

What Do The Hungarian Lupus Patients Really Want?

1. Introduction

This report is a part of the product of a unique survey undertaken some throughout various European countries. This report analyses only the results of the survey in Hungary. Presented below, are the primary aims and objectives of the study, why it was undertaken and the methodology adopted. The findings of the research are presented and analysed in detail in section 2.2. with key recommendations of the research drawn out in section 2.2.3.

2. The Statistics of the ELEF Project in Hungary

2.1. Methodology

The ELEF created the organizations and regulations necessary for this purpose. Already in the phase of publishing were the calls for proposals. What is more, it was already involved in the evaluation of the applications. The research is campaigned nationally in order to discuss topics and collect responses no later than May 10th of this year.

In Hungary we arranged both a small and a larger group from lupus patients to discuss it and collect responses. Moreover, the lupus patients can send the responses by e-mail, (they could read it on our website and forum).

Figure 1 A small group from lupus patients who is discussing ELEF project.



In order to fulfil the purpose of the research, a questionnaire was drawn up with a range of questions addressed to each of the main objectives of the study, outlined above. The questionnaire went through a process of some reviews to ensure that questions were clear and unambiguous. As a result of the piloting a number of minor changes were made to the working of certain questions, but the substantive document remained unchanged. A letter was drafted to accompany the questionnaire, outlining the purpose of the survey, and requesting co-operation in completing the document. So the survey had 2 PDF-files. The letter was made originally in English by ELEF, then issued to each of the partners, and translated into the appropriate language. We translated it into Hungarian. The size of the sample for each country was not agreed in advance amongst the partners. Each partner was responsible for distributing the questionnaires within their own country. In Hungary we, the Hungarian Lupus Society made this survey.

In retrospect, the large number of responses for main the question suggests that it may have been useful for this questionnaire to have subdivided this category, as we did. Therefore, the original questionnaire we extended with some more questions for more information.

2.2. Questionnaire Analysis, Findings

The following pages give a brief statistical overview of Hungarian research. The overview was based on aggregate statistical data provided by the Hungarian Lupus Society themselves. In line with the objectives of the study, findings are presented as follows. Some patients groups were set up in order to achieve these goals, meet with success, and the questionnaire can be sent us by e-mail, too.

The query of this questionnaire was made during April, 2008.

The analysis has been done based upon the responses to the different questions by the lupus patient. The data has been taken into account both individually and comprehensively to arrive at a conclusive result. The analysis gives us a picture of what the lupus patients expect.

2.2.1. Background Questions

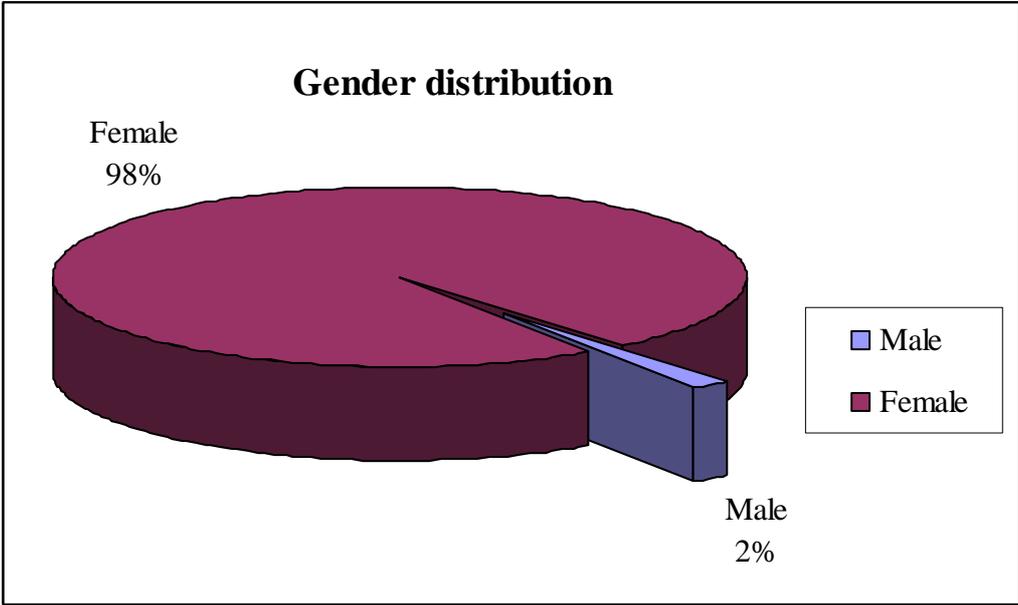
Background questions asked participants about their sociology and demographic data.

