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Effects of Childhood-onset Systemic Lupus Erythematosus on Academic Achievements and Employment in Adult Life

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ABSTRACT. ***Objective.*** Long-term outcome data in adults with childhood-onset systemic lupus erythematosus (cSLE) are limited. Here, we report the effects of cSLE on education, vocation, and employment in a large cohort of adults with cSLE.

Methods. Patients were seen for a single study visit comprising a structured history and physical examination. Medical records were retrieved to supplement information obtained during the study visit. Education and employment status were assessed by questionnaires. Health-related quality of life (HRQOL) was measured with the 36-Item Short Form Health Survey (SF-36).

Results. One hundred six patients with cSLE (93% female, 73% White), with a median disease duration of 20 years, completed the visit and questionnaires. Almost all patients stated that cSLE had influenced their education, but the level of completed education was similar to the general Dutch population. Half of the patients had adjusted their vocational choice due to the disease. Still, 44% of patients who had finished education did not have a paid job. Of the employed patients, 61% worked part time. Disease damage was equally prevalent in patients with and without paid employment. A high percentage of patients (51%) were declared work disabled, due to disease damage. Patients who did not have paid employment were often work disabled. Both had a negative effect on HRQOL.

Conclusion. The effect of cSLE on academic achievements and employment is substantial, despite patients adjusting their educational and vocational choices. To optimize participation in the community, ongoing support is necessary, not only to help patients find suitable education and vocations but also to offer guidance regarding potential adjustments during their career.

Key Indexing Terms: damage, educational status, employment, outcome assessment, quality of life, systemic lupus erythematosus

Systemic lupus erythematosus (SLE) is a chronic, multisystem autoimmune disease with an unpredictable disease course. In 10–20% of cases, SLE presents in childhood or adolescence.[1] Patients with childhood-onset SLE (cSLE) have an additional burden of having to cope with the disease during adolescence, an important period in their intellectual and physical development.[2,3,4,5] Aside from missing school due to hospital visits, disease-specific features such as arthritis, fatigue, and central nervous system involvement can attribute to a deviation from their original academic and vocational goals.

Poor childhood health affects education, career path, and employment.[6] Children with SLE have poorer school performance and meet fewer educational milestones than their healthy peers.[4] In children with juvenile idiopathic arthritis (JIA), poor

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school functioning was associated with disease activity, functional disability, and depressive symptoms.[7] Young adults with JIA achieved similar education levels as their healthy peers but took longer to complete their education.[8,9]

Higher academic achievements are correlated with higher frequencies of employment in the general population.[10] One cohort study of adults with cSLE reported that patients are less likely to be employed compared to patients with adult-onset SLE (aSLE), despite similar education levels.[3] In adults with JIA, associations between functional disabilities, disease duration, medication use, and educational and employment status were suggested.[11,12]

Chronic diseases can affect work productivity. Patients may call in sick (absenteeism) or may not be able to work as efficiently (presenteeism) due to their disease. The work productivity of patients with aSLE is often compared to the healthy working population but has not yet been studied in adults with childhood-onset rheumatic diseases.[13,14,15]

Health-related quality of life (HRQOL) of patients with (c)SLE is impaired compared to the general population.[16,17,18] No studies regarding the effect of employment status on the HRQOL of adults with cSLE have been performed. In adults with JIA and those with aSLE, being employed is associated with higher HRQOL.[19] Receiving a disability allowance in JIA was associated with lower physical HRQOL.[20]

The Childhood-onset SLE in the NetherLands (CHILL-NL) study aims to assess the burden of disease in adults with cSLE. Here, we report on education, vocation, and current employment status of adults with cSLE compared to the general Dutch population, and the association of employment status and work disability with the HRQOL of patients with cSLE.

METHODS

Patients. All patients diagnosed with SLE prior to their 18th birthday who were ≥ 18 years of age and met the American College of Rheumatology (ACR) criteria for SLE[21] were eligible for inclusion. The study was designed by the CHILL-NL study team together with a panel of 5 adult patients with cSLE. Details regarding enrollment and data collection have been described previously.[22] In short, all patients were seen for a single study visit. Information collected during this visit was verified and supplemented with information from medical records. Only data that could be verified in the medical records were reported. The Research Ethics Board of the Erasmus Medical Centre, Erasmus University approved this study (MEC-2013-163). Written informed consent was obtained from all patients. This article focused on education and job histories among patients with cSLE. Data from our cohort were compared to the general Dutch population (77% White, 13% non-White), matched for age.[23] If available, data from the female Dutch general population were used for comparison.[23]

