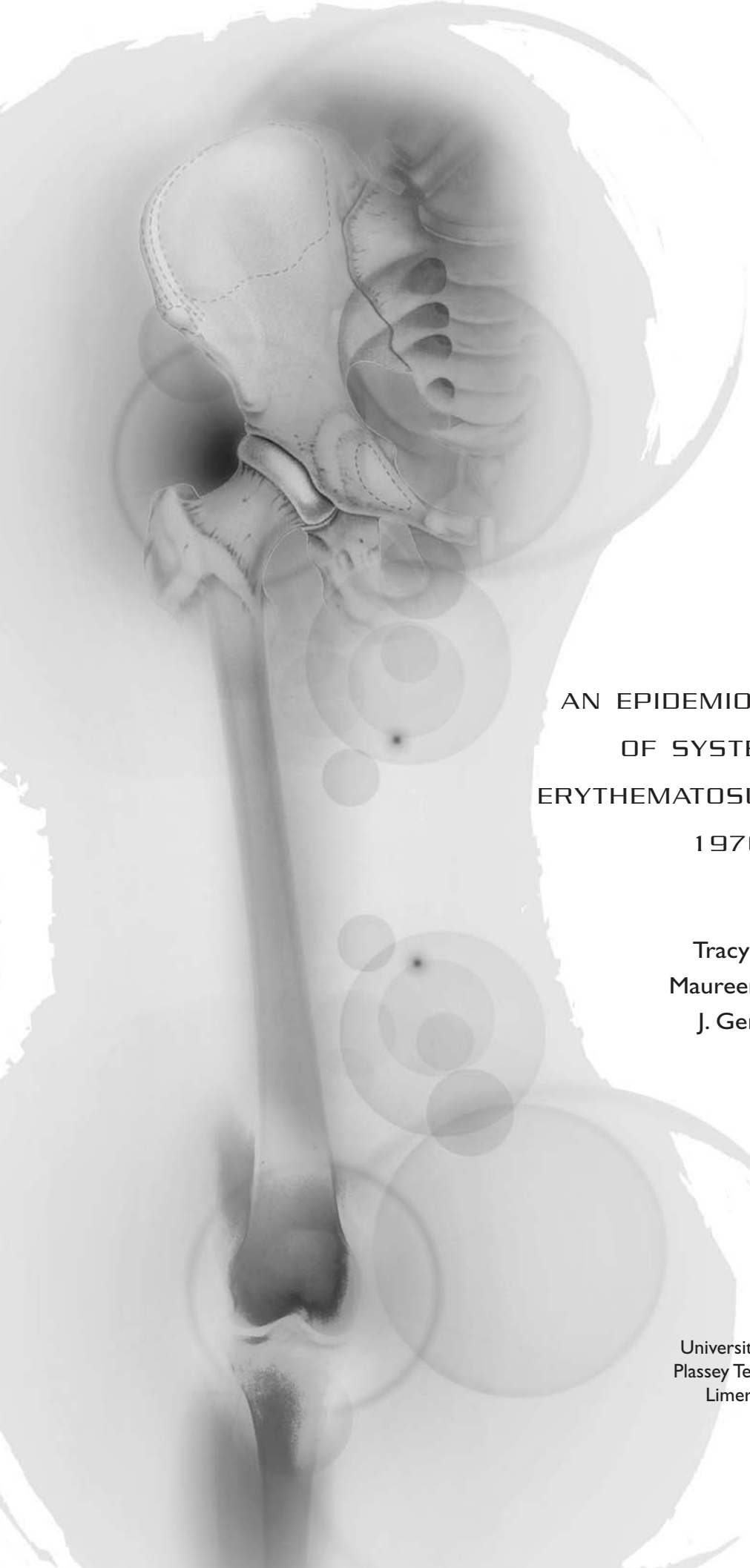

AN EPIDEMIOLOGICAL STUDY OF SYSTEMIC LUPUS ERYTHEMATOSUS IN PORTUGAL, 1970-2001

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ABSTRACT

Systemic lupus erythematosus is a multi-system autoimmune disease with highly variable symptoms. The purpose of this work was to carry out an analysis of SLE in Portugal, concentrating on such factors as clinical presentation, diagnosis information, lupus awareness and supports available to patients. Questionnaires developed by the European Lupus Erythematosus Federation were distributed to members of the Portuguese Lupus Support Group (Associação de Doentes com Lúpus) and the results from the 941 returned forms were analysed in our group.

