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# Sick leave and disability pension following delivery in women with systemic lupus erythematosus

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**Objective:** To investigate sickness benefits following delivery in mothers with systemic lupus erythematosus (SLE) and mothers without SLE.

**Method:** SLE and non-SLE mothers, matched by age and month of delivery, with a singleton liveborn (2004–2008), were identified from the Swedish Lupus Linkage cohort. Work loss (sum of sick leave and disability pension) was studied from 1 year prenatally to 3 years postpartum. Adjusted logistic regression models of covariates associated with > 30 days of work loss in the first and second years postpartum were estimated in SLE mothers.

**Results:** Among 130 SLE mothers and 440 non-SLE mothers, SLE mothers were more likely to have work loss from the prenatal year (42% vs 16%) to 3 years postpartum (49% vs 15%). In SLE mothers, work loss was on average 61 ± 112 days (mean ± sd) in the prenatal year and 38 ± 83 days in the first year postpartum, which increased to 71 ± 114 days in the third year postpartum. Having > 30 days of sick leave in the year of delivery [odds ratio (OR) 4.4, 95% confidence interval (CI) 1.5–12.9] and ≤ 12 years of education (OR 2.6, 95% CI 1.1–6.0) were associated with work loss in the first year postpartum. No covariates were associated with work loss in the second year postpartum.

**Conclusion:** SLE mothers more often had work loss in the prenatal year to 3 years postpartum compared to non-SLE mothers. Lower education and sick leave in the year of delivery were associated with a higher odds of work loss in the first year postpartum in SLE.

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Systemic lupus erythematosus (SLE) is a chronic autoimmune disease most often diagnosed in women of childbearing age. Pregnancy in women with SLE is riskier than in women without SLE owing to higher maternal and foetal risks (1, 2). The longer term effects of a pregnancy while having SLE are still largely unclear (3, 4). Sick leave and disability pension are interesting outcomes in this context as they give information about the overall health status and the ability to work (5–7). In Sweden, all individuals who are unable to work owing to illness are entitled to sick leave (short-

term absence) and may, in more severe cases, be granted disability pension (long-term absence) (5).

The literature shows that women with SLE take on average more than double the number of days of sick leave (25 vs 10) and are granted any full- or part-time disability pension three times more often (34% vs 10%) in a year compared to women from the general population, regardless of pregnancy status (8). SLE disease activity, flares, and common SLE manifestations such as fatigue, depression, physical impairment, pain, and cognitive dysfunction have been suggested to play a role in reduced work participation in women with SLE (3, 9–13). There is evidence that pregnant women with SLE take five times more sick leave on average than women from the general population during the pregnancy period (14). Pregnancy in women with SLE may lead to more disease activity of their lupus, as well

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as potentially increase the risk of pregnancy complications and comorbidities (4, 15–17).

Information on sickness benefits associated with SLE provides important insights into the burden on women's daily life and overall health status, rather than looking at separate outcomes. The current study investigated annual sick leave and disability pension from one calendar year before delivery to three calendar years after delivery in women with SLE and general population comparators. Although information on sick leave and disability pensions of women from the general population is well known, we included this group to put our results into a Swedish context. We hypothesized that women with SLE have other risk factors for sick leave than general population comparators due to the SLE disease. As such, we investigated risk factors for sick leave following delivery separately in women with SLE and general population comparators.

## Method

### Study setting and data sources

Access to healthcare is universal in Sweden, and Swedish residents have a unique personal identification number that can be used for the linkage of their records across registers. The Swedish Medical Birth Register includes information on maternal health during pregnancy and delivery, and neonatal outcomes of over 98% of deliveries in Sweden since 1973. The Total Population Register captures information on sex, year of birth, county of residence, and immigration from 1968 onwards. The Cause of Death Register collects the date of death. The National Patient Register captures hospitalization information (national coverage from 1987 onwards) and non-primary care/outpatient visits in public and some private practices (since 2001). The longitudinal integrated database for health insurance and labour market studies captures data on education, income, occupation, and employment by calendar year on all residents in Sweden  $\geq 16$  years old from 1990 onwards (5). Data on disability pensions are available starting in 2003.

