defined as having adequate knowledge of SLE by achieving a score of 11 or higher out of 30 scored options, which represents 36.7% of the overall scored options.

Data were analyzed using SPSS Version 21. Descriptive statistics were calculated in terms of mean and standard deviation. Participants' scores were compared based on their university tracts, previous high school and whether or not they are acquainted with someone with SLE using independent-samples t-tests. Chi-square was used to compare different subgroups for nominal variables. A p-value ≤ 0.05 was considered significant. The study was approved by the institutional review board of the college of medicine.

Results

Demographics

Six hundred and thirty participants completed the questionnaire and were included in the final analysis. Mean age ± (SD) was 18.6 ± 1.17, with 591(93.8%) being of Saudi nationality, and 607(96.3%) were single. The number of respondents in each university section was as follow: humanity 228(36.2%), health 201(31.9%), and science 201(31.9%) (Table 1). One participant reported the diagnosis of SLE, corresponding to the prevalence of 2/1000.

Variable	Value
Age	
N	630
Mean ± (SD)	18.6 ± (1.2)
Nationality	
Saudi	591 (93.8%)
Other	39 (6.2%)
Marital status	
Single	607 (96.3%)
Married	19 (3%)
Divorced	4 (0.7%)
Section	
Health	201 (31.9%)
Science	201 (31.9%)
Humanity	228 (36.2%)
High school	
Private	282 (44.8%)
Public	348 (55.2%)
Residence before enrolling in KSU	
Riyadh	605 (96%)
Other	25 (4%)

Table 1: Demographic characteristics of study participants (N=630).

Knowledge on SLE

Two hundred and fifty two (40%) have previously heard the term SLE. When participants were asked about symptoms of SLE (multiple-answer allowed), the majority of participants [118(56.1%)] selected hair loss, while only 18 (10.5%) of participants selected lung problems. Forty-seven (26.3%) participants selected depression as a symptom of SLE. The number of participants who thought symptoms of SLE are anemia 65(34.5%), weight loss and headache 51(28.4%) for both, reproductive problems 38(21.2%), mouth ulcers 36(21.2%), loss of energy 72(38.6%), heart problems 28(16.2%) and kidney problems 22(13.4%) were similar among all university tracts. The frequency of participants who thought skin rash is a symptom was higher (P=0.009) among health tract participants compared to the other tracts. The percentages of participants who did not select joints pain, fever, poor concentration, and hallucination options as symptoms of SLE were found to be higher (P=0.009, P=0.007 and P=0.006 respectively) among humanities compared with the other tracts.

In regards to the etiology of SLE, 71(28.2%) identified it as an autoimmune disease. While 39(15.5%) thought it is infectious, 56(22.2%) attributed it to evil eye and 12(4.8%) believed it is the result of an act of sorcery or witch crafting (Figure 1). When participants were asked about how SLE is diagnosed (multiple-answer allowed), 163 participants (64.7%) selected blood tests. The option "SLE is diagnosed by history and examination" was selected by 134 (53.2%) of participants, followed by 36 participants who chose urine tests as a way of diagnosing SLE (14.3%). The number of participants who selected imaging modalities as a method of diagnosing SLE is 44(17.5%). When participants were asked about the proper management of SLE (multiple-answer allowed), patient's education received the majority of selections by 166 participants (65.9%). Management with medications came in second place with 131 selections (52%). Roqiua/prayers option was selected by 96 participants (38%) among all included tracts. Participants who thought the management is by sunlight avoidance and psychotherapy are 52(20.6%) and 42(16.7%) respectively. While 43(17%) did not know what management of SLE was. The number of participants who selected "surgery", "no treatment" and "herbal treatments" options was 9(3.6%), 15(6%), and 24(9.5%) respectively. The only value that showed statistical significance was the percentage

of participants who chose healthy lifestyle (39.3%) as a management of SLE, which was higher (P=0.004) among heath tract students.
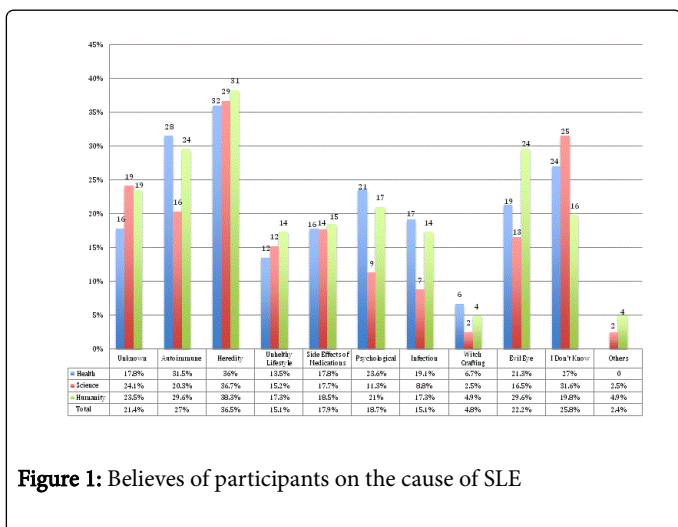