The Portuguese patient cohort displayed a characteristic female:male ratio of 11:1 and standard evidence of genetic involvement in the development of SLE. Amongst the broad range of symptoms reported, the most common were joint and muscle pains and skin problems of various kinds, which are also characteristic of SLE patient groups. Analysis of the length of time taken for diagnosis revealed that it remained relatively unchanged over the 1970-2001 study period. However, there was a sudden increase in lupus awareness in the mid-1990s, which coincided with a major lupus awareness campaign carried out by the Support Group.

Key Words: Systemic Lupus Erythematosus; Diagnosis; Epidemiology.

RESUMO

O Lúpus Eritematoso Sistémico (LES) é uma doença sistémica autoimune com sintomas muito variáveis. O objectivo deste trabalho foi o de efectuar uma análise do LES em Portugal, concentrando-se em factores como a apresentação clínica, a informação sobre o diagnóstico, conhecimento sobre a doença e apoios disponíveis para os doentes. Foram distribuídos questionários desenvolvidos pela Federação Europeia de LES aos membros da Associação Portuguesa de Doentes com Lúpus e os resultados de 941 formulários preenchidos foram analisados pelo nosso grupo.

A amostra de doentes Portugueses analisada apresentava uma típica relação sexo feminino:masculino de 11:1 e uma evidência de envolvimento genético no desenvolvimento do LES. Entre os sintomas relatados, os mais comuns foram dores articulares e musculares e problemas cutâneos de vários tipos, que são também característicos dos doentes com LES. A análise do tempo necessário para estabelecer o diagnóstico revelou que este manteve-se relativamente inalterado ao longo do período de estudo (1970-2001). No entanto, ocorreu um súbito aumento no conhecimento sobre a doença no meio da década de 1990, que coincidiu com uma importante campanha de informação desenvolvida pela Associação de Doentes com Lúpus.

Palavras Chave: Lúpus Eritematoso Sistémico; Diagnóstico; Epidemiologia.

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Introduction

Systemic Lupus Erythematosus (SLE) is a systemic autoimmune disease with a female dominance. The ratio of women to men with the disease is 8-10:1 among the general adult population and 5-7:1 among the elderly. It is generally considered a disease of fertile women, between the ages of 20-40 years[1]. In the United States at least 131,000 individuals have been afflicted with the disease, and in excess of 1,000,000 people worldwide. Various reports have also indicated that the incidence of SLE has increased significantly over the past four decades, *e.g.* from an incidence of 1.15 per 100,000 in 1950-79 to 5.56 per 100,000 in 1980-92[2]. Studies in the U.K report a prevalence of 20-30 per 100,000 which mean that approximately one person in 3,500-5,000 has lupus (UK Lupus Group)[3]. SLE also shows a marked variation in frequency between different racial groups, however, with the disease considerably more prevalent in African Americans, Latin Americans, Native Americans and Chinese than in Caucasians or Hispanics[4-6].

There has been a reduction in the case fatality rate over the past number of decades: the 10-year survival rate is 75-85% with more than 90% of patients surviving more than 5 years[7]. However, studies in countries with poorer access to medical care can still show 10-year survival rates as low as 60-70%[8]. The improvement in life expectancy in developed countries has been variously attributed to improved treatment regimes and to greater lupus awareness and the wider range of tests available, allowing the early detection of milder forms of the disease[7].

The objective of this work was to carry out a study of SLE patients in Portugal, concentrating on such factors as clinical presentation, diagnosis delay, and lupus awareness and supports available to patients.

In 1991 the European Lupus Erythematosus Federation (ELEF) conducted a Europe-wide survey on Lupus. The present work was based on the questionnaire developed by the ELEF for its 1991 study and was carried out at the University of Limerick, Ireland out as a collaborative project involving the Portuguese Association of Patients with Lupus (Associação de Doentes com Lúpus). It follows from a similar study carried out in the Republic of Ireland in 1997-9 in association with the Irish Lupus Support Group[9,10].

