

**EDUCATIONAL, VOCATIONAL AND SOCIOECONOMIC STATUS AND
QUALITY OF LIFE IN ADULTS WITH CHILDHOOD-ONSET SYSTEMIC
LUPUS ERYTHEMATOSUS
(LONG TERM FOLLOW UP DATA FROM A SINGLE PEDIATRIC CENTER)**

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Running Title: Long term follow-up of Children with SLE.

Key Words: Systemic Lupus Erythematosus, Children, Follow-up, Quality of Life

(Presented at the IV th Park City conference in Pediatric Rheumatology at Park City, Utah on March 14-18, 1998; Supported by grants from the Lupus Foundation of Southeastern Pennsylvania and The Gilbert Trust.)

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Abstract:

Objective: To document the educational status, work experience, marital status, child-bearing experience and quality of life of young adults who had childhood – onset SLE.

Method: Descriptive data was obtained from medical records. Patients who were contacted provided further descriptive and socio-economic data in a specially designed form and completed SF-36 forms. Their current rheumatologists completed a medical questionnaire including a SLEDAI.

Results: Descriptive data was available from 64 patients. Complete medical data including current condition, SLEDAI and SF–36 forms were completed on a sub-sample of 29 patients who were followed for a mean period of 13.0 years. This

report describes the sub-sample. Fifteen of 29 patients (52%) had active disease (SLEDAI > 4), and the mean SLEDAI score was 6.4. Chronic damage to organ systems was seen commonly in the kidneys, CNS, skin, bones and eyes. Approximately 55% of patients had enrolled in, or had completed college, another 33% had completed high school, and the remaining 11% had not completed high school. Just over 50% were employed, either part time or full time. Over 70% lived in a household with a total annual income less than \$30,000. Twenty-two of the patients in the sub-sample were women, nine of whom attempted to have children. All were eventually able to conceive and deliver normal children. Three had spontaneous abortions followed by normal deliveries. The score for the physical component of the SF-36 was lower than population estimates. The estimated cumulative proportion surviving following disease onset at 5, 10 and 15 years post-onset were 93.8%, 87.4% and 79.5% respectively.

Conclusions: More than 50% of young adults with childhood-onset SLE still had active disease at the time of follow-up. Most had completed high school, but were living in households earning less than \$30,000 per year. QOL measures showed limitation in physical functioning. Life table analysis showed that over 79% of the sub-sample had survived more than 19 years following disease onset.

Introduction:

Prognosis in childhood SLE has improved considerably in the past two decades, probably secondary to earlier diagnosis, better treatment of the disease and its complications, and improved critical care techniques. Consequently, children with SLE are living longer and enter adult life with a chronic disease and morbidity related to organ damage, treatment, and psychosocial impact. All of these factors affect patients' function [1]. It is interesting to note that most studies on prognosis of patients with SLE, even in adults, focus on morbidity and mortality and not on their ability to complete school or college, hold a job and earn a living - in essence to function in life. Now that children with SLE survive

into adulthood, it is important to assess their status at school, at work and in family life.

A number of health status instruments have been developed to measure functional outcome in patients with rheumatic diseases [2, 3]. Functional assessment scales such as Health Assessment Questionnaire (HAQ), Arthritis Impact Measurement scale (AIMS) and Child Health Assessment Questionnaire (CHAQ) measure function as affected by the disease and include items to assess morbidity, disability and discomfort. Thus, they measure function as related to health status. However, patients view life more broadly in relation to their ability to function in life. Non-health related factors such as energy level, role limitation, social functioning, psychological health and perceived health status all contribute to one's sense of well being. All of these items have been incorporated into special scales to measure quality of life such as Medical Outcomes Study Short Form 36 (SF-36) [4]. These scales are being used increasingly in clinical practice, research and health policy evaluations of chronic diseases in general. Functional measurement scales [5] and quality of life scales [6-10] have been used in adults with SLE.

There is no follow-up study of patients diagnosed with childhood SLE who are now adults which documents their educational level, work experience, income level, ability to lead an independent life and their quality of life. In the present report, we document our findings on 29 individuals with childhood-onset SLE followed for 5 to 26 years (Mean = 13.0, SD = 6.1), with special emphasis on the following functional areas: educational level, employment status, marital life, obstetrical history and quality of life. No attempts were made to correlate function with any disease-related or non-disease related variables.