All in all, approximately 1% of Hungarian lupus patients participated in this survey. We think this Hungarian questionnaire has a lower response rate compared with those from other countries. (However the correct data from other European countries we will know only in September 2008.) But we had less time because we latched on to this survey only in March of 2008, and so we were unable to send it to more patients. Despite this we think it could be a representative, because the features of respondents answering the questions almost agree on his proportions with the features of Hungarian lupus patients: for example more than 90% woman. It is clear, what are the primary concerns, aims, and on the case of bigger sample size we would probably have received same answers.

All of the respondents were Hungarian.

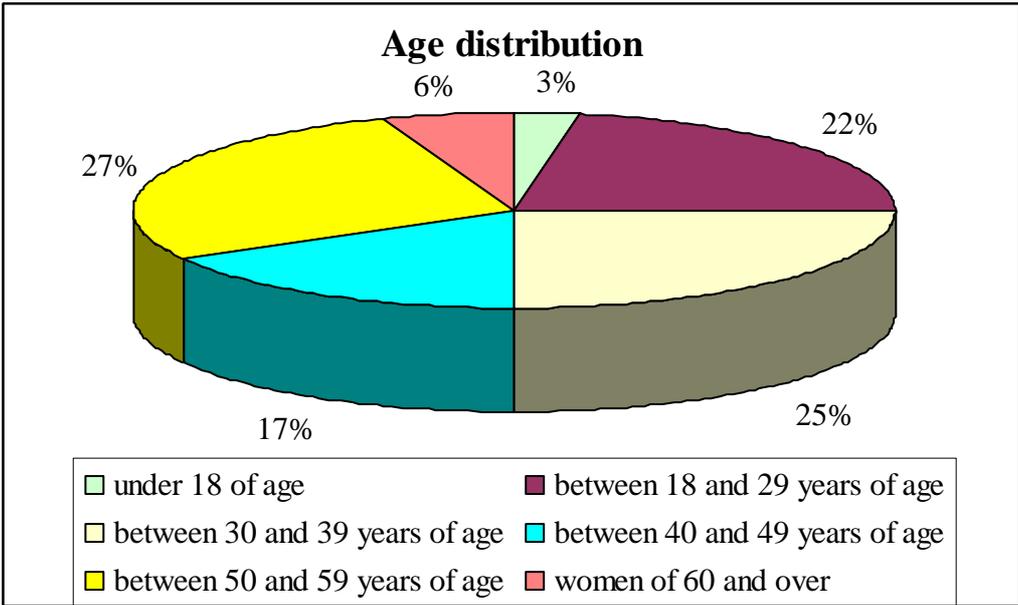
In this analysis, all but two respondents were women (2 percent male, 98 percent female).

Figure 2 Gender distributions.



