

A RESEARCH ON THE IMPLICATIONS OF LIVING IN THE UK OR SPAIN AND SUFFERING FROM LUPUS DISEASE

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Introduction:

Lupus is an autoimmune disease which affects 1 in 9.000 people, mainly affecting women. It causes many different symptoms, the most common ones being: fatigue, fever, joint and muscle pain and inflammation, and rashes. However, each patient presents different symptoms and in a distinct way, which makes it very hard to diagnose and treat. Nevertheless, lupus also has a social and a human side which are often ignored, and they are key for the wellbeing of patients and the developing of this disease. In order to study lupus I have compared its three sides — medical, social and human— between two European countries: Spain and the UK. The main goal for this research project was to study how differently a disease could affect two different countries which are close geographically and have a very similar economic development, yet a very different health system and “modus vivendi”. In the Research Project I explain the lupus disease (including the immune system and autoimmune diseases) and I analyse the results obtained from the comparison.

Hypothesis:

Lupus disease only affects patients from Spain differently than patients from the UK in a few aspects. Consequently, the differences between both countries in the medical side are not as contrasting as those in the social and human sides. The view of such disease in society and the way support is given to patients is notably dissimilar between each country.

Goals:

For this Research Project I had a list of goals I wanted to achieve. The first one was to fully understand autoimmune diseases, especially lupus. This included being deeply informed about the immune system and its malfunctions. Once this was achieved, my next goal was to get to know how lupus interferes patients’ life, how family members can help, what research is being done, what lupus charities do, and endless other lupus aspects. This was managed by polling and interviewing, and my next goal then became to analyse the data obtained from the UK and the data obtained from Spain and compare it. To do so, I had to learn about data administrating softwares, which was also a challenge.

I as well had personal goals, which were: enjoy the opportunity to profoundly learn about a disease and learn how to do a “professional” research project.

Methodology:

I needed to collect as much information as possible from lupus patients, lupus patients’ family members, lupus specialists and lupus charities, from Spain and from the UK. To make it possible I created a total of four polls: one to lupus patients in Spanish, one to lupus patients in English, one

to family members to lupus patients in Spanish and one to family members to lupus patients in English. The poll to lupus patients had a total of 48 questions whereas the poll to family members had a total of 21. Then, I interviewed male lupus patients, female lupus patients, family members to lupus patients, lupus specialist doctors and lupus charities staff members.

From the patients' poll there were a total of over 400 responses, and the poll to relatives had almost 100 responses. In order to make this data comparable I transcribed it to an excel document. In one excel book I had the lupus patients' poll responses and in another one the relatives' polls responses. Then, I selected the same amount of data from the poll done in Spain and the poll done in the UK so that the data was comparable. The unused data was either not meeting the requirements or chosen at random. Then, the Spanish was translated into English, and for every question of the poll, I created dynamic graphs and tables where the data was compared between both countries. The graphs used were bar graphs.

The interviews in Spanish were translated into English, and reading through them showed some differences between both countries which couldn't be seen with the polls' data.

All the polls' respondents and interviewees who made this project possible were contacted through Lupus UK and ACLEG, the two main lupus charities in the UK and in Catalonia.

Results:

After carefully analysing the results obtained I could spot some important dissimilarities in many aspects of lupus between Spain and the UK. From the polls to lupus patients the most important dissimilarities were quite more than expected. I could observe how the symptoms tend to appear at an earlier age in the UK than in Spain. Nevertheless, the frequent symptoms patients suffer from are very similar in both countries. Moving on, I saw how, in general, patients from the UK have a lot more lupus flares than the Spanish ones. We can then see this reflected in the drugs they take, as a lot of patients from the UK take immunosuppressants, which helps their immune system to dump down. Then, one of the most relevant conclusions reached is that it is more common for patients from Spain to suffer from renal problems. We see this reflected in the graphs representing the most frequent symptoms, the secondary illnesses (lupus nephritis), the medication taken and the doctor visited. Also, related to the doctors visited by patients it is curious to realise how in Spain, the most commonly visited doctor is the internist followed by there rheumatologist by a big difference. However, the rheumatologist is visited by almost every single British patient, whereas internists are barely ever visited. Related to the diagnostic process, it was clear how tests carried out to diagnose lupus are very similar in both countries, although general blood tests are very commonly performed in the UK and not so much in Spain. In the UK lupus is more often mistaken for another disease. Furthermore, patients from the UK considered they have a higher adherence to the treatment than those from Spain. Then, when analysing the family members' poll we see how most Spanish relatives consider themselves important when it comes to the patients' adherence to the treatment, a lot more than British relatives. Moreover, from the interviews to lupus charities staff members I realised how the one from Spain had a very different ideology yet similar goals to this from the UK. Finally, from the specialists' interviews, I learnt how the future of lupus are biological therapies, and how very different investigations on lupus have been performed in each country.