Clinical characteristics and HRQOL. Demographics, medication use, disease activity (SLE Disease Activity Index 2000 [SLEDAI-2k][24]) and damage (Systemic Lupus Erythematosus International Collaborating Clinics/ACR Damage Index [SDI][25]) at study visit were registered. High disease activity was defined as a SLEDAI score ≥ 8. Damage was defined SDI ≥ 1. The SLEDAI-2K domains "ongoing inflammatory rash" and/or "alopecia" were defined as factors affecting physical appearance.[22] HRQOL was measured with the 36-Item Short Form Health Survey (SF-36) and compared to SF-36 scores of the general female Dutch population.[23,26]

Education and employment. Completed level of education was categorized according to the International Standard Classification of Education 2011 by primary, secondary, or tertiary education.[27] Secondary education was defined as having finished secondary school (e.g., high school or vocational school), and tertiary education included academic education as well as advanced vocational or professional education. Patients still attending secondary or tertiary education were classified as having finished primary or secondary education, respectively. Patients were defined as students when they were currently pursuing secondary or tertiary education. Additionally, patients were asked what their parents' completed level of education was. Level of education was compared to the general Dutch population.[23,28] Patients were asked whether their disease had affected their educational achievements (yes or no); if yes, patients were asked to give the reason(s) for this.

Patients were asked which categories described them best: having paid employment, looking for work, doing volunteer work, being a homemaker (with/without children), being work disabled, studying, or being retired. These categories were not mutually exclusive. If categories were conflicting, patients were asked to clarify. The number of hours patients with paid employment worked weekly was used to define full time (> 36 h) or part-time (≤ 35 h) jobs, as in the Netherlands, a full-time job is defined as working > 36 hours.[23] Employment status in our cohort was compared to the Dutch female population.[23,29]

In the Netherlands, work disability of individuals aged 18 years or older is assessed during an objective process regulated by the Dutch government.[30] Individual capabilities are evaluated by a physician specializing in occupational medicine. The extent to which a patient is able to work determines the size of the disability allowance. Patients who reported being work disabled and had a (part-time) paid job were classified as (partially) work disabled. Work disability was compared to the Dutch female population.[31]

Patients were asked whether their disease had affected their career choice or working hours, and if they had to adjust work activities or change job type due to their disease. This was asked through yes or no questions and a comment box to indicate the reason(s). Questions from the Work Ability Index were used to assess work impairment.[32,33] Presenteeism on the most recent working day[33] and absenteeism in the 3 months prior to study visit[32] due to their disease or to other circumstances were assessed.

Statistical analysis. Descriptive statistics were used to describe patient characteristics. Regarding educational achievements, employment status, and work disability, data were compared to the Dutch population using chi-square tests. Between-group comparisons of HRQOL scores in work disability and employment were made using the Mann-Whitney *U* test. Analyses regarding the presence of damage in association with employment and work disability were done using the chi-square test. All analyses were performed in SPSS Statistics (v22; IBM Corp.). Unless referenced otherwise, all data regarding the Dutch general population were extracted from StatLine, the database of the Dutch Central Bureau of Statistics.[23]

RESULTS

Patients. Of the 111 adults with cSLE included in the national CHILL-NL study,[22] 106 (96%) completed questionnaires regarding education, work participation, and quality of life. Characteristics of the 5 patients who did not complete the questionnaires are described in Supplementary Table 1 (available from the authors on request). Patient characteristics of the 106 adults with cSLE are described in Table 1. Most patients were female (93%), and White (73%). Notably, the general Dutch population data to which we refer reflects a population with 13% non-White ethnicity.[23,34] The median disease duration was 20 years. Patients generally had low disease activity (median SLEDAI 4), and 61% had developed damage (SDI ≥ 1). Musculoskeletal, renal, and neuropsychological damage were the most common items scored on the SDI. HRQOL in the CHILL-NL cohort was lower compared to the general Dutch

Table 1. Cohort characteristics (n = 106).

	Median (Range) or n (%)
Female (n, %)	98 (93)
Ethnicity (n, %)	
White	77 (73)
Non-White	29 (27)
Age at study visit, yrs	33 (18–65)
Age at diagnosis, yrs	14 (4–17)
Disease duration, yrs	20 (1–55)
Current CS and DMARD use	71 (67)
CS + DMARD	38 (36)
CS only	16 (15)
DMARD only	17 (16)
Current HCQ use	72 (68)
HCQ + DMARD/CS	51 (48)
HCQ only	21 (20)
SLEDAI-2K score	4 (0–16)
SDI score	1 (0–8)
SDI ≥ 1	65 (61)

CS: corticosteroid; DMARD: disease-modifying antirheumatic drugs (i.e., azathioprine, cyclosporine, cyclophosphamide, leflunomide, methotrexate, mycophenolate mofetil, rituximab, tacrolimus); HCQ: hydroxychloroquine; SLEDAI-2K: Systemic Lupus Erythematosus Disease Activity Index 2000; SDI: Systemic Lupus International Collaborating Clinics/American College of Rheumatology Damage Index[36].