### Study population

Women with SLE and general population comparators were identified from those mothers included in the population-based Swedish Lupus Linkage (SLINK) cohort (1987–2012), which was created using the Swedish registers described in 'Study setting and data sources', above (18). In brief, SLINK included all individuals with at least one SLE International Classification of Diseases, 10th Revision (ICD-10)-coded visit (M32, excluding M32.0 drug-induced lupus) in the National Patient Register. SLINK also included five random general population comparators, who were identified in the

Total Patient Register, and matched with SLE cases on age, sex, calendar time, and county of residence. Because only mothers with a live birth were included, the original matched sets were no longer preserved in the present study and rematching was performed based on delivery-related variables (see below).

The study population of the current study was composed of primiparous women with and without SLE from SLINK whose start of pregnancy, calculated as the difference between the date of birth and gestational age registered in the Medical Birth Register, was between 1 January 2004 and 31 December 2008. Women with unknown registered sick leave or disability pension in the longitudinal integrated database for health insurance and labour market studies in the calendar year before the calendar year of delivery were not included in this study. Only singleton pregnancies in women with SLE and general population comparators were included. In this study, maternal SLE was defined as at least two ICD-coded visits in the inpatient or outpatient records of the National Patient Register and Medical Birth Register occurring before delivery, including at least one code from a specialist who typically treats or diagnoses SLE, i.e. rheumatology, dermatology, nephrology, internal medicine, or paediatrics, that should have occurred at any time before the start of pregnancy. The index date of SLE was defined as the first ICD-coded visit in the inpatient or outpatient records of the National Patient Register or Medical Birth Register, and used to calculate age at diagnosis and years between diagnosis and pregnancy. General population comparators had no SLE codes before the date of the first observed SLE ICD-coded visit of their matched case (original matching date in SLINK).

Women with SLE with a documented delivery were matched to women from the general population with a documented delivery by age at delivery and month of delivery (target ratio 1:3). Because data in the longitudinal integrated database for health insurance and labour market studies are reported by calendar year, we matched by month of delivery to make sure that we were able to compare sick leave, disability pension, and parental leave as outcomes and sick leave as a risk factor between women with SLE and general population comparators. The study period was from one calendar year before the calendar year of delivery (year before delivery), the calendar year of delivery (year of delivery), to three calendar years after the calendar year of delivery (first, second, and third year postpartum). Longer follow-up after delivery is necessary to observe the effect of SLE pregnancy on sick leave, as most mothers take parental leave in the first year, which will displace the sick leave registration.

Ethical approval was provided by the Regional Ethics Review Board in Stockholm (DNR 2011/920-31/1, 2021-01148). Informed consent was not required.

### Sick leave, disability pension, and parental leave

Days of sick leave, disability pension, and parental leave were registered in the longitudinal integrated database for health insurance and labour market studies, and studied from the year before delivery to three years postpartum. Sick leave exceeding 14 days was registered in the longitudinal integrated database for health insurance and labour market studies. In the first 14 days of sick leave, the employers are responsible for paying for sick leave, and after 14 days, compensation is paid by the Social Insurance Agency. Sick leave benefits are paid to individuals with an annual salary of > 10 000 SEK (roughly €1000 using the average exchange rate between 2003 and 2012) (14) and when disease or injury forces the individuals to be away from work for at least 25% of the working hours. Individuals who had at least 25% reduced work capacity expected for at least 1 year and were part of the social insurance system were granted part-time or full-time disability pension. As disability pension was registered in months, we recalculated this into days by using 30 days on average per month. Parental leave was available for parents from the birth of a child, and the maximum duration of the parental leave was 480 days to share between the parents during the study period (5). Net days of sick leave, disability pension, and parental leave were used for the calculations, which were calculated by multiplying the level of benefit received (i.e. 100%, 75%, 50%, or 25%) by the total number of days. The categories 0, 1–30, 31–90, 91–180, and > 180 days were created for registered sick leave, disability pension, and parental leave. In addition, work loss for each calendar year (the year before delivery to 3 years postpartum) was calculated by counting the total days of sick leave and disability pension per year.