Bibliography and Weblibliography:

FELIU L. *Guia pràctica per a pacients amb lupus*. Guissona, Lluís i Eulàlia, 2014

SHOENFELD Y; JARA LJ; CERVERA R. *Enfermedades autoinmunes: el enemigo interior*, Medellín, Corporación para Investigaciones Biológicas, 2006

CORBELLA, J. “Quiero derrotar las enfermedades autoinmunes”. *La Vanguardia*, 19-2-2017

CERVERA R. (2018) *Què és el Lupus* [Online] CLÍNIC BARCELONA [Accessed: July 2020] Available at: <<https://www.clinicbarcelona.org/ca/asistencia/malalties/lupus/definicio>>

FINK, D (2020) *Womens health: lupus* [Online] Office on Womens’s Health [Accessed: April 2020] Available at: <<https://www.womenshealth.gov/lupus>>

HIRSCH, L (2019) *Immune system* [Online] Kids Health [Accessed: July 2020] Available at: <[https:// kidshealth.org/en/parents/immune.html](https://kidshealth.org/en/parents/immune.html) >

TAVELLA, V (2020) *What is Lupus?* [Online] Medical News Today [Accessed: July 2020] Available at: < <https://www.medicalnewstoday.com/articles/323653#diagnosis>>

(2013) *Overview of the Immune System* [Online] National Institute of Allergy and Infectious Diseases [Accessed: August 2020] Available at: <<https://www.niaid.nih.gov/research/immune-system-overview>>

(2017) *Lupus A Guide for Patients* [Online] LUPUS UK [Accessed: April 2020] Available at: <<https://www.lupusuk.org.uk/wp-content/uploads/2015/09/LUPUS-A-Guide-forPatients-V2.pdf>>

(2017) *Lupus: The Symptoms and Diagnosis* [Online] LUPUS UK [Accessed: April 2020] Available at: <<https://www.lupusuk.org.uk/wp-content/uploads/2015/09/LUPUS-the-Symptoms-andDiagnosis-V1.pdf>>

(2017) *My Lupus: What I Need to Know* [Online] LUPUS UK [Accessed: April 2020] Available at: <[https:// www.lupusuk.org.uk/wp-content/uploads/2018/08/My-Lupus-What-I-Need-toKnow-V1.pdf](https://www.lupusuk.org.uk/wp-content/uploads/2018/08/My-Lupus-What-I-Need-toKnow-V1.pdf)>

(2018) *Lupus and Medication* [Online] LUPUS UK [Accessed: July 2020] Available at: <<https://www.lupusuk.org.uk/wp-content/uploads/2018/07/LUPUS-and-MedicationV.1.pdf> >

(2018) *How the immune system works?* [Online] Medical News Today [Accessed: July 2020] Available at: <<https://www.medicalnewstoday.com/articles/320101#immunity> Khan Academy>

(2018) *Malalties immunològiques* [Online] Vall d’Hebron Barcelona Campus Hospitalari [Accessed: May 2020] Available at: <<https://hospital.vallhebron.com/ca/malalties/malalties-immunologiques> >

(2020) *Autoimmune disorders* [Online] Medline plus [Accessed: May 2020] Available at: <<https://medlineplus.gov/ency/article/000816.htm> >