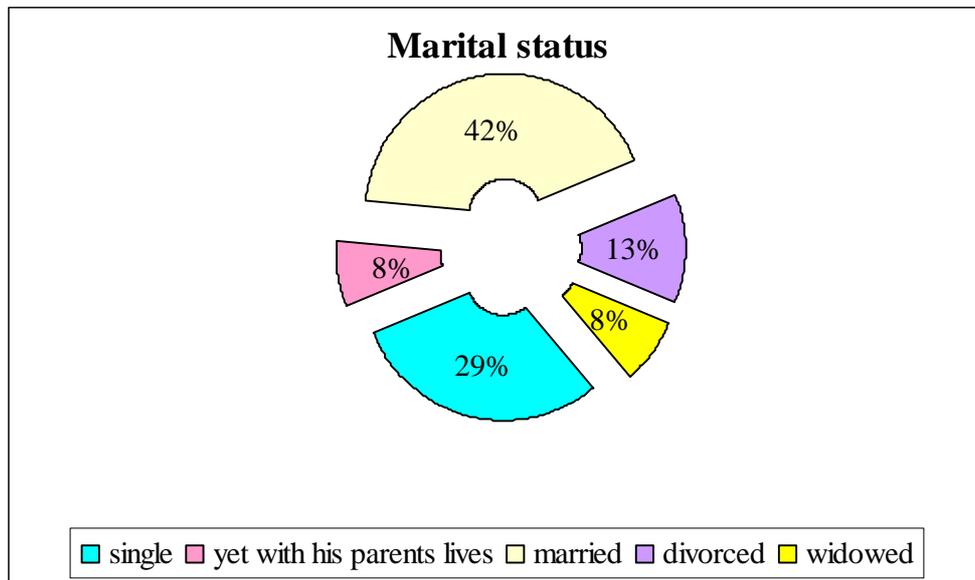
Lupus can be triggered for example at puberty, after childbirth, during the menopause, through sunlight, after a viral infection, or as a result of trauma, or moreover, after a prolonged course of certain medications. 90% of the lupus patients who suffer from lupus are female of childbearing age. Even young children can be affected by lupus. The 50-59 year age groups, the proportions of which 27 percent are inside the full sample size, constituted the largest category. Furthermore, the average age number of the respondents was 41 years, ranging from 17 to 61 years. On the other hand, the under 18 years old age group constituted the smallest category (the proportions of which 3 percent are inside the full sample size).

Figure 3 Age distribution.



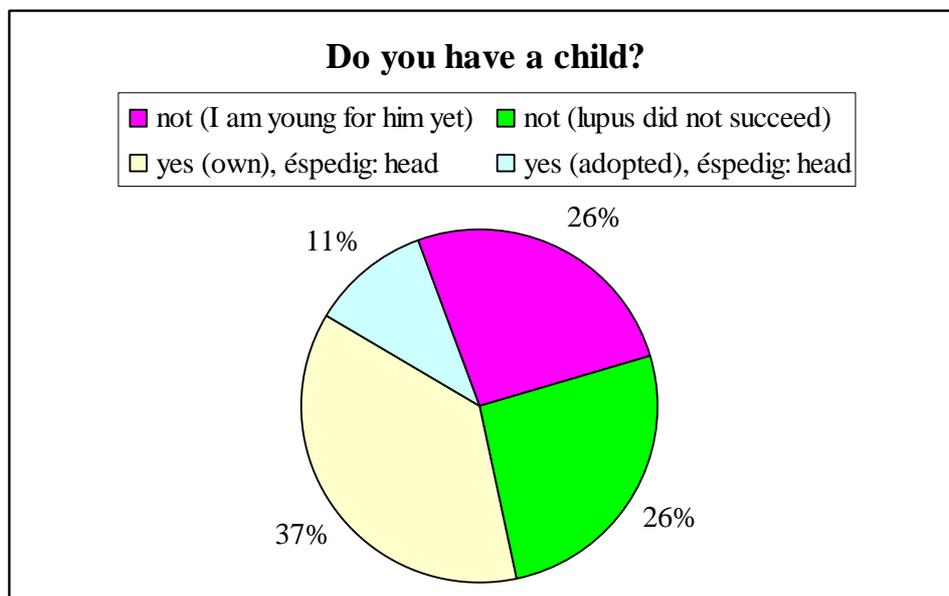
The 3rd marital status groups (she has a husband or he has a wife), the proportions of which 42 percent are inside the full sample size, constituted the largest category. If we draw together the 1st, 4th and 5th groups, the result will be the majority of the respondents, and it seems that the most respondents live alone (altogether half of lupus patients filled in this questionnaire). It seems that it is correct what ELEF said that “hard to say and harder to live with” lupus.

Figure 4 Marital statuses.