population. Lower HRQOL was associated with high disease activity (SLEDAI-2K ≥ 8) and changes in physical appearance. The presence of damage (SDI ≥ 1) negatively affected HRQOL in the physical functioning domain only.[22]

Effect of cSLE on education. Almost all patients (91%) reported their education to be affected by the disease (Figure 1A). Absence from school (69%) was most commonly reported; 29% of the patients were held back a year, and 22% of the patients had to go to a lower level of education. Of the 11% (n = 12) of patients who specified other effects of cSLE on education, 3 reported that education was affected by fatigue and arthralgia, 2 others by hospital admissions, 1 by the disease cSLE in general had, 1 by incapacity to fulfill the physical tasks needed for his education, and the last 5 of 12 patients reported their disease had led to educational delay or they had to quit their study of choice.

Choice of secondary or tertiary education was affected in 58% of patients by the limitations of their disease (Figure 1B). Five patients (5%) only completed primary education (Figure 1C). Of these 5 patients, 2 had followed special education for physically and mentally handicapped children due to the disease, 2 had started secondary education but were not able to complete their studies. The remaining patient was in high school at the time of study visit. Sixty-seven patients (63%) had completed secondary education (e.g., high school, college, vocational education) and 34 (32%) tertiary education (e.g., professional or academic bachelor's degree). Compared to the female Dutch population, patients had a similar educational level (chi-square 0.70, $P = 0.40$ for completing secondary education and chi-square 0.46, $P = 0.496$ for completing tertiary education [Figure 1C]). An individual's educational level may be related to the educational level of the parents.[35] A subset of 51 patients (48%), of whom 23 (45%) had completed tertiary education filled in a questionnaire regarding the education level of their parents. The majority of the patients had an equal (43%) or higher educational level (49%) than their parents. Educational levels of the parents were also similar to those of the general Dutch population (data not shown).

Twenty-seven patients in the CHILL-NL cohort were students (median age 22 yrs, range 18–27). They were either pursuing secondary (37%) or tertiary (63%) education. Eleven students (41%) reported being work disabled.

Vocation. More than half of the patients (58%) reported their choice of vocation to be affected by the disease (Figure 2). Some specified that their desired profession was not possible due to

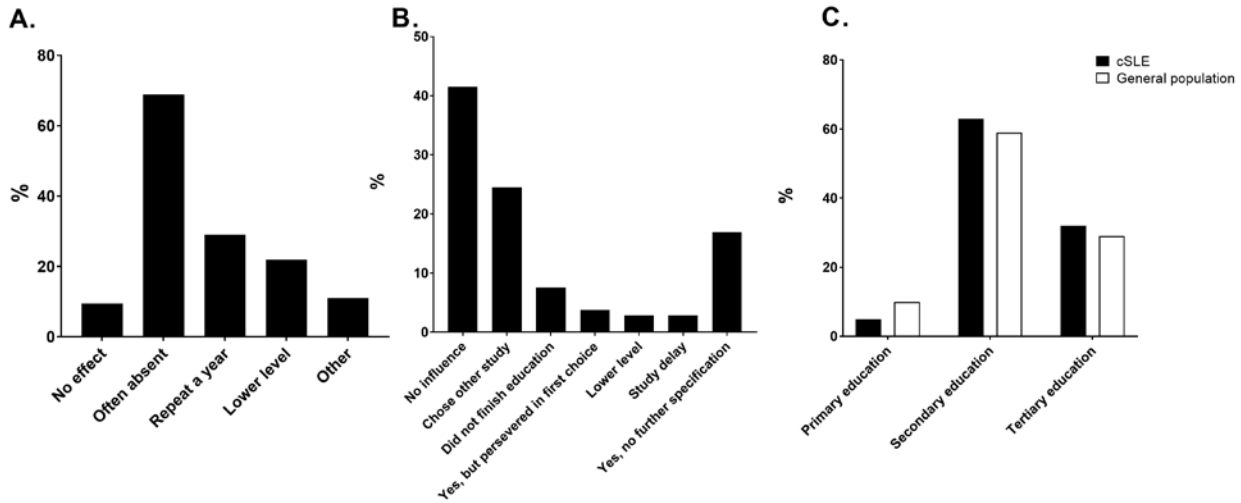

Figure 1. Effect of cSLE on education (n = 106). (A) Patient-reported effects of cSLE on education in general. (B) Patient-reported effects of cSLE on decision making regarding choice of secondary/tertiary education. (C) Completed level of education of patients with cSLE and the general population. Completed education level was classified according to the International Standard Classification of Education 2011 (primary, secondary, or tertiary education). cSLE: childhood-onset systemic lupus erythematosus.

