Insight Medical Publishing

JOURNAL OF SURGERY AND EMERGENCY MEDICINE

# Long-Term Clinical Outcomes in a Cohort of Adults With Childhood-Onset Systemic Lupus Erythematosus

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**Abstract**

Although survival of childhood-onset SLE (cSLE) patients has greatly improved, morbidity is still high and questions of children and parents regarding the future course of the disease are difficult to answer. In our study of adults with cSLE, we show that most adults with cSLE patients have low disease activity but still need to use disease-modifying anti-rheumatic drugs. Many patients also still used corticosteroids, despite their self-reported aversion against the drug. Other disease-modifying anti-rheumatic drugs, as well as hydroxychloroquine, were also commonly used. SLE-related disease manifestations in specific organ systems (e.g. kidneys, central nervous system, cardiopulmonary system) mainly occurred within two years after diagnosis. Hereafter, organ systems were generally newly affected due to comorbidities or damage. Most cSLE patients developed damage as well as comorbidities (e.g. myocardial infarctions, infections) in their twenties or early thirties. Prevention of damage and comorbidities therefore needs to be initiated early in this patient group, by reducing cardiovascular risk factors, reducing infections by vaccination and reducing cumulative corticosteroid use when possible. Health-related quality of life (HRQOL) was negatively affected by higher disease activity and changes in physical appearance due to disease or medication specifically, and was hardly influenced by the presence of damage.

In addition, cSLE has a substantial impact on academic achievements and employment. More than 90% of the patients reported their school career to be hindered in some way, and many patients reported their choice of secondary education to be affected by their disease. The disease also had an impact on employment, as more than half of the patients had to stop working or reduce working hours due to cSLE. Both being unemployed and being work disabled had a negative impact on HRQOL. Helping patients to find an education and career suitable to their capabilities may help improve HRQOL, as well as support their active participation in the community.

**Biography**

Kamphuis is a pediatric rheumatologist/immunologist with a PhD in cellular immunology and research focus on SLE since 2009. She was invited by prof. E.D. Silverman to work 2 years (2009-2011) as Lupus Clinical Research Fellow in the Hospital for Sick Children, Toronto. With Prof. Silverman as PI, she initiated and coordinated the international study 'How genotype influences Phenotype in SLE' (1000 cSLE patients & 1000 adult onset SLE patients). After her return to the Netherlands in 2011, she initiated a prospective cohort study for cSLE patients with biobanking of patients' samples. In 2012 she started to study adult outcomes of cSLE patients. Additionally, she started collaborating with Dr. Versnel, Immunologist at the Erasmus University Rotterdam, studying Interferon type 1 activation as potential biomarker in cSLE and unraveling underlying mechanisms for Interferon activation for which she received several grants.

14th International Conference on Rheumatology and Arthroplasty | London, UK | September 21-22, 2020

**Citation:** Sylvia Kamphuis, Long-Term Clinical Outcomes in a Cohort of Adults With Childhood-Onset Systemic Lupus Erythematosus, Rheumatology 2020, 14th International Conference on Rheumatology and Arthroplasty, London, September 21-22, 2020