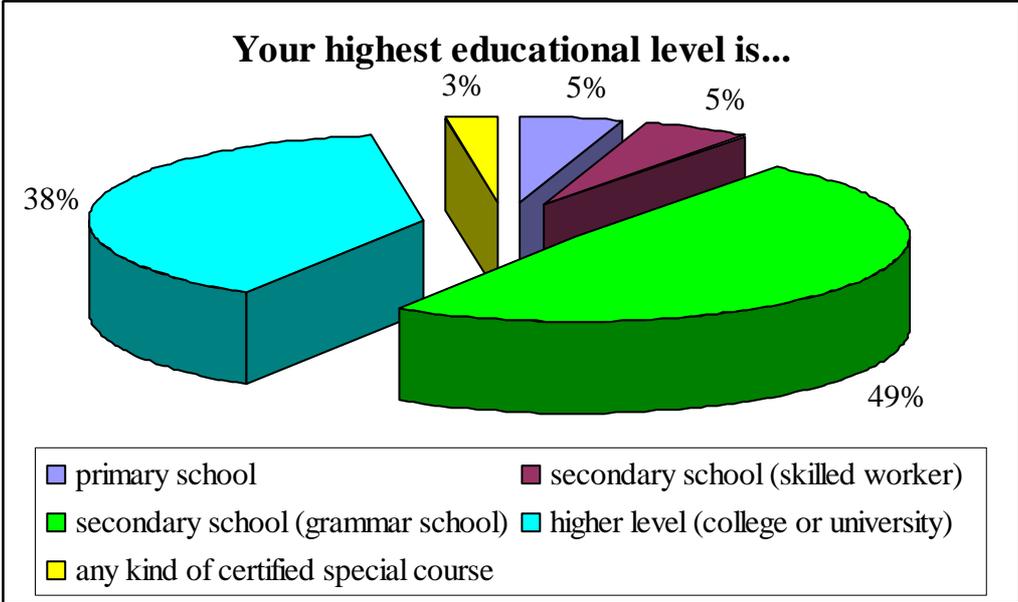
Almost half of respondents have a child (37 percent own and 11 percent adopted). The other groups (she/he does not have a child yet), the proportions of which 52 percent are inside the full sample size, constituted the largest category. On the other hand, 26 percent mentioned that they are too young to be child-bearing, and some lupus patients are not able to be bearing a child (it is 26 percent, too).

Figure 5 Child-birth.



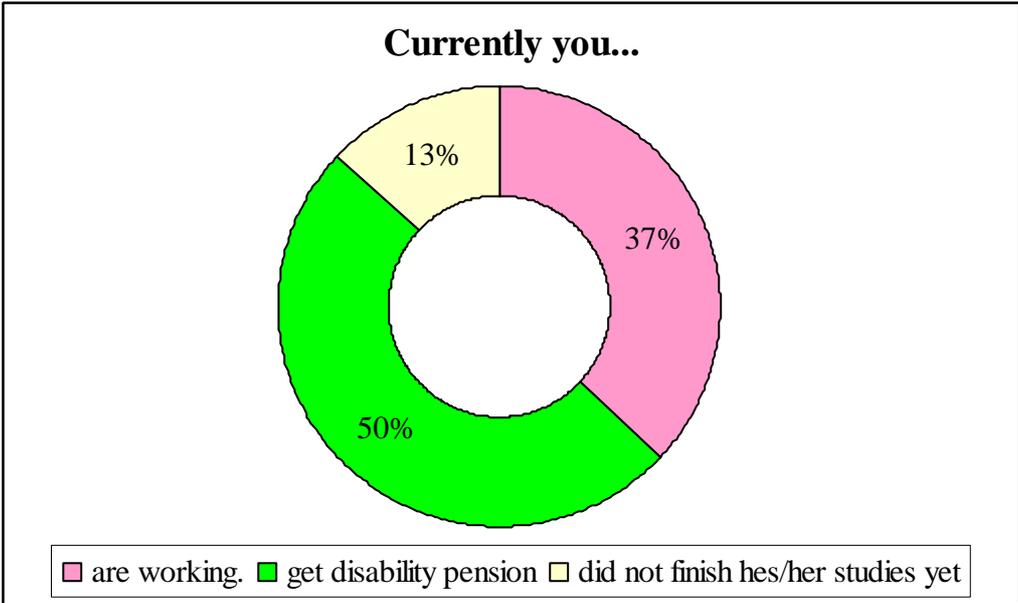
All but 5 percent of respondents, accordingly a majority of the respondents have matriculation. 38 percent of respondents have a higher level education or are currently college/university students. Furthermore, 49 percent of the lupus patients filled this questionnaire disposals grammar school qualification, and 5 percent is a skilled workman. 3 percent of respondents have any kind of certified special course.

