



Caregiver burden and related factors in caregivers of patients with childhood-onset systemic lupus erythematosus

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Abstract

Objective Having a child with a chronic illness is a source of stress for the whole family, especially the primary caregiver. The aim of this study was to evaluate the associations between caregiver burden and both the caregiver's and child's psychological symptoms in a cohort of children with systemic lupus erythematosus (SLE).

Methods Thirty-four patients (aged 9–18 years) with childhood-onset SLE and their caregivers participated in this study. The control group was composed of healthy children and their caregivers. Questionnaires were used to evaluate caregiver burden and the psychological status of parents and children and adolescents with and without SLE.

Results No significant difference was found between the study and control groups for caregiver burden, anxiety and depression in parents, and psychological status in children. Caregiver burden was positively correlated with parent's depression, anxiety, and behavioral and peer problems of the children, and it was negatively correlated with the children's prosocial behaviors. According to regression analyses, the parents' depression and children's peer relationship had a positive effect on caregiver burden scores.

Conclusion Physicians should be aware of the presence of psychological symptoms in patients with childhood-onset SLE and their caregivers because it can affect caregiver burden and the caregiver's psychological state.

Key points

- Caregiver burden was positively correlated with parent's depression and anxiety.
- Caregiver burden was positively correlated with children's behavioral and peer problems.
- Caregiver burden was negatively correlated with child's prosocial behaviors.

Keywords Caregiver burden · Children · Depression · Lupus · Psychopathology

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Introduction

Childhood-onset systemic lupus erythematosus (SLE) is a multisystem autoimmune disease that has either a persistent or remitting-relapsing course [1]. The most prevalent clinical features are mucocutaneous manifestations, and constitutional, hematologic, and musculoskeletal manifestations [2]. The overall prevalence of SLE was reported as 9.73 per 100,000 children [3]. The ratio of females to males in childhood-onset SLE is 3.4:1 and the mean age of onset is 12 years [2]. The prevalence of SLE in children is lower than that in adults, but children have more severe diseases and more widespread organ involvement [1]. If left untreated, SLE is a fatal disease with a 5-year mortality rate of 95% [4].

Having a child with a chronic disease is stressful for all members of the family and especially for the primary caregiver (in most cases, the mother) [5]. Caregiver burden is used to identify physical, psychological, social, or financial problems that may occur while providing care to another person with a physical or mental disability [6, 7]. It is stated that the burden of care varies according to the sociodemographic characteristics and mental health of the caregiver, the mental health of the patient, and the duration, intensity, and type of the disease [8]. Studies showed that having lower education, being single, the presence of physical illnesses, and psychosocial or economic problems were related to a higher burden on the caregiver [9–11]. Caregiver burden has also been shown to cause burnout, acute and chronic physical disorders, depression, social isolation, and financial concerns [12].

Although there are a limited number of studies evaluating caregiver burden in children and adolescents with chronic diseases in the literature, there are no studies related to rheumatologic diseases, including SLE. The objectives of this study in a cohort of children and adolescents with childhood-onset SLE and their caregivers were as follows: (1) to assess the levels of depression, anxiety, and caregiver burden in caregivers and to compare them with healthy controls; (2) to examine the levels of hyperactivity/inattention, conduct problems, peer relationship problems, emotional symptoms, and prosocial behavior in patients and to compare them with healthy controls; (3) to evaluate the correlations between these psychological symptoms, caregiver burden, and demographic–clinical variables related to SLE; and (4) to analyze the effects of caregiver’s psychological symptoms, child’s psychological symptoms, and demographic–clinical variables related to SLE on caregiver burden.

Materials and methods

Participants

This case–control study was conducted in Istanbul University-Cerrahpasa, Cerrahpasa Medical Faculty, in the outpatient clinic of the Pediatric Rheumatology Department. Thirty-four patients with childhood-onset SLE and their caregivers participated in the study. All patients fulfilled the revised American College of Rheumatology (ACR) classification criteria for SLE [13], and the diagnosis was made by pediatric rheumatologists. The inclusion criteria for patients with SLE were as follows: age 8–18 years, at least 3-month duration of illness, and no psychotropic drug treatments used for at least 3 months before the study. The main caregiver was defined as the person who most spent time caring for the child’s medical needs. The control group ($n=34$), which had a similar socioeconomic status to the patient group, was composed of healthy children and adolescents from the local

community who were matched for age, sex, and education level of the caregivers. The control volunteers were subjected to the same inclusion criteria.