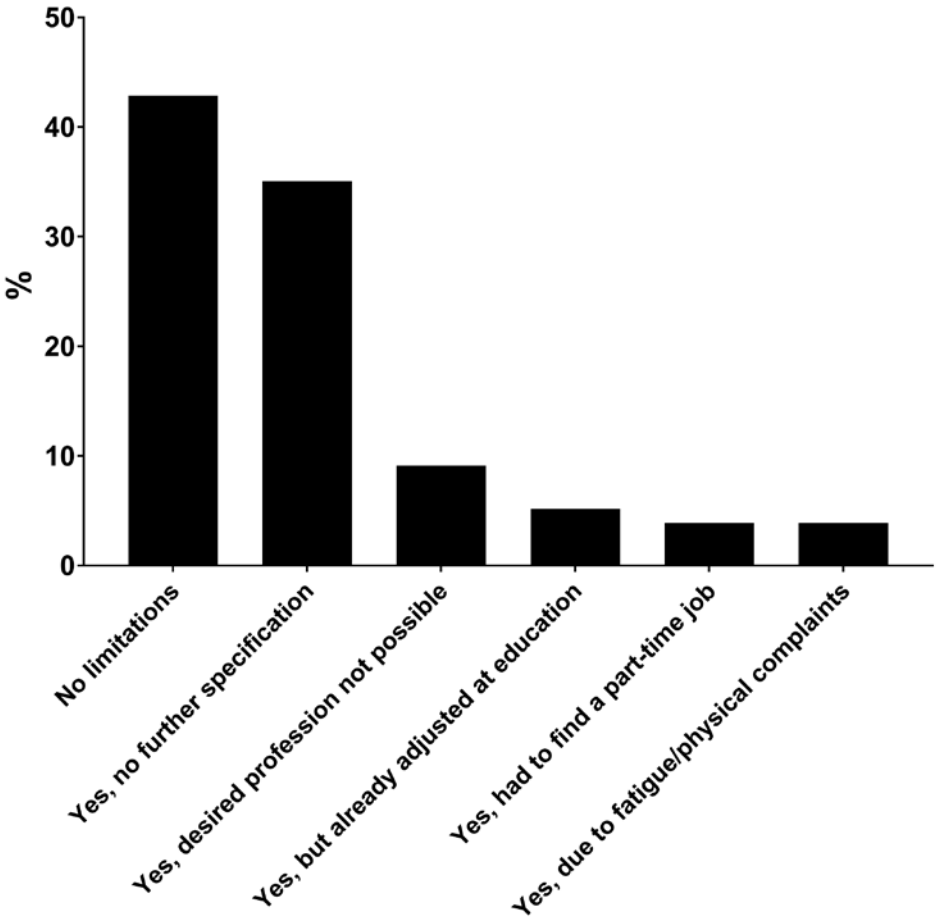

Figure 2. Patient-reported effects of cSLE on choice of vocation (n = 106). Patients were asked whether their disease affected their choice of vocation, with an option to specify in what way this was affected. cSLE: childhood-onset systemic lupus erythematosus.

their disease, whereas other patients specifically mentioned that fatigue or physical complaints affected their choices. Others reported that their choice of vocation was affected, but that they had adjusted their choice when deciding what to study. Whether patients adjusted their vocation on a similar educational level or changed to a lower level was unknown.

Employment. Students (n = 27) and retirees (n = 1) were excluded from analyses regarding employment. Of the remaining 78 patients (95% female), 44% (n = 34) did not have a paid job. Significantly more patients with a paid job had completed tertiary education (22/44 = 50%) compared to patients without paid employment (6/34 = 18%; chi-square 8.72, P = 0.003). Of the employed patients (n = 44), most (61%) worked part time, but that is significantly less than the 75% of the female Dutch population (chi-square 11.08, P = < 0.001; Figure 3A). Notably, part-time employment rate in Dutch women is very high compared to the mean part-time employment rate of 26% for women in Europe.[36] The majority of unemployed patients (n = 34) reported to have 1 or more (nonpaid) occupations in daily life: 45% were homemakers, 28% did volunteer work, and 21% took care of their children.

More than half of the 78 patients reported that the disease had influenced work participation (Figure 3B). Thirty percent of employed patients worked fewer hours (partially) due to their cSLE, at a median age of 28 years. Twenty-two percent reported having changed their type of job due to the disease. In total, 28% of all 78 patients had quit their job partially or completely due to cSLE, at a median age of 27 years. Work productivity was impaired in 52% of the employed patients, with 43% reporting absenteeism and 25% reporting presenteeism. Of the patients reporting work impairment, 39% reported that this was due to cSLE.

A substantial number of patients had developed damage, which was comparable in the employed and unemployed groups (77% vs 66%, chi-square 1.03, P = 0.31; Figure 3C).