Materials and Methods:

All patients followed at the Children's Hospital of Philadelphia from 1973-1990, with onset of lupus before the age of 17 years and followed for a minimum of three years (unless death occurred sooner) were included in the study. This study was approved by the IRB of The Children's Hospital of Philadelphia and

the participants signed an informed consent. Attempts were made to contact all eligible patients by letters and by telephone. For patients who did not have a current address or working phone number on record, attempts were made to contact their primary physicians or rheumatologists in an effort to locate them. Those patients who agreed to participate completed a specially designed descriptive data sheet. This was called the CSH – 1 questionnaire (complete CSH-1 questionnaire available from the authors) and was designed to gather information on their current status in education, employment, income, marital status, living arrangements, household income and medical insurance.

A subset of these patients, all of them over the age of 16.3 years, gave consent to be evaluated by their rheumatologists for this study. The rheumatologists completed another set of questions about organ damage, obstetrical history and current disease activity (SLEDAI). In addition, these patients completed a SF-36 questionnaire. This questionnaire was obtained either through the mail or over the phone. Medical charts were examined on all patients and, for deceased patients, autopsy reports were obtained whenever possible.

Percentages were used to summarize categorical data. Means and standard deviations were calculated for all continuous variables. A Kaplan-Meier analysis was performed to summarize survival following disease onset.

RESULTS

We contacted 93 patients with SLE seen between 1970 and 1993. We were able to collect data on school or college years completed, work, income level, marital status and child bearing experiences in 64. Data from recent physical examination by a physician, SLEDAI score and SF-36 form were completed in 29 of these 64.

Demographics:

We compared the demographic data from the 29 with complete data with the total group of 64 (Table 1) and found them comparable. This included

demographic and co-morbidity information obtained from the medical records at the time of the patient's last follow-up. Fifty-two of the patients were female (81.2%). The racial background of the group was mostly Afro-American (31 patients - 48.4%) and Caucasian (26 patients - 40.6%). The mean period of follow-up was 13.6 years [standard deviation (SD)=6.3, range=1-26]. The mean age of the patients at the time of their last follow-up appointment was 25.5 years (SD=6.4; range=12-38). The mean age at the onset of symptoms was 11.9 years (SD=3.1; range=1-16).

In the sub-sample of 29 patients with complete current data, 22 (75.9%) were female. The mean period of follow-up was 13.0 years (SD=6.1, range=5-26). The mean age at the time of their last follow-up was 23.6 years (SD=5.6; range=12-36), while the mean age at onset was 11.3 years (SD=3.1; range=5-16). The racial background of this group was mostly Afro-American (44.8%) and Caucasian (31.0%).

Medical and Life status:

The twenty-nine patients in the follow-up group completed the CSH-1 form. Physician collected information contained in CSH-1 is presented in Table 2, while socio-demographic information provided by patients is presented in Table 3. In some instances, data were available for less than 29 patients, in which case the number of patients evaluated is given.

Fifteen patients (51.7%) still had active disease as determined by a SLEDAI score of greater than 4. The mean SLEDAI score was 6.0 (SD=6.9). Because of the small sample size and the retrospective nature of the study, we did not attempt to correlate the SLEDAI score with any predictor.

Irreversible damage to organ systems, as documented by physicians is shown in Table 2. Twelve patients (46%) had renal impairment, 11 (42%) had permanent cutaneous lesions, six (23%) had CNS problems (CVA, seizures, or dementia), five (19%) had orthopedic problems (mostly AVN), and two (8%) suffered from eye disease. Cardiac (not including the 2 who died of myocardial

infarction), pulmonary and gastrointestinal impairments were found in one patient each (4% per impairment). No patient developed neoplastic disease.

Nine of the women attempted to have children. Three had spontaneous abortions followed by normal pregnancies, and one had a medical abortion followed by a normal pregnancy. All nine women were eventually able to conceive and deliver normal children.

Patient-reported socio-demographic details are noted in Table 3. Three patients (11%) had graduated from college and 12 (44.4%) were currently enrolled in college classes. Nine patients (33.3%) had completed high school and only three did not complete high school. Thirty-eight percent felt that their further education was impaired by their illness. Almost half of the patients were working either part time or full time and 25.9% were still attending school. Three patients (11%) were receiving disability and two (7.4%) were unemployed.

