

Marital status and age of systemic lupus erythematosus diagnosis: the potential for differences related to sex and gender

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ABSTRACT

Objectives Chronic rheumatic diseases can challenge social and family relationships. We compared marital status in patients with systemic lupus erythematosus (SLE) with their general population counterparts, stratified by sex and age of SLE onset.

Methods We performed a cross-sectional analysis of a cohort of 382 patients with SLE at our centre (349 females, 33 males). We determined how many were married or living common-law at the time of last study visit. Patients were then divided into: SLE diagnosis before 18, between 18 and 30, between 31 and 44 and after 45 years of age. We then compared marital status among male and female patients with SLE, to Quebec age-specific marital statistics.

Results Of 382 patients with SLE, 202 (52.9%) were married or living common-law, which was 9% lower than general population rates (95% CI 2% to 16%). One-third of women with paediatric-onset SLE were married or living common-law, which was 28% lower than their general population counterparts (95% CI 6% to 46%). Half of women diagnosed between age 18 and 30 were married or living common law, which was 14% less than general population rates (95% CI 4% to 25%). We could not establish significant differences for women diagnosed after age 30, or for males, versus their general population counterparts.

Conclusions Women diagnosed with SLE before age 30 were less likely to be married/living common-law, versus general population rates. This was not apparent for those diagnosed later in life. We did not clearly establish this effect in males, possibly due to power issues (vs a true effect of sex/gender). Additional studies (eg, focus groups) could elucidate reasons for our findings.

INTRODUCTION

Systemic lupus erythematosus (SLE) is a multi-systemic autoimmune disease with a prevalence in Quebec of 1 in 2000.¹ It is more common in women, particularly between ages of 15 and 44 and has a higher incidence in people of Asian, African or Aboriginal origin.² SLE can have debilitating physical consequences and can also significantly affect one's mental health, both of which can challenge social and family relationships,³ including

marriage.⁴ There are many ways to assess these effects and one approach is to examine marital status.⁵ There is little published on SLE and marital status; our hypothesis is that certain demographic characteristics, such as sex or age of SLE onset, might put patients more at risk of experiencing the negative effects of a chronic disease such as SLE on marital status.

METHODS

We performed a cross-sectional assessment of a cohort of 382 patients with SLE (349 females and 33 males) followed at the McGill University Health Center with yearly updates on health and demographics. At annual research visits, we collected demographic data included sex, race, age, diagnosis data and marital status (married or living common-law, vs never married or divorced). The SLE diagnosis was made using the American College of Rheumatology classification criteria. Data collection and use was approved by the McGill University Institutional Review Board (approval number 96–060 REC). We obtained the patient's written informed consent to publish the material.

We determined the number of patients married or living common-law at the time of the last study visit in 2016–2017. Patients with SLE were then categorised into separate groups: SLE diagnosis before 18, between 18 and 30, between 31 and 44 and 45 years of age or older. We then compared data from patients with SLE to the age-group specific marital statistics of the Quebec population, stratifying by sex (Statistics Canada).⁶ The choice of age groups reflects those used by Statistics Canada. The 95% CI for the difference between independent proportions was calculated using Wilson procedure without correction for continuity.



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Table 1 Demographic characteristics of the SLE population

Characteristics	Age at SLE diagnosis			
	Before 18 (n=43)	18–30 (n=171)	30–45 (n=102)	After 45 (n=66)
Sex				
Males	3 (7%)	11 (6%)	6 (6%)	13 (20%)
Females	40 (93%)	160 (94%)	96 (94%)	53 (80%)
Race				
Asian	11 (25%)	18 (11%)	15 (15%)	5 (8%)
Black	6 (14%)	22 (13%)	14 (14%)	8 (12%)
Caucasian	21 (48%)	106 (63%)	63 (62%)	47 (72%)
Natives	2 (5%)	4 (2%)	1 (1%)	2 (3%)
Others	4 (9%)	19 (11%)	8 (8%)	3 (5%)

SLE, systemic lupus erythematosus.

We also generated multivariate models estimated the adjusted OR for the effects of sex, race/ethnicity and age at SLE diagnosis, on marital status.