Material and Methods

Study design

The ELEF was formed in 1989 and currently has 16 member organisations, including the Portuguese Association of Patients with Lupus, in 15 member countries. The aims of ELEF are to collect information on all aspects of lupus and thereby assist in improving the knowledge of the disease for lupus patients, and members of the health, welfare and medical professions; to promote awareness of the disease and to assist in the establishment of groups in European countries where they do not exist; to gain representation on any European or International body whose interests could be of benefit to members of ELEF; and to encourage and undertake surveys and research projects related to the disease and to publish useful results of any such survey. Since its inception in 1992, the Portuguese support group has provided free psychological counselling, free accommodation in Lisbon and in Oporto for patients travelling for medical care and a national toll free telephone number for information about lupus and patients' legal rights. It also provides socio-economic support to patients in

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need and has gained exemptions for lupus patients from paying for medication and hospital assistance. Furthermore, a biannual meeting of lupus patients, family members and healthcare workers is organised to provide information and support while radio and television interviews, newspaper and magazine articles, and occasional art exhibitions, marathons, seminars and other events are organised throughout the country to raise awareness of the condition.

Questionnaires developed by ELEF were distributed to all patients upon joining the Portuguese Lupus Support Group and were returned either by post or to the Support Group offices in Lisbon, Oporto, Alentejo and Azores, on an ongoing basis from 1993-2001. Because identification of respondents was not recorded, it was not possible to determine the prevalence of the disease or to conduct interviews or consult patient records in order to determine whether the sample cohort was representative of the entire disease population. The 941 questionnaires that had been completed and returned by the beginning of this analysis (May 2001) were passed to the group at the University of Limerick for data analysis. Data analysis was carried out using Microsoft Excel statistics software and Minitab 13 for Windows. The Student's t test was used for statistical evaluation of differences of mean values, with *P* values of 0.05 or less considered significant.

Questionnaires

A copy of the questionnaire is provided in Appendix 1. It consists of eight main sections:

Section 1: General Information
This section gathered general information on the respondent's age, gender, marital status and number of siblings it also asked whether female patients had been advised against having (further) children.

Section 2: Family History
This group of questions investigated the patient's family history and determined whether any of the patient's immediate family had lupus.

Section 3: Medical History
Respondents were asked whether they had ever experienced a range of common lupus symptoms. They were also asked when they had experienced their first lupus symptom(s) and when they were diagnosed as having lupus.

Section 4: Social History
This section dealt with the psychological effects lupus can have on patients and the difficulties patients can have in explaining their disease to others.

Section 5: Employment
The occupations of respondents were identified; respondents were also asked whether their disease had affected their employment.

Section 6: Lupus Awareness
Here the patient's awareness of lupus prior to his/her own diagnosis was examined, as well as the various mechanisms that might be used to increase lupus awareness.

Section 7: Diet
Respondents were asked about their diets and whether they found any particular foods beneficial to their condition.

Section 8: Diagnosis
This section determined which medical professionals had diagnosed the respondent's lupus.

Results and discussion

Section 1: General Information
In total, 941 patients responded to the survey, of whom 848 were female and 80 male (13 respondents did not specify their gender). This corresponds to a female to male ratio of just less than 11:1, which is in agreement with results from other countries: in general, the F:M ratio is estimated at 8-10:1 in SLE, though this ratio decreases at lower and higher ages (ratios were 8:1, 13:1, 11:1 and 5:1 in age groups 15-24, 25-39, 40-59 and over 60 years, respectively, in this work).

As we did not attempt to identify additional SLE patients, other than those who responded to the survey, the overall prevalence of the condition in Portugal cannot be estimated. Similarly, the total number of questionnaires distributed was unknown and, thus, the response rate to the survey was not calculated. Respondents to the survey were primarily of Portuguese origin, as expected: 821 of the 835 respondents (> 98%) who specified their country of origin were from Portugal, while