Figure 6 Qualifications.



Here we had 3 categories, which the lupus patient could choose by this question below. Half of the respondents get disability pension (50 percent). In addition to that, also more marking was possible.

Figure 7 Works.

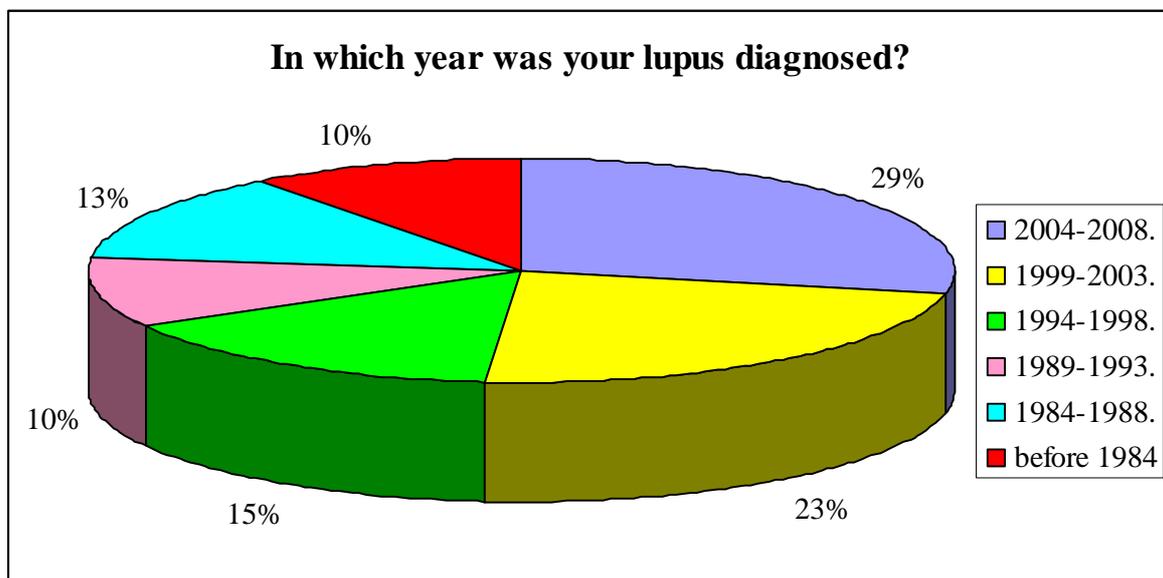


2.2.2. The Other Data of the Questionnaire Query

In the following graphs we have a detailed presentation of lupus patient requirements in different fields. A qualitative analysis of the other data showed that this analysis gives a holistic picture of the overall requirements of a lupus patient. The results are based on the queries formulated by respondents.