### Other covariates

Date of delivery, small for gestational age, and preterm delivery (gestational age < 37 weeks) were obtained from the Medical Birth Register. Admission to a neonatal intensive care unit was obtained from the National Patient Register using the MVO (Medicinska verksamhetsområden) code 207. Neonatal adverse pregnancy outcomes (none or any) were based on small for gestational age, preterm delivery, and admission to a neonatal intensive care unit. Maternal age at delivery ( $\leq 30$ ,  $> 30$  years) and age at SLE diagnosis ( $\leq 25$ ,  $> 25$  years) were calculated using date of birth from the Total Patient Register. Pre-eclampsia (ICD-10: O11 and O14) and eclampsia (ICD-10: O15) were obtained from the National Patient Register and Medical Birth Register. Hospitalizations in the calendar year before delivery (0, 1, or  $\geq 2$ ) were obtained from the inpatient register of the National Patient Register. Highest educational level achieved ( $\leq 12$ ,  $> 12$  years) was obtained from the

longitudinal integrated database for health insurance and labour market studies.

### Statistical analysis

Prevalence and means with standard deviation (mean  $\pm$  sd) were calculated to describe the characteristics of women with SLE and general population comparators. Women who were pregnant with their second baby were excluded from the analysis for the remaining years starting from the calendar year of the last menstrual period of their subsequent pregnancy. Frequencies and mean days of registered sick leave, disability pension, work loss, and parental leave from the year before delivery to 3 years postpartum, comparing women with SLE to general population comparators, are presented.

To investigate covariates for > 30 days of work loss in the first and second years postpartum, logistic regression models were used to estimate adjusted odds ratios (ORs) with 95% confidence intervals (CIs) separately for women with SLE and general population comparators. ORs were adjusted for age at delivery, calendar year, and registered sick leave in the year before delivery, except if it was the variable of interest. ORs of work loss in the second year postpartum were additionally adjusted for registered sick leave in the first year postpartum, except if it was the variable of interest. We investigated all covariates except for pre-eclampsia and eclampsia, as there were too few mothers with SLE with these covariates and work loss (< 5).

Data management and statistical analyses were performed in R version 4.1.1 and SAS version 9.4 (SAS Institute, Cary, NC, USA). Figures were created in GraphPad version 8.3.1 (GraphPad Software, La Jolla, CA, USA).

## Results

### Characteristics of mothers

We included 130 women with SLE and 440 general population comparators matched on age at delivery and month of delivery (Table 1). Mean age at delivery was 31 years, and 25% of women with SLE had been hospitalized at least twice in the year before delivery compared to 9% of general population comparators. Women with SLE had a higher level of education, were more likely to have pre-eclampsia during pregnancy, and more often had babies who were small for gestational age or were born preterm compared to general population comparators.

### Sick leave, disability pension, work loss, and parental leave

Women with SLE registered more often for sick leave than general population comparators in the year before

Table 1. Characteristics of 130 women with systemic lupus erythematosus (SLE) and 440 general population comparators matched by sex, age at delivery, and month of delivery with a pregnancy in the medical birth register between 2004 and 2008 in Sweden.

	Women with SLE (n = 130)	General population comparators (n = 440)
Age at delivery (years)	31 ± 4.1	31 ± 3.6
Age at delivery (years)		
≤ 30	66 (51)	226 (51)
> 30	64 (49)	214 (49)
Age at SLE index date (years)	24 ± 5.7	n/a
Age at SLE index date (years)		
≤ 25	76 (58)	n/a
> 25	54 (42)	n/a
Interval between SLE index date and delivery (years)	4.8 ± 4.6	n/a
Calendar period at time of delivery		
2004–2006	58 (45)	221 (50)
2007–2009	72 (55)	219 (50)
Hospitalizations in the calendar year before delivery		
0	23 (17)	72 (16)
1	75 (58)	329 (75)
≥ 2	32 (25)	39 (9)
Education at time of delivery (years)		
≤ 12	44 (34)	176 (39)
>12	85 (65)	263 (60)
Missing	1 (1)	1 (1)
Serious maternal adverse pregnancy outcomes		
Pre-eclampsia	18 (14)	24 (6)
Eclampsia	0 (0)	0 (0)
Neonatal adverse outcomes		
Small for gestational age*	17 (13)	12 (3)
Preterm birth (< 37 weeks)	31 (24)	21 (4)
Admission to a neonatal intensive care unit in first year of life	0 (0)	0 (0)
Postpartum death of the baby	< 5 (n/a)	0 (0)

Data are shown as mean ± sd or n (%).

n/a, not applicable.

