

PERFORMANCE OF THE “DO YOU KNOW WHAT I MEAN” QUESTIONNAIRE IN THE ASSESSMENT OF DISEASE KNOWLEDGE IN PATIENTS WITH SYSTEMIC LUPUS ERYTHEMATOSUS

Serrano, ER¹; Pérez, SK¹; Bande, JM¹; Sosa, J¹; Kohan, MP¹; Klajn, DS¹; Medina, MA¹; Papisidero, SB¹; Caracciolo, JA¹; Leguizamón, ML²; Mazza, SM²; Soria Curi, YJ²; Huttmann, FJ²; Bellomio, V²; Matellán, CE³; Micelli, M³; Kerzberg, EM³; Peon, C⁴; Mata, DO⁴; Isnardi, CA⁵; Capelusnik, D⁵; Yohena, VL⁶; Álvarez, A⁶; Machado Escobar, M⁷; Yacuzzi, MS⁷; Saurit, V⁸; Cucchiario, NL⁹; Crespo Espindola, ME⁹; Loayza Reynolds, GB¹⁰; Bottinelli, Y¹⁰; Garate Correa, G¹¹; Gómez, R¹²; Dubinsky, D¹²; De la Torre, ML¹³; Pisoni, C¹³; García Coello, A¹⁴.

¹ Hospital General de Agudos Dr. E. Tornú, Buenos Aires; ² Hospital Ángel C. Padilla, Tucumán; ³ Hospital General de Agudos J.M. Ramos Mejía, Buenos Aires; ⁴ Hospital de Agudos Cosme Argerich, Buenos Aires; ⁵ Instituto de Rehabilitación Psicofísica, Buenos Aires; ⁶ Hospital General de Agudos J.M. Penna, Buenos Aires; ⁷ Hospital Eva Perón, Tucumán;

⁸ Hospital Privado Córdoba, Córdoba; ⁹ Hospital Señor del Milagro, Salta; ¹⁰ Hospital Posadas, Buenos Aires; ¹¹ Sanatorio Güemes, Buenos Aires; ¹² Hospital de Clínicas José de San Martín, Buenos Aires; ¹³ Centro de Educación Médica e Investigaciones Clínicas Norberto Quirno, Buenos Aires; ¹⁴ Hospital General de Agudos Dr. Ignacio Pirovano, Buenos Aires.

BACKGROUND/PURPOSE: A high level of knowledge of the disease is essential in Systemic Lupus Erythematosus (SLE) patients to enhance adherence to treatment, and allow an early identification of symptoms anticipating a possible disease flare. “Do You Know What I Mean?” is a self-reported questionnaire recently developed by Meara et al. It is a 27-item true/false questionnaire based on disease outcomes, complications and treatment. The aim of this study was to validate this questionnaire in a cohort of Argentinian patients with SLE, to assess the level of knowledge of the disease and its association with disease characteristics.

METHODS: Multicenter, observational, cross-sectional, descriptive and analytical study. Consecutive patients ≥ 18 years old with SLE (ACR 97 and SLICC 2012) were included.

Sociodemographic variables, disease characteristics and those that could influence the level of knowledge were recorded: education level; age at SLE onset and disease duration, hospitalizations associated with SLE, proximity to SLE (defined as past or current contact with a relative, friend or partner with SLE), and educational exposure (use of internet and/or social networks and/or participation in support groups). The “Do You Know What I Mean?” questionnaire was filled out by all the patients. They were asked in addition to explain the reason for not answering an item (it wasn't understood or the answer was ignored?).

Statistical analysis: Sociodemographic and disease characteristics were described. Cronbach's alpha and test-retest reliability were determined. For each question, median and interquartile range (IQR) of correct, incorrect and missing answers were recorded. All the comparisons were made with Student's T test, Chi2 and Fisher's exact test or Spearman correlation.

RESULTS

A total of 277 patients from 14 centers in Argentina were included.

Table 1: Population characteristics

| | |
|--|-------------|
| Age in years, mean (SD) | 38.7 (13.0) |
| Women, n (%) | 247 (89.2) |
| Education Level, n (%) | |
| - Illiterate | 1 (0.4) |
| - Incomplete Primary education | 15 (5.5) |
| - Complete Primary education | 26 (9.5) |
| - Incomplete Secondary education | 57 (20.9) |
| - Complete Secondary education | 110 (40.3) |
| - Incomplete Tertiary education/University | 26 (9.5) |
| - Complete Tertiary education/University | 38 (13.9) |

SD: Standard Deviation.

Table 2: Disease characteristics

| | |
|--|--------------|
| Disease duration in months, median (IQR) | 96 (36-168) |
| Age at SLE onset, mean (SD) | 28.72 (12.5) |
| Previous SLE-related hospitalizations, n (%) | 178 (65.0) |

IQR: Interquartile Range; SD: Standard Deviation.