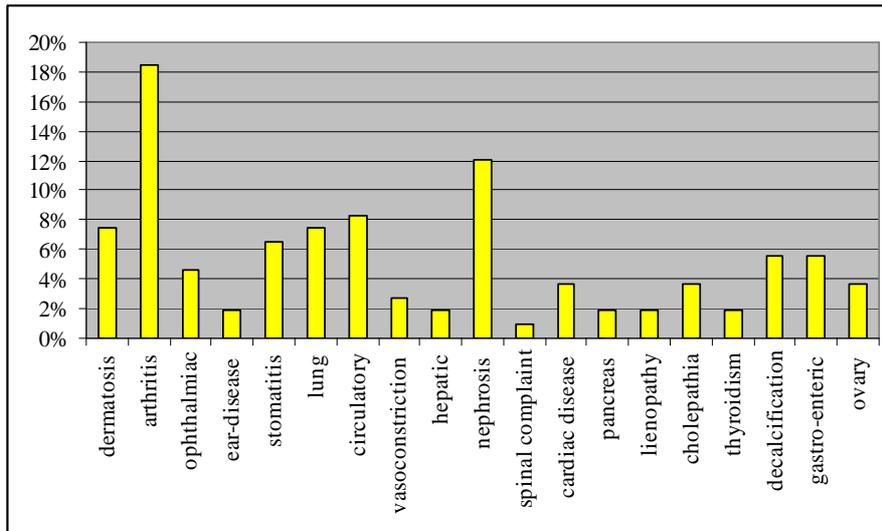
The most respondents were diagnosed after 2003, the proportions of which 29 percent are inside the full sample size, so it constituted the largest category. Over the last 10 years we have diagnosed the most lupus patients who filled this questionnaire. The oldest respondent is 61 years old and she is living with lupus more than 40 years.

Figure 7



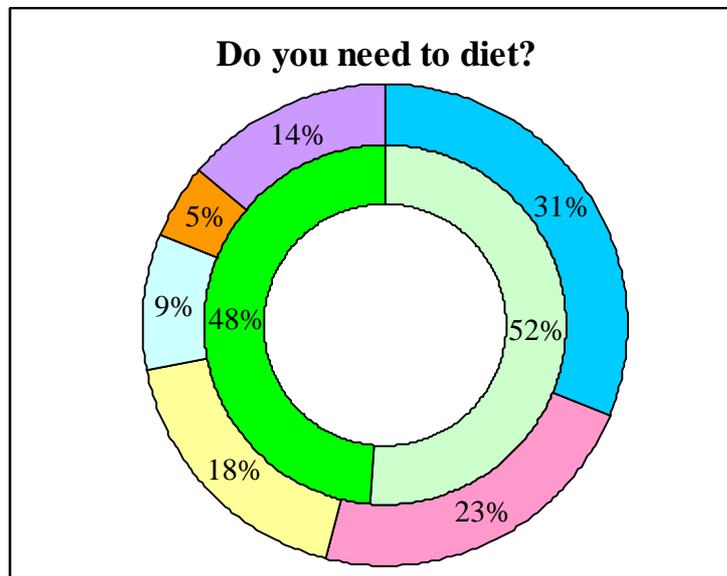
In the questionnaire, the participants were asked which organs are affected by the disease. More organs are often affected by lupus, for example kidney, and because of it can be renal insufficiency, renal colic, interstitial nephritis, sand or/and stone in the kidneys. Lupus stiffens one's joints and there is often arthralgia, rheumatoid arthritis (RA). Steroid can cause for example cataract in eyes. The more lupus can affect more organs the better lupus can assume a very grave character.

Figure 6



The results showed that almost half of respondents do not need to diet (48 percent). The other group (any special diets or changes in eating habits), the proportions of which 52 percentages are inside the full sample size, constituted the largest category. If he/she answered 'yes' to this question, we asked him/her to specify it. 31 percent mentioned that it is necessary for him/her to diet because of high cholesterol level, and some lupus patients are dieting because of osteoporosis (it is 23 percent). More respondents have nephropathy (see Figure 6), and therefore 18% are dieting. Food-allergy means for example because of flour, lactose or others.