Five of the twenty-nine patients were married. Seven lived with a spouse or a partner. Twelve lived with their parent(s). Six lived with another adult and only four were living alone. The majority of them lived in a household with yearly income of less than \$30,000. Approximately one-third depended on Medicaid for medical insurance and two had no insurance.

Short Form 36 (SF – 36)

Mean scores of our patients were compared to United States population norms in Table 4. All scores were lower in patients with lupus. The mean score for the physical component (PCS) was 40.3 (SD=11.3) and the score for mental health component (MCS) was 47.9 (SD=12.6). The confidence interval for PCS was 36.1 to 44.5 and for MCS it was 43.2 to 56.3. National norms for PCS and MCS are 44.3 to 55.7 and 43.7 to 56.3 respectively. Thus, the PCS score for patients with SLE is clearly below the lower limit of national normal. MCS scores fell within the normal range.

Survival

A Kaplan-Meier analysis was performed to estimate the survival function in the entire sample (n=64; Figure 1). Individual observations were censored if patients had not expired since the time of their last follow-up appointment. Eight of the 64 patients (12.5%) expired. Death occurred 1 to 18 years after diagnosis (mean=9.3, SD=6.2).

Kaplan-Meier survival curve is shown in Figure 1 and life table summarizing estimated survival of the group is shown in Table 5. The estimated cumulative proportion surviving following disease onset at 5, 10 and 15 years post-onset were 93.8%, 87.4% and 79.5% respectively. The causes of death included sepsis (3), myocardial infarction (2), CNS disease (1), hypertensive crisis (1) and suicide (1).

DISCUSSION

This report is a descriptive analysis of an available sample of 29 young adults with childhood onset SLE. Although information on education and current life situations was available for 64 patients, we included in this report only the 29 in whom all of the data was completed including a recent physical examination by a physician and SF-36 form. This pre-selection is an inherent limitation of this report. However, since information on educational level, work experience, income and marital status are not documented adequately in the literature for this group of patients, we felt it was worthwhile to document this experience spanning a period of 26 years from one center. Furthermore, in a recent report on adult patients from a single center lost to follow up, Gladman et al noted that the survival data of patients continuing in follow up was not affected significantly by the missing group [11]. We realize that extrapolation from this small and selected sample is not justified and prospective studies including controls are needed.

Most of the studies on prognosis and follow up of adults with SLE focus on mortality and morbidity and coping strategies, and a few recent studies in adults include measurement of QOL [6-10]. Very little information is available on the impact of the disease on other aspects

of life such as education and work status [12]. There are several studies documenting the educational level, work experience and employment status of children with JRA growing up to be adults [13-18].

In our group we found that more than 85 % of patients completed high school and 11% completed 4 years of college. It is also interesting to note that approximately one third felt that the disease interfered with their education. If those with CNS disease were to be evaluated separately, this number may be higher. In the report from Canada, Dobkin et al [12] documented that most of their adult patients with SLE had completed 3 to 18 years of education (mean 13.77 years). Follow up studies on patients with JRA show that more than 90 % completed high school and 15-30% completed college [13-19].

In our group, 25% had full time employment and 22% had part time jobs. Eleven percent were on disability and 7.4% were unemployed. The Canadian data on adults with SLE does not mention the work status but states that the mean income was in the \$ 20,000 to 30,000 per year range [12]. In contrast, 62 to 66 % of patients who had JRA hold full time job and 16% were disabled. [13, 15]. Although most of our patients were drawn from a central city population with poorer socioeconomic condition, it appears that patients with SLE may have problems holding full time jobs. This, together with the low income and the fact that over 75% live with parents suggest that the impact of SLE on education, job and income is significant. Moreover this data clearly points to the importance of transition and career planning [19]. A prospective study should focus on these areas and analyze the reasons for these problems.

The study in adults with SLE from Canada gives a figure of 42.5 % for married and 22 % for divorced and 4.4% widowed. In our group 24% were married or living with a partner. Of the 29 included in the study, 22 were women. Nine had successful pregnancies with

normal children. We did not collect data about their past or current medications, their disease activity during pregnancy and whether any of them were taking immunosuppressive medications. It is interesting that none of the offspring were reported to have any medical problems. Spontaneous abortion occurred in three (30%), but the numbers are too small for comparison to the general population. The reported abortion rate in patients with SLE is 16% [20].