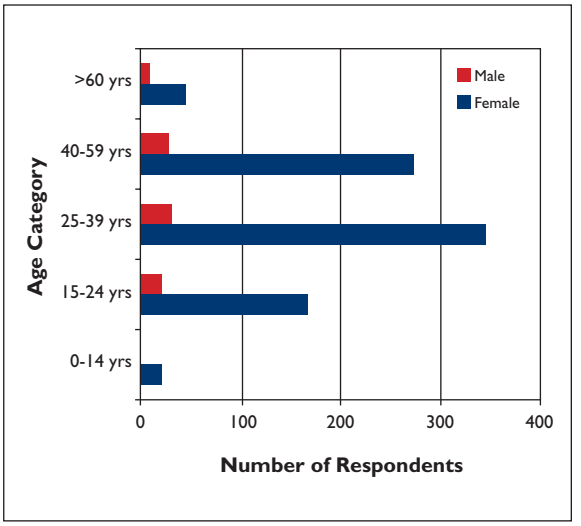

Figure 1. Age distribution of respondents (N=928).

the remainder were from Angola (5 respondents), Mozambique (3), France (2), and Brazil, Holland, Luxembourg or America. Meanwhile, 56% of respondents were married, with 34% single, 7% divorced and 3% widowed.

The age distributions of female and male respondents are shown in Figure 1. In both cases, the highest prevalence of SLE was observed in the 25-39 year age group. This is unsurprising, in women in particular, as SLE occurs most commonly throughout the reproductive years in women. Thus, SLE tends to arise less frequently before puberty and after menopause, which is reflected in the Figure.

The Portuguese and Irish surveys differ in this respect, with the largest age groups affected in the latter being 40-59 years of age in both women (44% of cases) and men (45% of cases). This apparent bias towards older patients in the Irish group compared to other studied populations could be due simply to older patients being more active in the Support Group – through which the survey respondents were identified – though additional work would be necessary to check this.

Section 2: Family History

As SLE is known to have a genetic input, patients were asked whether their parents, siblings or any other relative also suffered from lupus. 3.1% of respondents had at least one relative with lupus and, while this may seem low, it should be remembered that the prevalence of lupus in countries such as Portugal is typically calculated to be in the region of 20-50 cases per 100,000 individuals. Thus, the prevalence of SLE estimated in family members of SLE patients in this work may be as much as 100-fold higher than the prevalence in the general Portuguese population. As expected based on the female:male ratio outlined above, more female relatives of patients had SLE than males: 0.9% of patients' fathers, 1.7% of mothers, 1.5% of sisters and 0.3% of patients' brothers.

Flares in disease activity in SLE have been associated with increased risks to the mother and foetus during pregnancy, and flares in the disease may also be exacerbated by pregnancy. In the Portuguese population, 27% of female respondents had been advised against having (more) children due to these adverse effects experienced during pregnancy, whereas 51% of respondents had not been advised against having children (and 22% did not answer the question).

Section 3: Medical History

The symptoms associated with SLE are highly diverse. In this study, painful joints, aching muscles and sensitive skin were the three main symptoms affecting both female and male lupus patients.

A number of symptoms were found to be significantly ($P \geq 0.05$) more prominent in females than in males: swollen and painful lymph glands, anaemia and frequent headaches (Table I). Conversely, male lupus patients suffered slightly more than females from various skin rashes.

Diagnosis of SLE is traditionally difficult, due largely to the diversity of symptoms with which different patients present. Therefore, we studied the average length of time taken for diagnosis of Portuguese SLE patients over the period 1970-2001 and compared this to diagnosis delay reported in the scientific literarature for other populations (Tables II and III). We defined the length of time taken to diagnose SLE as the time between onset of the disease (based on patients' recollection of their first symptom attributable to SLE) and their diagnosis with SLE. The response to this part of the questionnaire was approximately 60%, and this relatively low response rate was most likely due to difficulties amongst respondents in recalling the precise month of occurrence of sometimes distant events. Due to the fact that respondents were not identified in questionnaires, it was not possible to determine whether the ~60% of respondents who provided the relevant information in this section

Table I. Prevalence of Symptoms in Male and Female Respondents

Symptom	% Females	% Males
Painful joints	83	76
Persistent aching muscles	70	67
Sensitive skin	69	61
Numb fingers and toes	60	50
Hair loss	60	49
Puffiness of the hands and feet	60	42
Skin eruptions	55	54
Frequent headaches	54	25
Rashes after being in the sun	49	52
Persistent dryness and grittiness of the mouth	48	40
Bad reaction to insect bites	41	37
Night sweats	40	39
Recurring flu-like symptoms	40	36
Anaemia	39	22
Persistent dryness and grittiness of the eyes	38	31
Mouth ulcers	33	14
Swollen/Painful lymph glands	32	19
Protein in urine or kidney inflammation	28	17
High blood pressure	26	26
Rashes lasting longer than one month	25	30
Allergies to drugs	23	14
Convulsions, epileptic fits, fainting	15	10

were representative of the entire cohort but an analysis of responders and non-responders revealed no significant differences between the two groups in terms of age or sex (data not shown).