\*There was one woman with SLE with missing information. Percentages exclude missing values.

delivery (35% vs 15%), year of delivery (52% vs 30%), first year postpartum (20% vs 14%), second year postpartum (30% vs 16%), and third year postpartum (32% vs 13%) (Table 2, Supplementary Table 1). Women with SLE had on average 37 ± 82.9 days on sick leave in the year before delivery, which increased to 49 ± 74.4 days in the year of delivery, after which it decreased to 30 ± 70.9 days in the third year postpartum (Table 2, Figure 1). General population comparators had a similar pattern of sick leave, although, as expected, their mean number of days was lower compared to women with SLE (Table 2, Figure 1).

Women with SLE were more often granted disability pension compared to general population comparators from the year before delivery (13% vs 1%) up to the third year postpartum (22% vs 2%) (Table 2, Supplementary Table 1). Women with SLE had on average 24 ± 76 days of disability pension in the year before delivery, which increased to 42 ± 96 days in the third year postpartum, compared to 2 ± 26 days in the year before delivery and 5 ± 39 days in the third year postpartum in women from the general population (Table 2, Figure 2).

Women with SLE had on average 61 ± 112 days of work loss in the year before delivery and 71 ± 114 days in the third year postpartum in SLE, compared to 13 ± 50 days in the year before delivery and 15 ± 66 days in the third year postpartum in women from the general population (Table 2). Parental leave was similar between women with SLE and general population comparators for the year before delivery up to 3 years postpartum (Supplementary Table 2).

#### Variables associated with work loss in SLE

Twelve or fewer years of education (OR 2.6, 95% CI 1.1–6.0) and over 30 days of sick leave in the year of delivery (OR 4.4, 95% CI 1.5–12.9) were significantly associated with a higher odds of work loss (> 30 days) in the first year postpartum. None of the potential covariates evaluated in women with SLE was significantly associated with work loss in the second year postpartum (Table 3). A similar pattern was found in women from the general population; however, in this

Table 2. Sick leave, disability pension, and total work loss by calendar year for 130 women with systemic lupus erythematosus (SLE) matched on age at delivery and month of delivery to 440 women from the general population with a pregnancy in the medical birth register between 2004 and 2008 in Sweden.

Women with SLE					
	Year before delivery (N = 130)	Year of delivery (N = 129)	Year 1 postpartum (N = 125)	Year 2 postpartum (N = 108)	Year 3 postpartum (N = 72)
On sick leave	45 (35)	67 (52)	25 (20)	32 (30)	23 (32)
Sick leave (days)	37 ± 83	49 ± 74	12 ± 39	25 ± 64	30 ± 71
On disability pension	17 (13)	17 (13)	17 (14)	16 (15)	16 (22)
Disability pension (days)	24 ± 76	28 ± 87	26 ± 77	32 ± 93	42 ± 96
Total work loss (days)	61 ± 112	77 ± 108	38 ± 83	57 ± 106	71 ± 114
Not included	0 (0)	1 (1)*	5 (4)†	22 (17)‡	58 (45)§
General population comparators					
	Year before delivery (N = 440)	Year of delivery (N = 440)	Year 1 postpartum (N = 421)	Year 2 postpartum (N = 310)	Year 3 postpartum (N = 178)
On sick leave	68 (15)	134 (30)	59 (14)	49 (16)	24 (13)
Sick leave (days)	10 ± 43	15 ± 37	4 ± 28	10 ± 46	11 ± 55
On disability pension	4 (1)	5 (2)	4 (2)	4 (2)	3 (2)
Disability pension (days)	2 ± 26	2 ± 25	2 ± 25	3 ± 29	5 ± 39
Total work loss (days)	13 ± 50	16 ± 44	6 ± 38	12 ± 55	15 ± 66
Not included	0 (0)	0 (0)	19 (4)	130 (30)¶	262 (60)**

Data are shown as mean ± sd or n (%).