RESULTS

There were 382 patients with SLE who had had an annual visit in 2016–2017. Overall, 349 (91%) were female and 237 (62%) were Caucasian. The average age at SLE diagnosis was 31 years (SD 13.2 years). The average SLE duration at the time of assessment was 6.5 (SD 8.3) years. The demographic distribution by sex, race and age of onset is shown in [table 1](#).

Of the total 382 patients with SLE studied, 202 (53%) were married or living common-law, which was 9% lower than the age-specific and sex-specific Quebec general population rates (95% CI 2% to 16%). One-third of

women diagnosed with SLE before age 18 were married or living common-law, which was 28% lower than the age-specific and sex-specific Quebec general population counterparts (95% CI 6% to 46%). Half of women diagnosed between age 18 and 30 were married or living common law, which was 14% less than the age-specific and sex-specific Quebec general population rates (95% CI 4% to 25%). Two-thirds of women diagnosed between age 31 and 44 and half of women diagnosed after age 45 were married or living common-law, which was similar to the age-specific and sex-specific Quebec general population rates. Difference of marital status between SLE population and the Quebec general population are shown in [table 2](#).

In men with SLE, we were unable to determine clear differences compared with the general population, likely

Table 2 Difference in terms of marital status between SLE population and Quebec general population

Sex	Age at SLE diagnosis	Married or living common law in SLE population, N (%)	Per cent difference between SLE and general population (%)*	95% CI for the per cent difference between SLE and general population (%)†
Males	<18	0 (0)	–33	–79 to 29
	18–30	6 (55)	–9	–43 to 28
	31–44	2 (33)	–33	–67 to 19
	≥45	12 (92)	15	–14 to 43
	All males	20 (61)	–6	–28 to 17
Females	<18	13 (33)	–28	–46 to –6
	18–30	80 (50)	–14	–25 to –4
	31–44	63 (66)	1	–12 to 14
	≥45	26 (49)	–6	–24 to 13
	All females	182 (52)	–10	–18 to –3
All patients		202 (53)	–9	–16 to –2

*A negative number represents a lower frequency of being married/common-law in SLE vs the general population.

†When the 95% CI includes the null value of zero, we cannot conclude whether a true difference exists between the SLE group vs the general population.

SLE, systemic lupus erythematosus.

Table 3 Multivariate ORs with 95% CIs for marital status of patients with SLE

	Adjusted OR (95% CI)	Adjusted OR (95% CI)
Female sex N(%)	0.80 (0.36 to 1.70)	0.69 (0.32 to 1.45)
Caucasian race/ethnicity	1.81 (1.18 to 2.78)	1.76 (1.15 to 2.72)
Age at SLE diagnosis (years, continuous)	1.02 (1.01 to 1.04)	–
Age at SLE diagnosis (dichotomised, 19+ years)	–	2.68 (1.46 to 5.08)

Models include all variables shown (with age alternately being characterised as continuous or dichotomised).
SLE, systemic lupus erythematosus.

due to the fact that SLE is such a female-predominant disease, and thus we had few male patients to study.

The multivariate model results shown in table 3 indicate that Caucasian race/ethnicity and older age at SLE onset were both independently correlated with greater odds of being married. There was a stronger correlation between age at SLE onset and marital status when the age was dichotomised (below and above age 19) instead of being treated as a continuous variable.

DISCUSSION

Paediatric-onset disease corresponds to 20% of SLE cases and is more common within non-Caucasian populations. Paediatric-onset SLE may be associated with a more severe clinical presentation than in adults (eg, more frequent lupus nephritis) and treatment toxicity has the potential to accumulate over a long period.³

Physical changes associated with SLE itself (eg, malar rash, alopecia) or its treatment (eg, steroid-induced changes in habitus) can be psychologically distressing, especially during adolescence.⁷ Though this issue has not been studied in paediatric-onset SLE, the impact of other dermatological conditions (eg, port wine stains, atopic dermatitis, acne, hidradenitis) on the self-esteem of children has been well documented and is associated with social isolation, lower levels of self-esteem and greater risk of depression.⁸ All of these issues may affect relationships later in life; in particular, high self-esteem has a positive effects the quality of love relationships and happiness with partners, which is believed to arise because healthy self-esteem promotes the development of secure attachments.⁷

Living with a chronic disease is often challenging, and there are complex potential reasons why this may affect one's marital status: some may prefer to focus on improving their health than pursuing long-term relationships or marriage; others may fear placing stress on themselves or a potential partner, due to the demands of marriage or living common-law. Depression or anxiety is not uncommon in SLE,⁹ which creates additional challenges in terms of long-term relationships. Sutanto *et al*¹⁰

conducted a systematic review and thematic synthesis of qualitative studies that explored the experiences of adults living with SLE. They found that patients often felt ostracised by loved ones. Female subjects with SLE were prone to fears of being unattractive and rejection, and some postponed parenthood due to their disease.