Work disability. Half of the 78 patients with cSLE (51%) were work disabled, compared to the 3.7% work disability rate in the female Dutch population (Figure 4A).[31] As expected, the proportion of patients who were work disabled was higher in the group without paid employment (82% vs 30%, chi-square 21.45, P < 0.001; Figure 4B). Patients who were employed despite being (partially) work disabled (n = 13) worked fewer hours compared to the employed patients who were not work disabled (median 20 vs 31 hours, Mann-Whitney U test P = 0.01; data

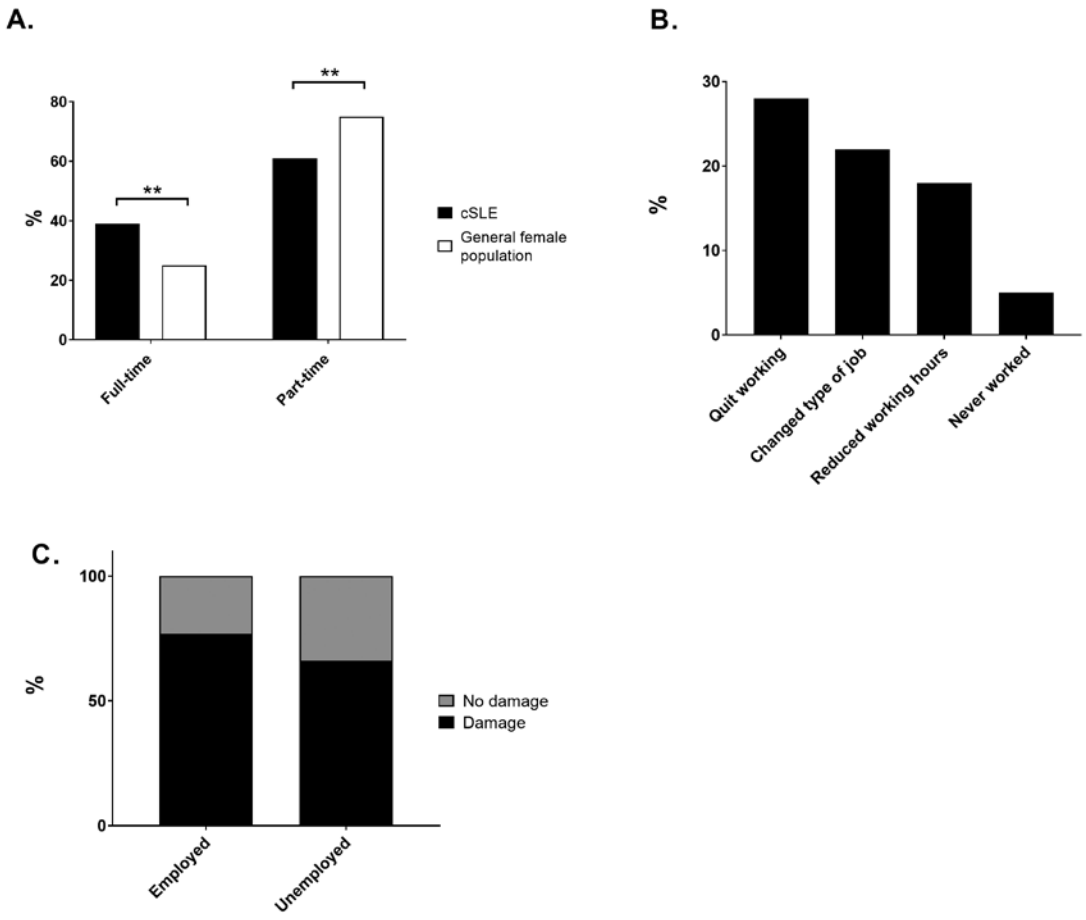

Figure 3. Effects of cSLE on employment. (A) Percentages of full-time and part-time working patients with cSLE (n = 44) and the general female population. (B) Patient-reported effects of the disease on employment (n = 78). (C) Presence of damage in patients with and without paid employment (n = 78). ** $P < 0.01$ with chi-square test. cSLE: childhood-onset systemic lupus erythematosus.

not shown). Patients who were work disabled reported that choice of education (68% vs 46%) and vocation (76% vs 35%) had been affected by the disease more often than patients who were not work disabled (chi-square 3.98, $P = 0.046$ and 12.96, $P < 0.001$, respectively).

Not surprisingly, the number of patients with damage was significantly higher in the work disabled group (81% vs 60%, chi-square 4.14, $P = 0.04$; Figure 4C). Neuropsychiatric damage was overrepresented in the patients who were work disabled (chi-square 4.06, $P = 0.04$). No significant difference in musculoskeletal (chi-square 2.998, $P = 0.08$) or renal (chi-square 0.04, $P = 0.85$) damage between patients with and without work disability was found.