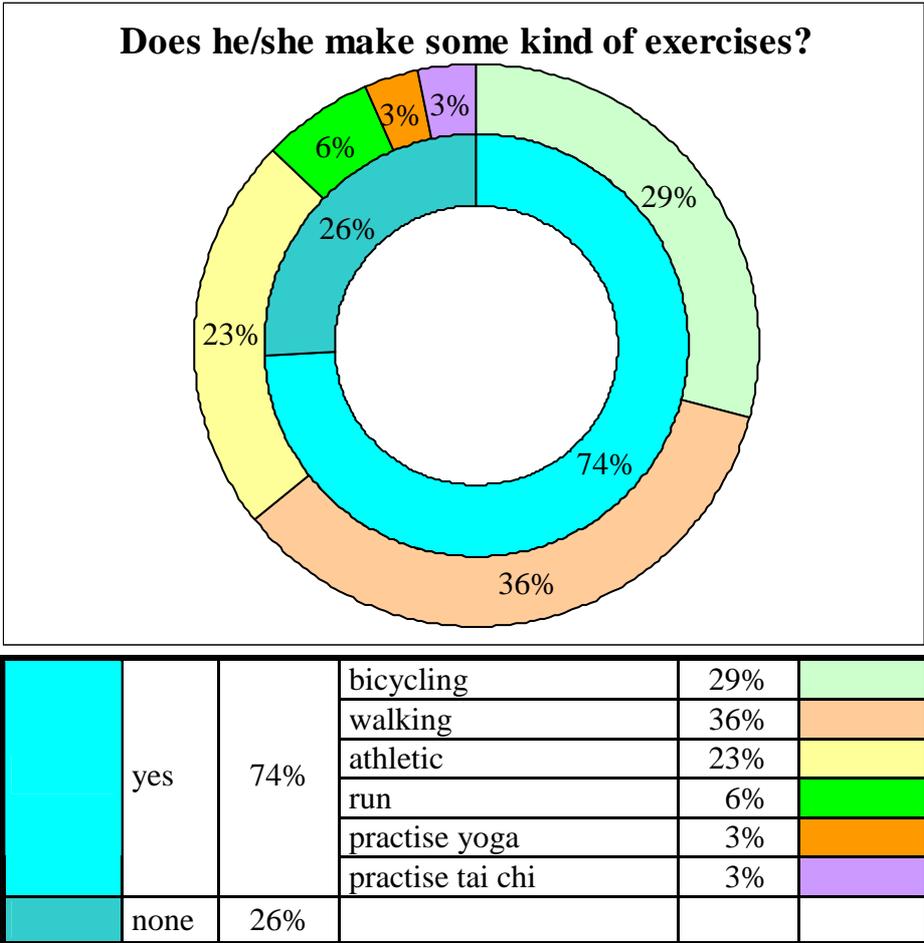
Figure 8



	yes	52%	namely because of	high cholesterol level	31%	
				osteoporosis	23%	
				nephrosis	18%	
				diabetes	9%	
				thyroidism	5%	
				food-allergy	14%	
	no	48%				

Almost three-quarters of respondents take some gentle exercises, especially if his/her lupus is not active. If he/she answered 'yes' to this question, we asked him/her to specify it and describe one or two of the exercises. The most respondents go for a walk and take a turn in the city to get an airing (36 percent). 23 percent mentioned that he/she does gymnastics (athletic), often it is a remedial gymnastics. Some lupus patients filled this questionnaire feel an interest in oriental treatment, so they practice yoga or tai chi.

Figure 9



2.2.3. Holistic View of Comments. Priorities, Arguments, Other Aspects

One question was exploratory (open-ended) asking participants to emphasize upon that, as a lupus patient, what is the main lupus issue, the largest problem, question, and idea, experiment that he/she would like ELEF to address. This question was taken from the original questionnaire from ELEF. Various groups within Hungary that have discussed the Common Cause project have highlighted the issues below. The qualitative analysis of main question showed that the one question, project, idea or trial that has to be answered and followed through:

- ◆ Lupus can not be known sometimes.

Who?

1. Lupus patients and belongings
2. Doctors and medical students
3. "Everyday" people

Why?

- Often they do not know what will happen...
A few doctors are skilled at lupus.
Lupus is unbeknown to them.