Another factor influencing marital rates in SLE could theoretically be educational attainment. It has been suggested that patients with some juvenile-onset rheumatic conditions may be more likely to pursue higher level education than their peers.¹¹ Advanced academic pursuits theoretically could cause individuals with paediatric-onset SLE to delay getting married. On the other hand, in the general Canadian population, women with higher education levels are similar to other women in terms of marital status.¹² Moreover, a Canadian study from 2002 showed that, compared with national statistics, fewer female patients with juvenile arthritis received postsecondary education, and unemployment rates for patients 20 to 24 years of age were higher.¹³ Thus, it is unclear whether educational pursuits and/or employment explain any of the lower frequency of being married, in our subjects with paediatric-onset SLE.

We found Caucasian patients with SLE had a higher likelihood of being married than non-Caucasians. This finding is in concordance with general population trends in North America, where Caucasian women are more likely to get married and stay married (compared with Hispanic and Black women).¹⁴

Among males with SLE, we did not see a clear difference in marital status compared with the male general population. This could be due to low power in the present study, or it could represent real differences in the effects of SLE according to sex/gender. Interestingly, the literature does suggest differences in the way chronic diseases of paediatric onset affect males versus females, supporting important gender-related issues. One relatively low-powered study of cystic fibrosis (24 females and 24 male patients) demonstrated a difference in terms of marital status in females but not in males when comparing with the general population.¹⁵ A meta-analysis of several chronic paediatric diseases (eg, asthma, arthritis, cancer, cerebral palsy, diabetes) found more self-esteem difficulties in females than in males,¹⁶ which might be explained by gender differences affecting the relation between body dissatisfaction and self-esteem. Indeed, a questionnaire-based study with 235 participants showed that despite males and females having similar rates of body dissatisfaction, body discontent had a greater impact on self-esteem in females.¹⁷

We noted that women in whom SLE had been diagnosed at ages 18–30 were less likely to be married than their general population counterparts; it may be that similar factors are at play in young adulthood as in the paediatric population. Mental health difficulties may be important, and one recent study found that female patients with SLE were more likely than male patients with SLE to have depression or anxiety.¹⁸ These issues

could be driven by biological (ie, sex-related) differences, but there may also be gender-related factors at play (eg, roles related to parenting, education, work, income and so on).

These studies suggest that more research is needed to better understand how paediatric-onset SLE may affect females versus males, in terms of key personal relationships. Ultimately, whether someone marries is clearly not the principal indicator of well-being, and in our own future research we plan to use focus groups and other methods to better understand how age of SLE onset may affect future relationships and well-being.

We acknowledge important potential limitations in the present study. This study was cross-sectional; thus, it is unclear whether a lower number of patients with SLE being married/living common-law is related to fewer patients establishing marriage or common-law relationships or if the lower frequency is related to maintaining these relationships or seeking a new one should the first relationship end. We did not attempt to describe other parameters such as divorce rates or satisfaction within existing marriages, which are likely important in understanding relationship issues in SLE. We did not collect information regarding potential reasons for patients with SLE to either marry or not. Our dataset did not include information on gender-related roles (including those related to reproduction, parenting and career) that might affect long-term relationships in SLE. The small number of males included in the study limited the conclusions that could be drawn for this sub-population. Qualitative assessments (eg, interviews and/or focus groups) could provide a better perspective on these complex questions.

CONCLUSION

Women diagnosed with SLE before age 30 were significantly less likely to be married or living common-law than similarly aged women in the Quebec general population. No difference was established between SLE men and their general population counterparts, possibly due to power issues or because of differences in the way chronic diseases affect males compared with females. We suggest that gender issues be considered in future studies of this topic. Ultimately, whether someone marries is clearly not the principal indicator of well-being. However, our study suggests that more research is needed to better understand how SLE may affect relationships and well-being and how this effect may be moderated by age of onset, sex and other factors.

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