

The CHILL-NL study - Adult outcomes of childhood-onset SLE

Education and work participation

A. Kardolus¹, N. Groot^{1,2}, M. Bijl³, R. Dolhair⁴, K. de Leeuw⁵, I. Bultink⁶, R. Fritsch⁷, S. Kamphuis¹ on behalf of on behalf of the CHILL-NL study group

¹Department of Pediatric Immunology, Sophia Children's Hospital - Erasmus MC, ²Department of Pediatrics, Wilhelmina Children's Hospital/University Medical Centre Utrecht, ³Department of Internal Medicine and Rheumatology, Martini Hospital, Groningen, ⁴Department of Rheumatology, Erasmus MC, Rotterdam, ⁵Department of Rheumatology and Clinical Immunology, University Medical Center, Groningen, ⁶Amsterdam Rheumatology and Immunology Center, Location VUmc, Amsterdam, ⁷ Department of Rheumatology and Clinical Immunology, University Medical Center, Utrecht

Introduction

Childhood-onset systemic lupus erythematosus (cSLE) is a severe, chronic multi-system autoimmune disease. Little is known regarding outcomes in adult life. This study addresses effects of the disease on education and work participation

Methods

In this cross-sectional study, patients diagnosed with childhood-onset SLE (diagnosis <18 years) who are now older than 18 years were included. Outcome measures were: Ethnicity, age at diagnosis, ACR/SLICC classification criteria at diagnosis, clinical features over time, medication use, current disease activity, disease damage, questionnaire regarding education and work participation.

Conclusions

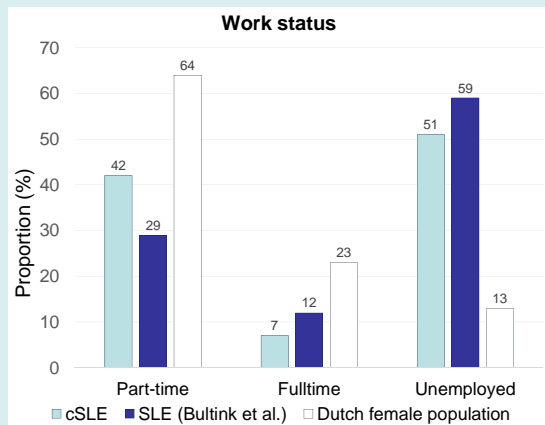
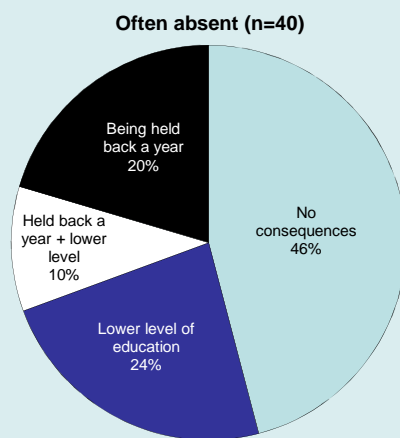
These results show that cSLE can greatly influence education and work participation:

- During education, cSLE limits the patients: it has a negative influence on choice of education and frequently results in delay of the educational career.
- Work participation is negatively influenced. Career choice and career course is affected. There is a high prevalence of unemployment and work disability.
- The percentage of cSLE patients that were unemployed is higher than the unemployment rate of the Dutch norm population, and similar to SLE patients in the Netherlands
- Disease related damage could be associated with work disability.

Results

Disease Characteristics	Outcome
(n = 56 females with cSLE)	
Ethnicity	
White	75%
Age at diagnosis (median+range)	14 yrs (6 – 17)
Disease duration (median+range)	20 yrs (1 – 55)
Current SLEDAI-score (median+range)	4 (0 – 14)
Patients still using immunosuppressive medication	91%
Medication use	<u>Ever</u> <u>Current</u>
Prednisone	98% 64%
Hydroxychloroquine	84% 66%
MMF	41% 29%
Azathioprine	68% 27%
ACE-I or ARB	54% 39%
SLICC damage index (median + range)	1 (0 – 8)
SLICC damage index ≥ 1	31/56 (55%)
Musculoskeletal damage	13/31 (42%)
Renal damage	9/31 (29%)
Neuropsychiatric damage	9/31 (29%)

Influence of cSLE on education	
Negative influence by disease	50/55 (91%)
- Often absent	40/50 (80%)
- Lower level of education	15/50 (30%)
- Being held back a year	14/50 (28%)
- Other	13/50 (26%)
Limitations in choice of education	32/55 (58%)



cSLE and employment	
Career choice negatively influenced by SLE	25/41 (61%)
Provocation of disease related symptoms due to work activities	14/39 (36%)
Change of position at work due to SLE	10/39 (26%)
Adjustment of work activities	14/39 (36%)
Reduced working hours	8/39 (21%)
Quit their job	11/39 (28%)
Reduced hours or quit job (partially) due to SLE	17/19 (89%)
Completely	11/17 (57%)
Work disability	21/41 (51%)
Complete	12/21 (57%)
Partial	9/21 (43%)