SLEDAI score of >4 is considered to be an evidence of active disease for purposes of this study. Based on this definition, 15 (51.7% of the sub-sample) had active disease. This is an important observation and is not surprising. Long term studies on patients with JRA show that approximately 45 % patients had active disease at 10 year follow-up [21]. Although the prevalence of SLE in children is less than JRA, SLE is a devastating disease. The persistence of the disease, the effects of damage to organs such as the kidney and the CNS, and the chronic fatigue are more likely to interfere with attaining higher education and holding a permanent job. Future studies need to focus on these needs of young adults with SLE. This study was done before the availability of instruments to measure cumulative organ damage. This was not the focus of the study either. However it is obvious that the majority of these patients enter adult life with active disease and substantial damage to kidneys, CNS and musculoskeletal system. Bone demineralization, growth retardation and cataract were some of the treatment-related damage that were noted.

SF-36 is an instrument developed to measure quality of life (QOL) in patients with all chronic diseases [4, 22]. This instrument has been used in several studies to measure QOL in adults with SLE [6-10]. However this instrument has not been used, to our knowledge, to measure QOL of adults with childhood-onset SLE. Nor is there any study in children with SLE using comparable QOL measurements. Sutcliffe et al showed that patients with SLE scored lower than controls

by more than 20 points on the SF-36, particularly in the physical aspects of QOL [8]. Lower scores correlated with increased disease activity. Dobkin et al did not use normal controls but compared SF-36 scores between patients with mild and severe disease as documented by SLAM scores [7]. Patients with more active SLE scored lower in PCS and MCS compared to less active SLE. Those with more active disease also reported more bodily pain, worse general health status, and decrease in social and physical functioning.

In a more recent prospective study, Thumboo et al [9] used a slightly different method of scoring SF-36 questionnaires. The primary Focus of their study was change in function over time in adults with SLE. They noticed that the disease activity was not a strong indicator of QOL in general. However, after adjusting for variables, they noted that disease activity influenced mental health aspects of life, which in turn affected overall QOL.

In our study, patients with SLE scored lower on SF-36 scores compared to US general population in the physical component scale but not in the mental component scale. When the scores for the individual items were analyzed, SLE patients did poorly in physical function, body pain, general health and vitality. These findings are comparable to results from other studies in which mental health functions were found to be less affected than the physical function components [6-10]. Because of small numbers, we did not attempt to correlate SLEDAI or SF-36 scores with any variables.

Eight patients (12.5% of the overall sample) died during the period of follow-up. The estimated cumulative proportions surviving following disease onset at 5, 10 and 15 years post-onset were 93.8%, 87.4% and 79.5% respectively compare favorably with data from adult studies [23]. In a review of the literature of lupus nephritis in children, maximum rates of survival at 5 years was noted to be 92%; and figures for 10 and 15 year survival were 88% and 84% respectively [24]. In a

report by Lacks and White who followed children with SLE for a period of 1 month to 10.7 years, 5 year survival was 85% [25]. In a study comparing clinical features and outcome of SLE with onset in childhood and adults, Tucker et al noted that the 10 year survival was 95% in childhood – onset type compared to 85% in the adult – onset variety [26].

Analysis of the cause of death showed that three of our patients died of sepsis. In most studies on mortality in SLE, sepsis is clearly a leading cause of death in adults and in children [23, 25, 26]. Two of our patients died of myocardial infarction (MI), one male at age 19 and another female at age 31. MI has not been mentioned in two studies on organ damage in childhood SLE [27, 28]. Results from two large studies in adults indicates that active SLE and infections are common causes of death soon after the onset of the disease, whereas cardiovascular causes and malignancy become major causes of death for later deaths [29, 30]. Early onset of atherosclerosis in patients with SLE was considered to be secondary to steroid therapy until recently. However, there are evidences to suggest inadequate control of inflammation as a more probable cause [31]. In childhood onset SLE this becomes more important since one of the goals should be to minimize such complications.

In summary, 50% of children with SLE followed up to 25 years still had active disease at the time of our study. The majority of them had completed high school and almost 50% of the study population was in college or had some college level education. Most of them were employed but earning low income. Those with active disease were experiencing low QOL, particularly in physical function.

ACKNOWLEDGMENT

Our sincere thanks to the following physicians who helped us evaluate patients and score them on the SLEDAI scale for disease activity: Drs.

Sally Pullman-Moar, Gregory Keenan, Bonnie Dorwart, Steven Berney and Maria Rizzo. We would also like to thank the Lupus Foundation of South Jersey.