Figure 1: Believes of participants on the cause of SLE

The family physician was thought to be the best physician to treat SLE by 108(42.9%), while the rheumatologist was chosen by only 48(19%) (Figure 2).
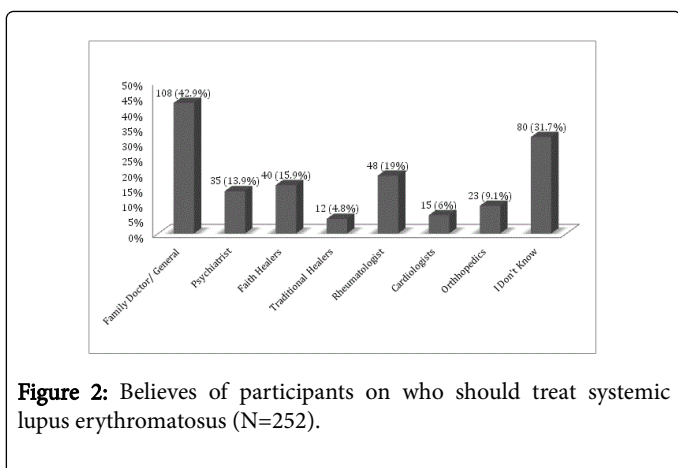

Figure 2: Believes of participants on who should treat systemic lupus erythromatosus (N=252).

Source of information

When asked about the source of information on SLE, 149 (59.1%) participants acquired it from books, newspapers and magazines, followed by Twitter [142 participants (56.3%)] and informative paper documents [55 (21.8%)]. Information delivered by health care providers consisted of a minority (13.1%) (Figure 3). Future source of information preferred by participants (multiple answers were allowed) included information directly from health care providers (75.6%), informative paper documents (38.7%), Twitter (29%) and television programs (18.3%).
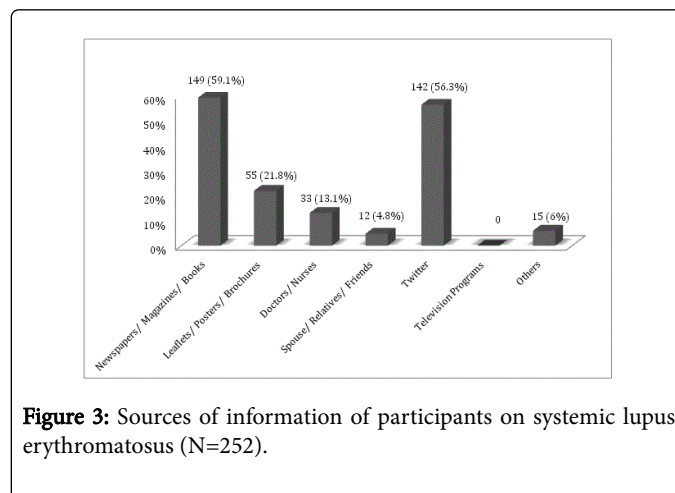

Figure 3: Sources of information of participants on systemic lupus erythromatosus (N=252).

Scoring

Out of the 252 participants who heard the term SLE, 73(29%) have adequate knowledge based on the criteria proposed with a maximum score of 24 out of 31. Participants who knew someone with SLE had higher scores than those who did not (p=0.018). We found no significant differences in the level of adequacy of knowledge when comparing the scores between the different university tracts and between the types of high school.

Discussion

This study evaluates awareness and explores many misconceptions about SLE in a homogenous cohort controlled for age, gender and level of education. We have found that a minority of the participants who had previously heard the term SLE had an actual knowledge of this condition. Therefore, it seems inadequate to evaluate disease awareness subjectively. This observed failure to recognize the disease's characteristics and symptoms may cause a delay in seeking medical advice which may result in a more severe form of the disease [6], leading to greater financial burden on both patient and society [7,8].

Only one patient reported to have SLE, this might reflect the prevalence of the childhood onset form in this selected population (as the mean age was 18 years).

We have found misconceptions concerning SLE that need attention and can have devastating consequences. Despite that our sample was from a middle educational level, witchcraft and evil eye were identified as etiologies of SLE. Witchcraft has been deemed the cause of certain diseases [9,10] or as a preventive measure in other instances [11]. Similar to our findings, Jassim and Whitford evaluated the perception of Bahraini female patients suffering from breast cancer and found that evil eye was believed to be a fundamental cause of their illness [12]. These beliefs might lead patients to seek treatment through alternative medicine or faith healers at the period of diagnosis, or when medical therapy inadequately controls the disease. Those are the most crucial times when SLE patients need to be followed closely.

Similarly, the assumption that SLE is an infectious disease and is contagious influence individuals not to maintain social relations with lupus patients, and the conviction of it being vertically transmitted might affect marriage and family planning.

Only one fourth of the participants recognized the rheumatologist as the best physician treating SLE. This means that not only do diseases

need increasing awareness, but also the rheumatology subspecialty itself needs promotion in the public section.

The majority of participants acquired information from unreliable sources as the information transmitted through these means becomes distorted, and disease processes are confused; hence, greater misunderstanding regarding SLE spreads among the population.

Social media platforms such as Twitter are emerging and promising tools for healthcare providers to educate the public. This was shown by a study performed on women's health in Saudi Arabia [13]. When evaluating social networking services, a larger proportion of participants preferred Twitter over Facebook. These results might be a reflection of the number of participants who use these networks, or perhaps the availability of medical accounts on both networks [14].

Overall, the degree of knowledge did not vastly differ between the university tracts, nor did the types of school attended previously have any bearing. It is theorized that this uniformity may be due to the commonly shared curriculum throughout the country. Furthermore, participants' education and knowledge haven't had time to be adequately shaped by their respective fields.

The main limitation of our study is the use of a non-validated tool which was designed by the investigators. Additionally, the results cannot be generalized to the Saudi population, for that reason there is a need to reproduce the results on the general public.

Conclusion

Awareness on SLE among female university students is inadequate, with a number of misconceptions. The disease and its treating subspecialty need adequate promotion and advertisement.

Funding Source

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