Influence of employment and work disability on HRQOL. Patients without paid employment reported lower HRQOL in all SF-36 domains (Figure 5A; Supplementary Table 2, available from the authors on request). Patients who were work disabled also reported lower HRQOL in all SF-36 domains compared to patients who were not work disabled (Figure 5B; Supplementary Table 2). As work disability is closely related to employment status, the effect of the combination of both is shown in Figure 5C. Interestingly, HRQOL of patients who were work disabled was lower in the majority of the domains, irrespective of having a paid job.

DISCUSSION

To our knowledge, this is the first study that addresses not only academic achievement and employment in adults with cSLE but also the self-reported influence of the disease on education and career.

Almost all adults with cSLE reported that their education was hindered by the disease. Indeed, a cross-sectional study in children with cSLE showed that school attendance of most patients was negatively affected by the disease.[5] Additionally, patients struggled with schoolwork; this is associated with disease activity and treatment.[4,5] Academic outcomes of patients in the CHILL-NL cohort, however, were similar to the general Dutch population. In the only other cohort of adults with cSLE reporting on educational outcomes, educational levels of adult patients with cSLE were similar to patients with aSLE.[3] Comparing educational outcomes of patients with cSLE with that of aSLE is difficult, as the latter group is generally diagnosed

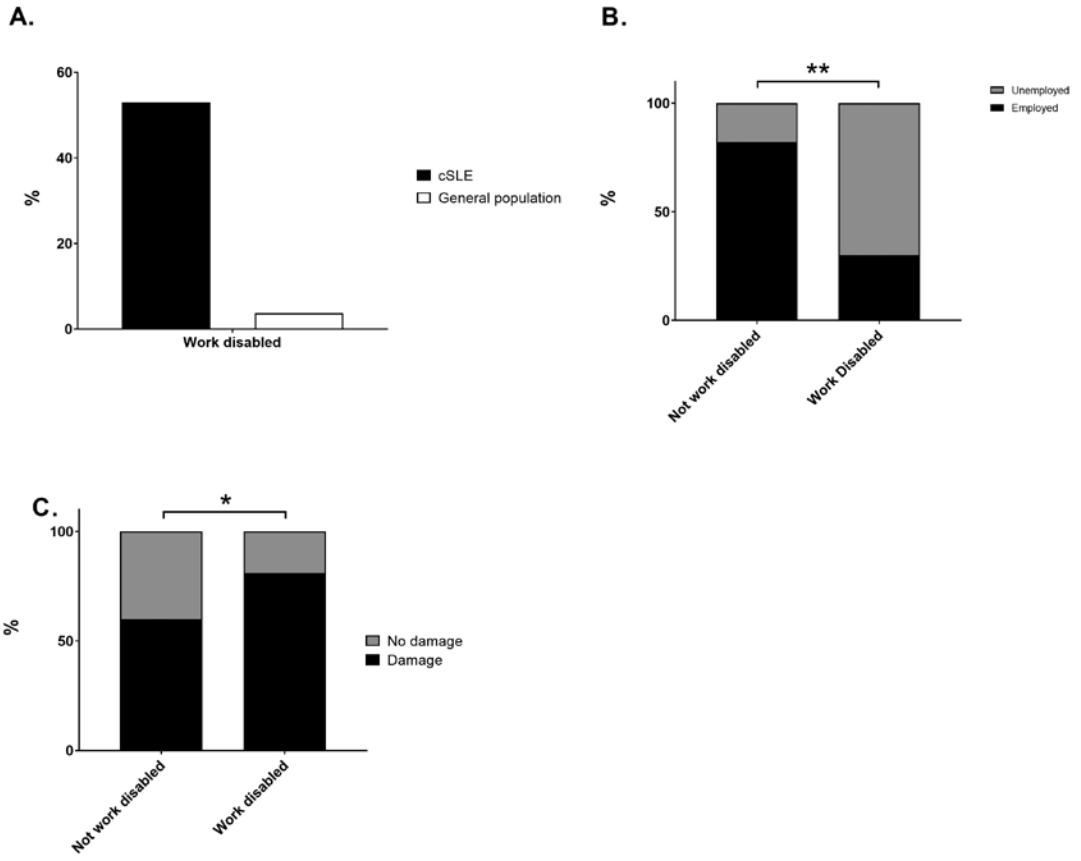

Figure 4. Work disability in patients with cSLE and the relation with employment status and disease damage (n = 78). (A) Work disability in patients compared to the general Dutch population. (B) Employment status of patients with (n = 41) and without (n = 37) work disability. (C) Presence of damage in patients with (n = 41) and without (n = 37) work disability. * $P < 0.05$. ** $P < 0.01$ with chi-square test. cSLE: childhood-onset systemic lupus erythematosus.