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Table 1 – Demographic Analysis

VARIABLE	TOTAL SAMPLE PERCENTAGE (n=64)	SUB-SAMPLE PERCENTAGE (n=29)
GENDER		
Female	52 (81.2%)	22(75.9%)
Male	12(28.8%)	7 (24.1%)
RACIAL BACKGROUND		
Afro-American	31(48.4%)	13(44.8%)
Asian	2(3.1%)	2(6.9%)
Caucasian	26(40.6%)	9(31.0%)
Hispanic	3(4.7%)	3(10.3%)
Other	2(3.1%)	2(6.9%)
OTHER		
	mean (SD)	mean (SD)
Age at onset (years)	11.9 (3.1)	11.3 (3.1)
Age at follow-up (years)	25.5 (6.4)	23.6 (6.0)
Mean period of follow-up (years)	13.6 (6.3)	13.0 (6.1)

Table 2 – Physician Collected Medical Information

<u>VARIABLE</u>	<u>PERCENTAGE</u>
Active Disease – SLEDAI > 4	15 (51.7%)
Permanent Organ System Impairment Due to SLE (n=26)	
Renal	12(46.4%)
Skin	11(42.3%)
CNS	6(23.1%)
Orthopedic	5(19.2%)
Visual	2(7.7%)
Cardiac	1(3.8%)
Pulmonary	1(3.8%)
Gastrointestinal	1(3.8%)
Neoplastic Disease (n=28)	
Present	None (0.0%)
Pregnancy related issues in Women (n=22)	
No Pregnancies	12 (54.5%)
Pregnancies	9 (45.5%)
Spontaneous Abortion	3
Medical Abortion	1
Spontaneous and Medical Abortion	1
Health Complications in Children born to the Study's Participants (n=9)	
Health Complications	None (0.0%)

Table 3 – Patient Reported Socio-demographic Data

<u>VARIABLE</u>	<u>PERCENTAGE</u>
Highest Educational Status (n=27)	
Incomplete High School	3 (11.1%)
High School Graduate	9 (33.3%)
Incomplete University/College	12 (44.4%)
University/College Graduate	3 (11.1%)
Was Further Educational Progress Impaired by SLE (n=24)	

No	15 (62.5%)
Yes	9 (37.5%)
Work Status (n=27)	
Part-Time	9 (29.6%)
Full-Time	6 (22.2%)
Student	7 (25.9%)
Disabled	3 (11.1%)
Unemployed	2 (7.4%)
Marital Status (n=29)	
Never Married	24 (82.8%)
Married	5 (17.2%)
Living Arrangement (n=29)	
Lives with Parents	12 (41.4%)
Lives with Relatives (other than parents)	6 (20.7%)
Lives with Partner/Spouse	7 (24.1%)
Lives Alone	4 (13.8%)
Household Income (n=24)	
Under \$10,000	4 (16.7%)
\$10,000-\$19,000	5 (20.8%)
\$20,000-\$29,000	8 (33.3%)
\$30,000-\$39,000	1 (4.2%)
\$40,000-\$49,000	0 (0.0%)
\$50,000-\$59,000	1 (4.2%)
\$60,000-\$69,000	0 (0.0%)
\$70,000-\$79,000	3 (12.5%)
\$80,000 and Up	2 (8.3%)
Medical Insurance Type (n=29)	
HMO	7 (24.1%)
Medicaid	10 (34.5%)
Traditional	7 (24.1%)
PPO	3 (10.3%)
No Insurance	2 (6.9%)

Table 4 – SF-36 Physical Component Scores (PCS) and Mental Component Scores (MCS)

Group	Mean PCS (SD)	Mean MCS (SD)
SLE Sample	40.3 (11.3)	47.9 (12.6)
General Population*	50.0 (10.0)	50.0 (10.0)

*General United States Population Norm. (9)

Table 5 – Life Table

FOLLOW-UP TIME PERIOD	ESTIMATED CUMULATIVE PROPORTION SURVIVING	STANDARD ERROR
1.0 years	0.992	0.011
5.0 years	0.938	0.030
10.0 years	0.874	0.043
15.0 years	0.795	0.059
20.0 years	0.663	0.082
25.0 years	0.398	0.146

Figure 1 – Kaplan-Meier Survival Function

SLE Survival Function

Kaplan Meier Analysis

● Complete ▲ Censored