Percentages for sick leave and disability pension variables exclude those women who are not included per year. Percentages for the variable 'not included' are calculated from the total group of women with SLE (N = 130) and general population comparators (N = 440). Sick leave exceeding 14 days was registered in the Swedish Longitudinal Integrated Database for Health Insurance and Labour Market Studies (LISA), so the numbers on sick leave do not include the first 14 days.

Number of women with missing data on sick leave and disability pension: \*†n = 1, ‡§n = 2, ||¶n = 3, \*\*n = 5.

Number of women for whom follow-up was ended because they had their second child in that year: †n = 4, ‡n = 20, §n = 56, ||n = 16, ¶n = 127, \*\*n = 257.

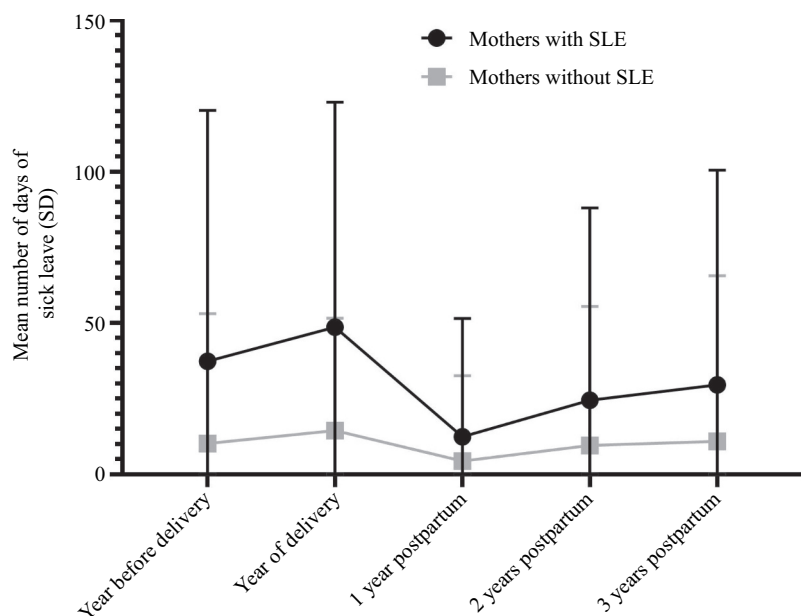


Figure 1. Mean number of days on sick leave before and after delivery in mothers with systemic lupus erythematosus (SLE) and mothers without SLE.

population, sick leave in the first year postpartum was significantly associated with a higher odds of work loss in the second year postpartum (OR 26.2, 95% CI 7.5–91.1) (data not shown).

## Discussion

This population-based study in Sweden showed that women with SLE took on average substantially more days of sick leave than women from the general

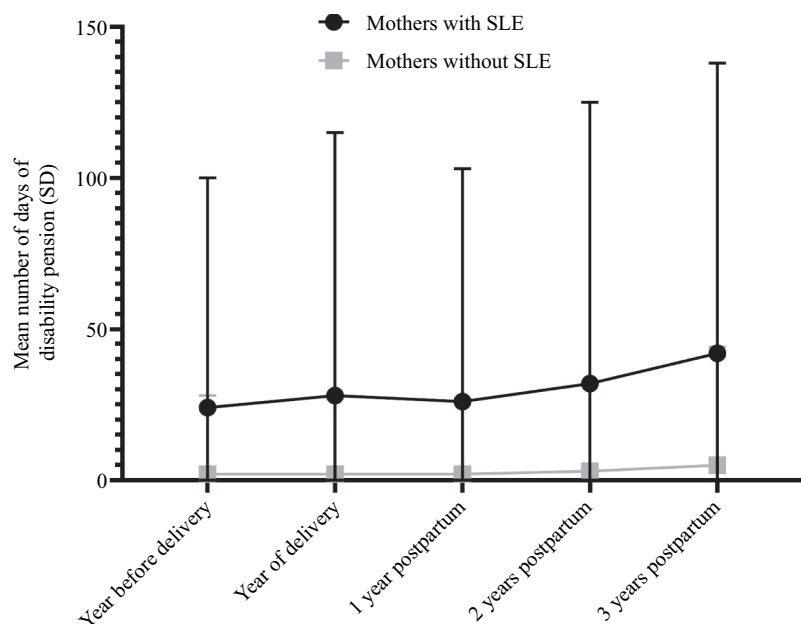


Figure 2. Mean number of days of disability pension before and after delivery in mothers with systemic lupus erythematosus (SLE) and mothers without SLE.