after finishing their academic career. Although parental education level was known for only half the cohort, the level of education of patients and their parents was similar or higher. Patients may take longer to finish their education; similar results have been reported in adults with JIA and other chronic childhood-onset diseases.[8,37]

Finding suitable education and vocation is part of the preparation of young people with chronic diseases for adult-oriented healthcare systems, where they need skills to manage their disease independently. Many patients in this cohort reported that their choice of education and vocation was affected by their disease. Patients who struggle with these choices during the transition process in adolescence need optimal support to give them the best chance to get a paid job in future.[38,39]

Recommendations for a successful transition to adult-centered care of young people with rheumatic diseases have been formulated by the European Alliance of Associations for Rheumatology and the Paediatric Rheumatology European Society.[38] Disabilities, strengths, and abilities should be assessed by the patients, parents, and pediatrician together. Career exploration should be embedded in this transition.[38]

In the CHILL-NL cohort, 44% of patients did not have a paid job. This is lower compared to the reported percentage (59%) of patients without paid employment in a Dutch aSLE cohort (93% female, mean age 38.4 yrs).[40] This might be because patients with cSLE have had the opportunity to adjust their vocational choice. As this was reported by many patients in the CHILL-NL cohort, they may therefore be better prepared when entering the work force. When diagnosed with SLE in adulthood, career choice is often already made and disease manifestations may prevent patients from continuing their job.[3] The only other study available that looked into employment in cSLE showed conflicting data: adults with cSLE had a higher risk of not having paid employment compared to patients with aSLE.[3] As this study was performed in the United States,[3] local circumstances may contribute to this difference. For instance, the opportunities to work part time and receive (partial) disability allowance may be more easily available in the Netherlands.[36]

Another factor accounting for the differences in employment rate may be the education level. Employed patients in the CHILL-NL study had completed tertiary education more often than patients without a paid job. That higher education can partly counteract the adverse effects of disease on paid employment has also been shown in adults with JIA and patients with aSLE.[19,41]