While a progressive decline was originally observed in mean diagnosis times from the pre–1970s to 2001 (the year in which the study was completed), it is clear that many patients whose disease began in 2001 are likely to still not have been diagnosed, whereas there are presumably far fewer such patients still undiagnosed from the 1970s or 1980s (as more time has elapsed in which their disease might have been identified). We therefore attempted to «normalise» the average diagnosis times for all decades to take this bias into account (Table II). Thus, data were analysed after a fixed interval had elapsed at the end of each decade rather than from a single, common time point in order to eliminate bias and more accurately investigate trends in diagnosis times throughout the study period. Therefore, the period 1970-9 was analysed based on the data available in December 1981, 1980-9 from December 1991, and January 1990-May 1999 from May 2001, when the survey was completed. In this analysis, patients with disease onset prior to 1970 were excluded due to their small numbers, while the normalisation procedure did not allow us to calculate data for patients with onset of SLE in 2000 or 2001. Therefore, diagnosis figures are given for 1970-99 only.

Here, statistical analysis revealed that the decrease in the normalised mean ("average") diagnosis time is not significant, while only minor decreases and increases are seen in the percentages of patients diagnosed in less than 3 months and greater than 12 months, respectively, over the same period. Thus, while diagnosis times for SLE appear to have shortened over the past 30 years in Portugal – which, if true, could be attributable to an improved awareness of lupus amongst patients and clinicians and/or to advances in diagnostic tests to identify the disease – the improvement remains so small that rigorous statistical analysis cannot confirm that an improvement has occurred.

The issue of SLE diagnosis times decreasing remains controversial in general, with evidence reported for and against in various populations around the world. A number of these studies are summarised in Table III.

In a direct comparison between Portugal and Ireland (data not shown), the most notable difference between the two populations was observed in the 1970s: in Ireland, the mean diagnosis time for diagnosis was 103 months, compared with 41 months in Portugal. Furthermore, diagnosis took longer than 12 months for 82% of Irish but only 28% of Portuguese patients with disease onset in this decade. By the 1990s, however, diagnosis of the condition was similar in Portugal and Ireland, with, in this case, a statistically significant improvement in diagnosis in Ireland over the investigation period[9].

Diagnosis times were generally shorter in Portugal than in other studies, which may be related to the age of the patient group surveyed. SLE is often more difficult to recognise in older patients, due to being obscured by other medical complaints. Analysis of the diagnosis data shown in Table III revealed that the Portuguese patient cohort had an average age of 36.2 years, which was

Table II. Detailed Analysis of Diagnosis Times[11]

Time period (N)[a]	mean[b]	('normalised')[b]	median	Q1, Q2, Q3[a]	<3 months[c]	>12 months[c]
1970-9 (21)	41.1± 15.6	14.3 ± 4.8	10	2, 5.5, 13	38.9	27.8
1980-9 (94)	34.5 ± 5.5	13.3 ± 2.8	5	1, 3, 13	41.6	26.0
1990-9 (395)	10.2 ± 0.8	10.2 ± 0.8	5	2, 5, 12	42.3	23.0

[a]abbreviations: N = number of respondents, Q1 = 1st quartile, Q3 = 3rd quartile; [b]means are expressed ± the standard error of the mean; [c]percentage of patients diagnosed within 3 months of, or greater than 12 months after, the first appearance of symptom.