Table 3. Work loss (> 30 days) in the first and second calendar years postpartum among 130 women with systemic lupus erythematosus (SLE) by patient characteristics with risk estimates.

Variable and category	First year postpartum		Second year postpartum	
	Work loss n/N (%)	Adjusted OR* (95% CI)	Work loss n/N (%)	Adjusted OR† (95% CI)
Age at delivery (years)				
≤ 30	21/66 (31.8)	1.1 (0.5–2.3)	18/66 (27.3)	1.4 (0.6–3.4)
> 30	19/64 (29.7)	1 (reference)	13/64 (20.3)	1 (reference)
Age at SLE onset (years)				
≤ 25	26/76 (34.2)	1.6 (0.7–3.6)	21/76 (27.6)	1.9 (0.8–4.9)
> 25	14/54 (25.9)	1 (reference)	10/54 (18.5)	1 (reference)
Interval between SLE onset and delivery (years)				
≤ 2	13/50 (26.0)	0.5 (0.2–1.2)	9/50 (18.0)	0.3 (0.1–0.9)
> 2	27/80 (33.8)	1 (reference)	22/80 (27.5)	1 (reference)
Number of hospitalizations during pregnancy				
0	5/23 (21.7)	1 (reference)	2/23 (21.7)	1 (reference)
1	21/75 (28.0)	1.5 (0.3–6.4)	15/75 (20.0)	2.7 (0.5–14.3)
≥ 2	14/32 (43.8)	0.8 (0.2–4.4)	11/32 (34.4)	1.6 (0.3–9.6)
Education at time of delivery (years)				
≤ 12	21/44 (47.7)	2.6 (1.1–6.0)	17/44 (38.6)	2.3 (0.9–5.9)
> 12	19/85 (22.4)	1 (reference)	14/85 (16.5)	1 (reference)
Number of neonatal adverse outcomes‡				
0	25/92 (27.2)	1 (reference)	18/92 (19.6)	1 (reference)
≥ 1	15/38 (39.5)	1.4 (0.6–3.3)	13/38 (34.2)	1.8 (0.7–4.6)
Sick leave in the year of delivery (days)				
≤ 30	15/76 (19.7)	1 (reference)	12/76 (15.8)	1 (reference)
> 30	25/53 (47.2)	4.4 (1.5–12.9)	19/53 (35.9)	2.9 (0.9–9.5)
Sick leave in the first year postpartum (days)				
≤ 30	n/a	n/a	24/116 (20.7)	1 (reference)
> 30	n/a	n/a	7/13 (53.9)	2.1 (0.5–8.5)

CI, confidence interval; OR, odds ratio; n/a, not applicable.

There is one missing value each for education at time of delivery, sick leave in the year of delivery, and sick leave in the first year postpartum. \*Models are adjusted for age at delivery, sick leave in the year before delivery, and calendar year of delivery, all as continuous variables, except if it was the variable of interest.

†Models are adjusted for age at delivery, sick leave in the year before delivery, sick leave in the first year postpartum, and calendar year of delivery, all as continuous variables, except if it was the variable of interest.

‡Consists of small for gestational age, preterm birth, and admission to a neonatal intensive care unit in the first year of life.

population from the year before delivery (37 vs 10 days) up to 3 years postpartum (30 vs 11 days), with the highest sick leave registration in the year of delivery (49 vs 15 days). Women with SLE had on average more days of work loss in the third year postpartum (71 days) compared to the year before delivery (61 days). This may suggest that women with SLE are not fully recovering from pregnancy and delivery in their postpartum years. Among women with SLE, lower education and more than 30 days of registered sick leave in the year of delivery were significantly associated with a higher odds of work loss in the first year postpartum. None of the covariates was significantly associated with work loss as an outcome in the second year postpartum in women with SLE.