- ◆ Database of services/doctors with knowledge of lupus to be available to patients, and the need for special combined clinics. The public health has to have "special" patient centres, too. More lupus patients emphasize that it is necessary for decision makers to work together on the educational, social and economic area.
- ◆ Better and more training for medical students, family doctors, and other doctors about lupus, and other autoimmunity diseases, who do not know it yet. Only a few doctors are skilled at lupus, so patients often feel they only guess. More respondents said that lupus could not be recognized for many years and meanwhile doctors thought he/she is a hypochondriac, so he/she had to go from one doctor to the other. However, the treatment may be effective if it is cured with suitable expertise.
- ◆ Information to patients regarding access to appropriate treatment. For example the lupus patients should know that the steroids can cause more damage to the organisms because of its side-effects. A respondent said that her largest problem is that she got only inadequate information from her first doctor. She did not get this from him: "Did you get all the information you needed? If not, what other information would you like to be given?" Therefore she went to another doctor who could give a satisfactory answer to all her questions. She said that this case unfortunately is not unique, from very many fellow sufferers can hear this.
- ◆ The length of time taken for diagnosis. Lupus is a chronic illness and takes a long time for the exact diagnosis which can cause more damages in the body, or sometimes it can be tragic, rarely mortal. Because of it this gives rise to difficulty in diagnosis and the condition can be overlooked, sometimes for years.
- ◆ Waiting times to see consultants. That is often the case that a lupus patient can wait 3 months or more for the one of the best consultants in Hungary.
- ◆ Prescription charges. There is not a cure-all, an infallible remedy, a remedy of remedies for all lupus patients. The active remedy is often very expensive. Few medicines are completely innocent and there could be chance that a lupus patient be intolerant of a drug and they do not administer these drugs in minor conditions.

4. Conclusions

This is a highly significant survey both in terms and findings. It is intended to present the report at the international conference of ELEF in September, and to publish an article, based on the report, in the literature.

Based on the results presented above from this questionnaire study, three main factors are suggested, as follows. The conclusion throws up a very stable response by the lupus patients. In the above analysis we find that the most important, preferred requirement for a lupus patient is “Communication” followed by “Time” and then “Charges”.

Therefore the common concern with them has been effective communication, shorter timing and low charges. Not surprising to find that “Communications” is the most important factor. It is evident that the knowledge gives hope for patients. The most preferred method of communication is “Training” followed by “Patients' better knowledge”. These two also happen to be the fastest method of communication and also the most effective one. The less informed person gets into a hospital with a greater probability, understands the essence of the treatments less, and is able to adapt to the therapy less. She is able to bring a correct decision with a smaller chance, and the curing-cost are higher. The hardly informed individual is less elastic, is less successful in her working. The means of communication again are typically where it is instant and there is no delay in communication. Effective communication helps in speedy communication. The lupus patients are unhappy with those doctors who are not able to communicate effectively and hence a late cure. The authentic transmission, a fruitful dialogue is necessary. From the “educated” patient can be expected that she understands and acknowledges the basic information concerning her illness and she is capable of making correct therapeutic decisions and representing her interests. It is expected hopefully that sooner or later, these challenges will also appear in Hungary. It is very fortunate when a patient can know more about lupus. From the knowledge of the diagnosis a lupus patient follows a specific path: her new view of life, her values take shape, others will be her aims and expectations. She wants to heal. The “educated” patient, in the possession of proper information and a support of her doctor, puts an implement onto a new method with an inestimable value, if she learns to acknowledge her disease. So she can learn her illness-awareness, too.

5. The Future of the ELEF Project

The countries represented in the full survey offer a wide cross section of Europe. We think they can not be fully representational of the whole continent, but they can nevertheless give an indication of diversity of desires of lupus patients. It is the diversity which is most clearly demonstrated expectantly by the whole survey (from all countries participated). It is evident that ELEF can play an important role to reach target groups. Clearly, this is a relationship which benefits both partners. The survey has demonstrated, beyond any doubt that action research, of the kind undertaken by the partners to develop effective methodologies, and the results will be of value and significance to both the patients and public health sectors.

6. Acknowledgements

We would like to thank all the lupus patients who filled in this questionnaire for valuable comments and we are also grateful for all the participants for their time.