Table III. Diagnosis Data From SLE Studies Worldwide[11]

Country of study	N	Diagnosis delay median / **mean** (range)[a,b]	Reference
Portugal	510	5 m / **16 m** (0-248 m)	(this work)
Australia	24	4-6 m / **10.8-13.3 m** (1-72 m)	Segasothy & Phillips, 2001[12]
Rep. Ireland	96	6.5 m / **27 m** (1-239 m)	Corcoran et al., 1999[9]
Denmark	513	2 y / **4.6 y** (0-33 y)	Jacobsen et al, 1998[13]
Senegal	30	n.r. / **24 m** (1 m-8 y)	Ka et al, 1998[14]
U.K.	147	n.r. / **61 m** (0-518 m)	Hopkinson et al., 1994[15]
Europe-wide	1,000	n.r. / **2 y** (n.r.)	Cervera et al, 1993[16]
Iceland	76	n.r. / **8.8 y** (0-50 y)	Gudmundsson & Steinsson, 1990[17]
Sweden	86	3 y / **n.r**. (0-33 y)	Jonsson et al, 1989[18]
Netherlands	110	7 y / **n.r**. (1 m – 12 y)	Swaak et al, 1989[19]
Sweden	57	3 y / **n.r**. (0-60 y)	Nived et al, 1985[20]

N = number of patients in study, m = month, y = year, n.r. = not reported;
[b]diagnosis delay is given in months or years, according to the units in which it was reported in each study.

the youngest in any of the studies shown[11]. This is most likely due to patient retrieval being based exclusively on Support Group records in this investigation, while in many of the other studies patients were identified using hospital records, which may identify predominantly older patients who are more likely to be hospitalised due to lupus or unrelated health problems.

Section 4: Social History

SLE can be exacerbated by stress and is often associated with depression, which can be caused by a variety of factors – including, for example, other people's lack of understanding of a patient's illness. In questioning about their worries about SLE, the most widespread fear among female patients was of their children getting lupus (Table IV).

Men were most worried about the side effects of their medication but concerns about their children having lupus also featured strongly. A large proportion of both female and male respondents felt that their families and friends provided a good support network in understanding the disease. Table IV shows that female and male patients showed generally similar responses to these questions but that women with lupus suffer more from these characteristic psychological effects of SLE.

Section 5: Employment

SLE can have a detrimental effect on patients' employment due to the debilitating nature of the disease. 43% of the respondents to the survey were in full-time employment and 6% were employed part-time. Housewives constituted 17% of respondents and students 15%, with just 8% unemployed. Respondents' occupations were diverse, with nurses and doctors, lawyers, hairdressers, television producers, travel agents and computer programmers included amongst those listed. Difficulties in deciphering and translating replies meant that it was not possible to compare occupations prior to and subsequent to diagnosis.

Respondents were also questioned about their employer's attitude to their illness as it is thought

Table IV. Common Fears of SLE Patients

Worries or fears of SLE patients	% Females	% Males
Do you worry about …your children having SLE?	69	49
… side-effects of your medication?	65	60
Do you have difficulty in explaining your illness?	52	40
Are you worried about losing your self-confidence?	42	25
Do you feel … embarrassed by your condition?	40	31
… your illness is not understood by friends?	31	19
Do you worry about not being believed by others?	34	24
Do you try to hide your symptoms?	30	28
Do you feel people think you are a hypochondriac?	27	16
… your illness in not understood by family?	25	15
Do you worry about travelling?	22	10
… about going out?	17	9

that lack of understanding of SLE, particularly on an employer's part, can lead to problems for patients in the workplace. 47% of patients did not believe that their illness had affected their employer's attitude, however, compared to 18% who thought otherwise, and 35% who did not reply.

Section 6: Lupus Awareness

Increased lupus awareness in the population is generally thought to have a positive effect on SLE patients, both in terms of earlier diagnosis due to faster recognition of the condition and to increased ease of social interactions. In this work, we asked SLE patients about their awareness of the disease prior to their own diagnosis, using them as a rough indicator of disease awareness in the general Portuguese population.

It should be noted here that the genetic predisposition for SLE means that respondents are themselves more likely to have a family member with the condition and, thus, to have a somewhat higher awareness of the disease than the general population. Nevertheless, analysis of the trend in pre-diagnosis disease awareness over the period 1979-2001 shows a very interesting increase, with a major increase in awareness of SLE having occurred between 1994 and 1995 (Table V). This corresponded with a major lupus awareness campaign carried out by the Portuguese Lupus Support Group in May 1994, which utilised television, radio, newspapers and advertising on billboards and public transport to raise awareness of the condition. This campaign appears to have been extremely successful in raising the profile of SLE, based at least on our analysis of disease awareness, and it would be interesting to determine if this increased awareness is maintained and has an effect on improving disease recognition and, thus, shortening disease diagnosis times in Portugal over the years to come.