Pre-pregnancy counselling is a widely acknowledged pivotal step in the management of women with SLE who wish to become pregnant, to improve knowledge on the risks of pregnancy and to improve pregnancy outcomes (19–21). They are generally advised to wait to conceive until the SLE disease is in remission or under good control. Information on sick leave, disability pension, and work loss as a composite outcome in the year before conceiving can be used in pre-pregnancy counselling by women with SLE and their caregivers, so that women with SLE know what the risks are when it comes to work loss after pregnancy.

The results of our study are generalizable to women with SLE living in Sweden, and other countries with similar social insurance benefits, who are pregnant with their first baby. One could hypothesize that women with SLE with multiple pregnancies have less active SLE than primiparous women, as active SLE disease and its associated factors, such as cytotoxic agents, other medications and psychosocial effects of the disease, are thought to influence fertility (22). In Sweden, the parental leave system is unique, with 480 days of parental leave per child to share between caregivers. This directly influences sick leave registration in the first postpartum years after delivery, as the mother can apply for either sick leave or parental leave.

Studies investigating the association between sickness absence and pregnancy in women with SLE are scarce. Similarly to Blomjous et al, we found that more women with SLE registered any day of sick leave in the year of delivery compared to women from the general population (14). However, it is difficult to compare these studies as the parental leave systems in the Netherlands and Sweden are different. For example, in the Netherlands women are obliged to take parental leave from week 36 of pregnancy, while in Sweden it is common for women to work until week 39 of pregnancy. In our study, we found that 25% of women with SLE had had at least two hospitalizations in the calendar year before delivery compared to 9% of women from the general population. This could reflect complications during pregnancy or some time before,

which is subsequently reflected in the sick leave registration. There is evidence that hospitalized pregnant women with SLE have a longer inpatient stay than pregnant women without SLE, which may indicate that the need for care immediately after pregnancy is higher in SLE-related pregnancies (2).

The population-based design using registry data limited selection bias, and all health care data, sickness benefits, and parental leave were registered prospectively. Women with SLE were identified before pregnancy using an established register-based case definition, although there may be some misclassification of SLE using ICD codes (23). The identification of SLE before pregnancy reduces misclassification and selection bias compared to definitions requiring that SLE is recorded as a diagnosis at delivery (24).

Data on the severity of SLE disease are unavailable in the Swedish national registers, so we could not study this important factor. To address this limitation, we examined hospitalizations in the year before delivery as a proxy of overall health status of women with SLE and general population comparators in our study population. The study period of this work is until 2012, and the frequency and duration of sickness benefit registration of women with SLE may have changed over the past decade owing to improvements in the management of pregnant women with SLE (21). Studies with more recent data are necessary to show whether that is true. There are probably multiple factors related to sickness benefit registration before and after SLE pregnancy that are missing from these data (e.g. SLE severity, medication, attitude of manager, type of work, susceptibility to infections, and government policies). Another limitation of this study is that the data on sick leave and disability pension are by calendar year, which are less precise than daily, weekly, or monthly data. To deal with this, we matched women with SLE to general population comparators by age at delivery and month of delivery to be able to investigate sick leave and disability pension as outcomes and sick leave as a risk factor.

## Conclusion

This study found that women with SLE took sick leave substantially more often than women from the general population in the year before delivery, which persisted for up to 3 years postpartum. Disability pension was granted in the third year postpartum to 22% of women with SLE compared to only 2% of women from the general population. In women with SLE, the total days of work loss was, on average, somewhat higher in the third year postpartum (71 days) compared to the year before delivery (61 days). Women with SLE and their physicians can use information on sickness benefits and work loss as an insight into the overall health status when planning and preparing for pregnancy.



## Disclosure statement

No potential conflict of interest was reported by the authors.

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## Supplementary material

Supplemental data for this article can be accessed online at <https://doi.org/10.1080/03009742.2024.2321057>