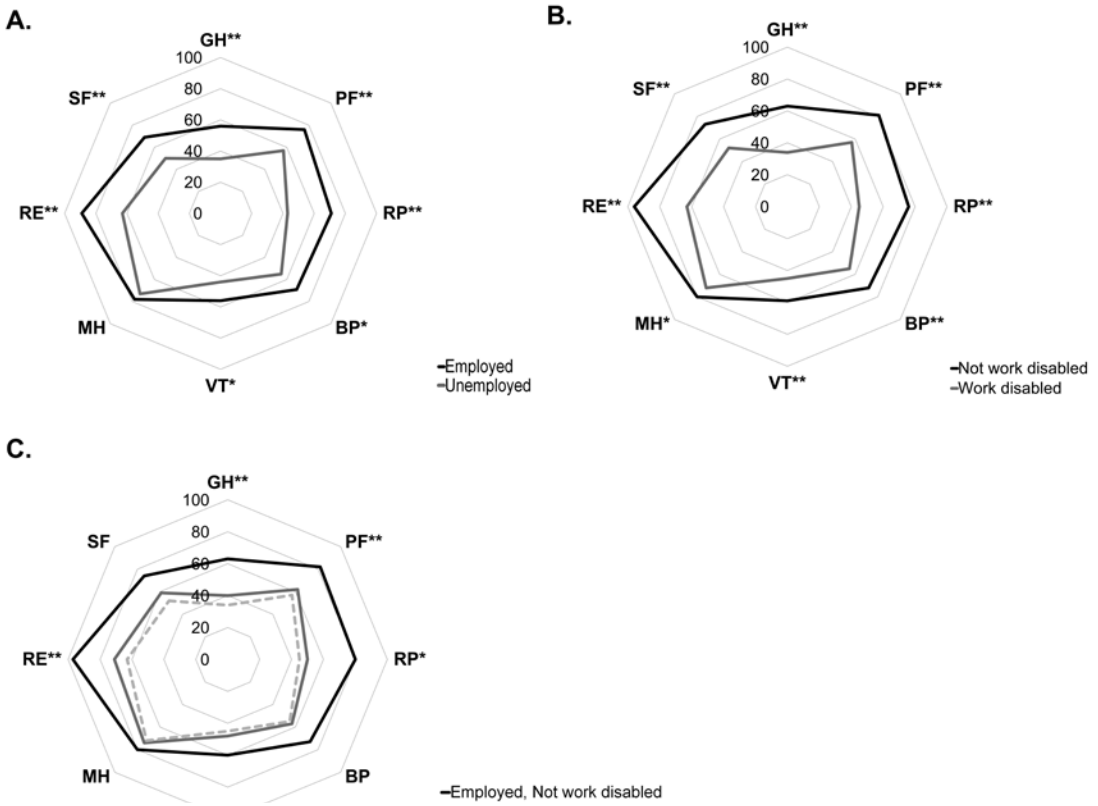

Figure 5. HRQOL in patients with cSLE related to employment and work disability (n = 78). HRQOL is expressed as mean SF-36 scores per domain. Spider plots show mean scores within each domain of the SF-36, ranging from 0 (worst) to 100 (best). (A) SF-36 scores of unemployed and employed patients with cSLE. (B) SF-36 scores of patients with cSLE who were work disabled. (C) SF-36 scores of employed patients with cSLE who were work disabled, compared to SF-36 scores of employed patients who were not work disabled. * $P < 0.05$. ** $P < 0.01$ with Mann-Whitney *U* test. BP: bodily pain; cSLE: childhood-onset systemic lupus erythematosus; GH: general health perception; HRQOL: health-related quality of life; MH: mental health; PF: physical functioning; RE: role limitations due to emotional problems; RP: role limitations due to physical problems; SF: social functioning; SF-36: 36-item Short Form Health Survey; VT: vitality.

Work productivity was affected by the disease, which has also been reported in patients with aSLE.[15,42] High autonomy regarding work activities is important for maintaining paid employment.[43] This holds true for SLE as well, as it has an unpredictable course. A flexible workplace with autonomy regarding working activities and opportunities to work part time should support adults with childhood-onset chronic illnesses to remain employed.[3]

Work disability in the CHILL-NL cohort was very high compared to the general population. Although the majority of the patients with work disability did not have paid employment, several had a paid job. No studies of work disability in adults with cSLE are available. In a systematic review of 26 studies in aSLE with a mean disease duration of up to 14 years, work disability was estimated to be 34%, which is lower than the 51% in the CHILL-NL cohort.[41] Several risk factors affecting work disability have been identified in aSLE, such as presence of damage, specifically neuropsychiatric and musculoskeletal damage.[40,44,45] Indeed, in our cohort, damage and neuropsychiatric damage was more prevalent in patients with work disability.

Patients without paid employment had lower HRQOL, which is also seen in patients with aSLE.[15,40] Employment status may facilitate higher HRQOL due to higher financial rewards and feelings of independence and self-worth.[19] A negative effect on HRQOL was seen in patients who were work disabled. Being work disabled appeared to overrule the positive effect of employment on HRQOL in this group. Further, patients who were work disabled had damage more often. Although damage on its own hardly affected HRQOL in the CHILL-NL cohort, we speculate that specific damage may affect work disability and thereby HRQOL. For example, cerebral infarction is more likely to affect the capacity to work than having cataract. However, our study was underpowered to perform subanalyses on damage type and association with work disability and/or HRQOL.

The number of patients who were not aware or not interested in the study was unknown. All included patients were cSLE survivors; patients with current high disease activity and/or damage may have found the study too taxing to participate in. Our results might be an underrepresentation of the severity of cSLE and its effect on education and work participation.[46,47] A selection bias toward patients with a high level of education cannot be excluded. As higher educational levels have been associated with higher employment rates,[12] it is possible that our results are an underrepresentation of unemployed adults with

cSLE. Although all data were verified with clinical records, it is possible that information was missed as data were collected retrospectively. In the questionnaires, we asked whether SLE affected education, vocation, and employment, and if yes, we asked for the reason in an open-ended question. We did not specifically ask for other (confounding) factors that could influence employment and education outcomes besides SLE.

This is a cross-sectional study in which data regarding employment were limited to current work status. Prior studies have demonstrated that patients with SLE move in and out of work based on their disease status,[44] which cannot be assessed for patients with cSLE in this study. The intended follow-up of this cohort will help our understanding of the employment status of patients with cSLE over time.

The percentage of inhabitants of the Netherlands with a non-Western background is 13%,[23] which is lower than the 27% found in our cohort. Our study was underpowered to assess the effect of ethnicity on educational and vocational achievements.

The statistical tests were performed without correction for multiple testing, so it is possible that some significant results may be due to chance. Additionally, our study lacked power to perform regression analysis to adjust for possible confounders and to assess predictors of disability and unemployment.

Despite the large perceived effect of cSLE on education, academic achievements in adults with cSLE were similar compared to the general population. Although vocational choices were often adjusted due to the effects of the disease, 44% of patients did not have a paid job. A high percentage of patients (51%) were work disabled, which was related to not having paid employment and the presence of damage, specifically neuropsychiatric damage. Employed patients had a higher HRQOL, but being work disabled outweighed the positive effect of employment on HRQOL. Ongoing support to help patients find suitable education and vocation and to offer guidance regarding potential adjustments during their career is necessary, to facilitate independence and participation in our community.

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