We also investigated the sources of respondents' information on SLE and found that most comes from television and magazines (Figure 2). These questions were concerned with information found by lupus patients in the media after their own diagnosis and, thus, do not necessarily demonstrate the effectiveness of the different forms of media in communicating lupus information to the general population. The data in Portugal differ slightly from those found in Ireland, where television was also the most common source of information but radio featured much more strongly than in the Portuguese patient group[9].

Table V. Detailed Analysis of Increase in Lupus Awareness

Time period	% Respondents (N)
1970-9	6.1 (33)
1980-9	10.7 (131)
1990-9	37.0 (568)
[of which:	
1990-3	11.0 (145)
1994	29.5 (44)
1995-9	47.9 (379)]
2000-1	47.8 (82)

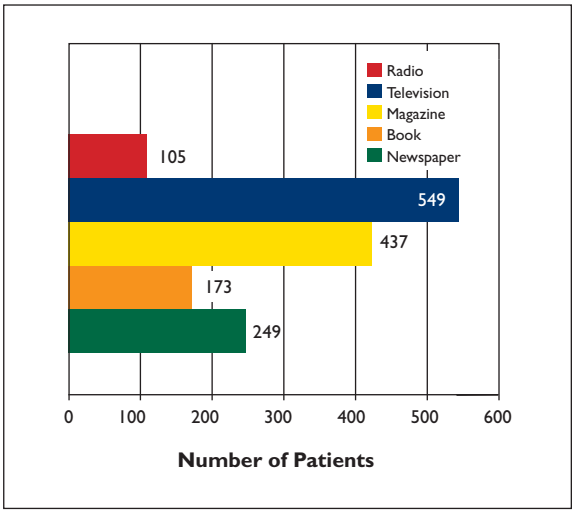

Figure 2. Sources of respondents' information on SLE.

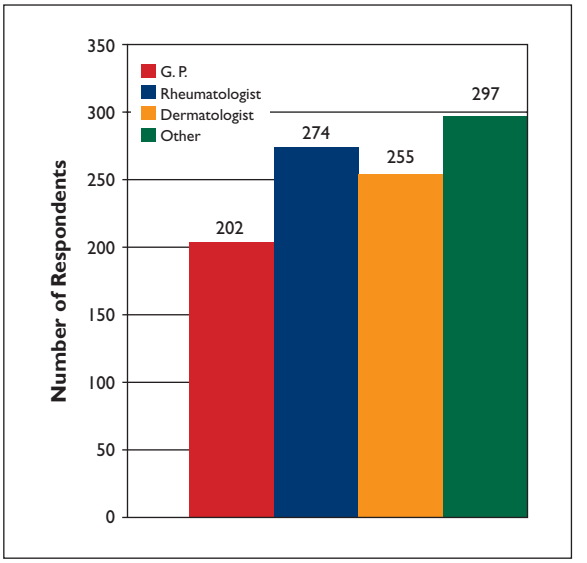

Figure 3. Clinicians who diagnosed SLE

Section 7: Diet

Respondents were asked whether they felt that any particular foods affected their condition. 57% replied that their diet caused neither an improvement nor a deterioration in their disease activity, whereas 23% thought that various foods could affect disease severity. When asked what types of diets are found to be beneficial, the most common answers were «normal», «healthy» and «balanced». More specific examples of beneficial diets or foodstuffs that were provided by individual respondents included a broad range of items, including vegetarian, fat-free and salt-free diets, as well as grilled foods, stews, cereals, yoghurts, salads and greens, fruits and vegetables.

Section 8: Diagnosis

The medical practitioners who most frequently diagnosed respondents' SLE were rheumatologists, followed by dermatologists and general practitioners (Figure 3). This coincides with the fact that painful joints and skin problems were amongst the most common disease symptoms reported by patients (Table I). In the category of «Others», the most common practitioners were internal medicine (36%), nephrologists (16%), haematologists (6%) and neurologists, cardiologists and paediatricians (3% each).

In Ireland the clinicians involved in the diagnosis of SLE follow a similar trend to that observed in Portugal, with rheumatologists again diagnosing the greatest highest number of patients, followed by dermatologists and general practitioners[9].