Table 3: SLE Indexes

| | |
|--------|---------|
| SLEDAI | 0 (0-4) |
| SLICC | 0 (0-1) |

IQR: Interquartile Range; SLEDAI: Systemic Lupus Erythematosus Disease Activity Index; SLICC: Systemic Lupus International Collaborating Clinics/American College of Rheumatology (SLICC/ACR) Damage Index for SLE

elianaserrano87@gmail.com

Acknowledgment: Meara, A.

Bibliography

- 1- Meara A, Yedimenko J, Steigelman H, et al. “Do You Know What I Mean?” a Tool to Understand What Lupus Patients Comprehend [abstract]. Arthritis Rheum. 2017; 69 (10): 2265-67.
- 2- Sullivan S. Development of a Systemic Lupus Erythematosus Knowledge Questionnaire: The Relationship Among Disease Proximity, Educational Exposure and Knowledge. Theses and Dissertations 2016; Paper 1312.
- 3- Young SP, Henderson E, Cheseldine DL, et al. Development and assessment of a World Wide Web site for systemic lupus erythematosus patient information. Lupus 2002; 11: 478-84.

Figure 1: Types of involvement in SLE patients



PNS: Peripheral Nervous System; APS: Antiphospholipid Syndrome; CV: Cardiovascular; NP: Neuropsychiatric; MC: Mucocutaneous.

Table 4: Treatment

| | |
|-----------------------|------------|
| NSAIDs | 20 (7.2) |
| Glucocorticoids | 158 (57.0) |
| Hydroxychloroquine | 249 (89.9) |
| Azathioprine | 48 (17.3) |
| Methotrexate | 28 (10.1) |
| Mycophenolate Mofetil | 64 (23.1) |
| Cyclophosphamide | 11 (4.0) |
| Belimumab | 8 (2.9) |
| Cyclosporine | 5 (1.8) |
| Rituximab | 7 (2.5) |
| Others | 5 (1.8) |

NSAIDs: Non-Steroidal Anti-Inflammatory Drugs.

Table 5: Factors with possible influence in the level of knowledge of the disease

| | |
|---------------------------------------|-----------|
| Contact with individuals with SLE | 61 (22.8) |
| Educational exposure to SLE (N = 254) | 59 (23.2) |
| • Social networks | 32 (71.1) |
| • Internet | 23 (52.3) |
| • Patient support groups | 8 (19.1) |

Twenty three percent of patients had educational exposure; 71% of them sought information on social networks, 52% on internet and only 19% attended informative talks.

Table 6: Number of correct answers according to SLE exposure (N = 254)

| SLE exposure | Median (SD) | | p-value |
|----------------------|---------------|------------------|---------------|
| | With Exposure | Without Exposure | |
| Educational exposure | 18.9 (3.9) | 17.01 (4.01) | 0.0012 |
| SLE Proximity | 17.6 (3.6) | 17.5 (4.1) | 0.2609 |

SD: Standard Deviation

Between 55-77% of patients do not consider SLE as a cardiovascular risk factor or cause of death. Between 16-36% gave incorrect answers to corticosteroid-related questions, while 11-50% stated that they did not know the answer.

QUESTIONNAIRE

Internal consistency: Cronbach's alpha 0.73.
Test-retest reliability (n = 32) : 0.78.

Median number and IQR for each type of response (N = 277)

| Correct answers | Wrong answers | "I don't understand" answers | "I don't know" answers |
|-----------------|---------------|------------------------------|------------------------|
| 18 (15-20) | 5 (3-7) | 0 (0-0) | 3 (1-5) |

IQR: Interquartile Range

The number of correct responses was higher with an earlier age at onset of the disease (**p < 0.0001**).

Table 7: Number of correct answers according to education level (N = 277)

| Education level | Median (IQR) | p-value |
|--|--------------|----------------------|
| Illiterate | 16 (16-16) | p < 0.0001 |
| Incomplete Primary education | 16 (12-18) | |
| Complete Primary education | 15 (12-17) | |
| Incomplete Secondary education | 17 (14-19) | |
| Complete Secondary education | 18 (16-21) | |
| Incomplete Tertiary education/University | 20 (18-22) | |
| Complete Tertiary education/University | 20.5 (18-23) | |

IQR: Interquartile Range

CONCLUSION

“Do you know what I mean?” proved to be a valid and reliable questionnaire in patients with SLE, to assess their knowledge about their disease. In addition, this study showed that the areas of highest lack of knowledge were those associated with cardiovascular impact of the disease and glucocorticoid-related adverse effects. We believe that the use of this questionnaire could be useful as a guide of educational strategies in patients with SLE, in order to improve adherence to treatment and prognosis.