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APPENDIX 1:

EUROPEAN LUPUS ERYTHEMATOSUS FEDERATION (ELEF)

Section 1	**General information**	
1.1	Age:	
1.2	Sex:	
1.3	Marital status:	
	(Tick one of the following:)	
	Single Married Divorced Widowed	
1.4	Number of brothers:	
1.5	Number of sisters:	
1.6	Have you been advised against having any more children?	(Y/N)
1.7	Country of origin:	
Section 2	**Family history**	
2.1	Does your father suffer from Lupus?	(Y/N)
2.2	Does your mother suffer from Lupus?	(Y/N)
2.3	Does a brother suffer from Lupus?	(Y/N)

2.4	Does a sister suffer from Lupus?			(Y/N)
2.5	Does any other close relative suffer from Lupus?			(Y/N)
	If so, how is this person related to you?			
2.6	How many children have you?			
Section 3	**Medical history**			
	Do you suffer from:			
3.1	Rashes lasting for over one month (not sunburn)?			(Y/N)
3.2	Rashes after being out in the sun?			(Y/N)
3.3	Skin eruptions?			(Y/N)
3.4	Sensitive skin?			(Y/N)
3.5	Mouth ulcers (lasting over 2 weeks)			(Y/N)
3.6	Hair loss?			(Y/N)
3.7	Persistent dryness and grittiness of eyes?			(Y/N)
3.8	Persistent dryness of the mouth?			(Y/N)
3.9	Frequent headaches?			(Y/N)
3.10	Swollen or painful lymph glands?			(Y/N)
3.11	Recurring 'flu-like' symptoms			(Y/N)
3.12	Night sweats?			(Y/N)
3.13	High blood pressure?			(Y/N)
3.14	Convulsions, epileptic fits, fainting?			(Y/N)
3.15	Anaemia?			(Y/N)
3.16	Protein in urine or kidney inflammation?			(Y/N)
3.17	Allergies to food? (see question 7.00 Diet)			(Y/N)
3.18	Allergies to drugs?			(Y/N)
3.19	Bad reaction to insect bites?			(Y/N)
3.20	Persistent aching muscles?			(Y/N)
3.21	Painful joints?			(Y/N)
3.22	Puffiness of hands and feet?			(Y/N)
3.23	Numb fingers or toes?			(Y/N)
3.24	When did you first have Lupus symptoms?	Month:	Year:	
3.25	When were you first diagnosed as having Lupus?	Month:	Year:	
Section 4	**Social history**			
	Do you fear or worry about:			
4.1	Your medication your medication having side effects?			(Y/N)
4.2	Your children getting Lupus?			(Y/N)
4.3	Going out?			(Y/N)
4.4	Travelling			(Y/N)
4.5	Losing self-confidence?			(Y/N)
4.6	Not being believed by others?			(Y/N)
4.7	Do you feel people think you a hypochondriac?			(Y/N)

4.8	Do you feel that your illness is understood by your family?	(Y/N)
4.9	...by your friends?	(Y/N)
4.10	Do you feel embarrassed by your illness?	(Y/N)
4.11	Do you have difficulty explaining your illness?	(Y/N)
4.12	Do you try to hide your symptoms?	(Y/N)

Section 5 **Employment**

Are you:

5.1 A student?

5.2 A housewife?

5.3 Employed full-time?

5.4 Employed part-time?

5.5 Unemployed?

5.6 Retired?

If you are working at the present time:

5.7 What is your occupation?

5.8 What was your occupation when you were diagnosed?

5.9 Has your disease affected your employer's attitude? (Y/N)

5.10 If no longer working, what was your occupation when diagnosed?

Section 6 **Lupus awareness**

6.1 Had you ever heard of lupus before you were diagnosed? (Y/N)

6.2 Have you ever seen Lupus mentioned:

In a newspaper? (Y/N)

In a magazine? (Y/N)

On television? (Y/N)

On radio? (Y/N)

Section 7 **Diet**

7.1 Do certain foods affect your disease? (Y/N)

7.2 What type of diet do you find helpful to you?

Section 8 **Diagnosis**

8.1 Who diagnosed your disease:

General Practitioner?

Rheumatologist?

Dermatologist?

Another - give profession