Study procedures

All participants were informed about the study protocol and those who volunteered to participate were included in the study. In our study, all children were aged over 8 years and literate. For this reason, they signed the informed consent form together with their parents. The caregivers independently completed the individual questionnaire packets in patient waiting rooms. Research team members provided instructions to the participants regarding completing the forms. The study protocol was approved by the local Ethics Committee.

Demographic variables and clinical severity

A standardized form was used to collect demographic (age, sex, education of child, and caregiver) and clinical (age at onset of illness, duration of illness) data. The severity of the SLE was graded using the SLE disease activity index (SLEDAI; range 0–105; a higher score corresponds to higher disease activity) [14]. The SLEDAI was classified as no activity (SLEDAI=0–4), mild activity (SLEDAI=5–9), moderate activity (SLEDAI=10–14), and high activity (SLEDAI \geq 15) [15].

Psychological measures

The Zarit Burden Interview (ZBI), Beck Depression Inventory (BDI), and Beck Anxiety Inventory (BAI) were used to assess caregiver burden and the caregiver’s psychological state. The Strengths and Difficulties Questionnaire (SDQ)-parent form was completed by the caregiver to assess the psychological state of children and adolescents.

The ZBI is a widely used scale evaluating the stress experienced by caregivers of patients or older adults who need care [16]. The ZBI is a 4-point Likert scale consisting of 22 items. The range of possible scores on the scale is 0–88, with higher values indicating a greater burden. It can be completed by the caregiver or an interviewer. The Turkish validity and reliability of this scale were studied by Inci et al. in 2008 [17]. Its internal coefficient of consistency was 0.95, with a test–retest reliability of 0.71. Cronbach’s alpha of the scale in our sample was 0.83.

The BDI was developed to determine an individual’s risk of depression and measure depressive symptom levels and severity changes [18]. The Turkish validity and reliability of this scale were studied by Hisli et al. in 1989 [19]. The BDI is a 4-point Likert scale consisting of 21 items.

Total scores range between 0 and 63. A score of or above 17 is consistent with depression on the Turkish Language version. Cronbach's alpha for the current sample was 0.90.

The BAI is a self-report scale used to determine the frequency of anxiety symptoms experienced by an individual [20]. The BAI is a 4-point Likert scale consisting of 21 items. Possible scores range between 0 and 63, with higher total scores indicating a higher severity of anxiety. The Turkish validity and reliability of this scale were studied by Ulusoy et al. in 1998 [21]. Cronbach's alpha for the current sample was 0.93.

The SDQ is a validated behavioral screening tool comprising 25 items on 5 psychological attributes including hyperactivity/inattention (5 items), conduct problems (5 items), peer relationship problems (5 items), emotional symptoms (5 items), and prosocial behavior (5 items) along with an impact supplement [22]. As each title can be evaluated within itself, the sum of the first four titles gives the total difficulty score. High scores in social behavior reflect the strengths of the individual in the social field; high scores in the other four areas indicate that the problem areas are severe. The Turkish validity and reliability of this scale were studied by Guvenir et al. in 2008 [23]. In this study, the 4–16 years parent form was used.

Statistical analysis

Data were analyzed using the SPSS 22.0 statistical software (Chicago, IL, USA). Descriptive statistical methods (frequency, percentage, mean, standard deviation) were examined and the Shapiro–Wilk distribution test was used to examine the normality of data distribution. For comparing the groups, chi-square tests were used for categorical variables and the Mann–Whitney *U* test was used for continuous variables. Intercorrelations between parameters were computed through Spearman's correlation analysis. Linear regression analyses (forward conditional model) were performed to evaluate the effects of caregiver's psychological symptoms, child's psychological symptoms, and demographic–clinical variables related to SLE on caregiver burden in the patient group. Before these analyses, variables that did not have normal distributions were converted to become normally distributed using logarithmic transformations. The results with reliabilities of 0.95 or greater were interpreted, and *P*-values < 0.05 were considered as significant.

Results

Comparisons of patients and controls

The study included 34 children who met SLE criteria and 34 healthy children as a control group and their caregivers. The

majority of the caregivers was the mother (85% in the patient group and 88% in the control group). The mean age of the children and caregivers in the patient group was 14.35 ± 2.83 and 39.91 ± 5.19 years, respectively, and it was 15.62 ± 1.46 and 42.44 ± 7.12 years in the control group. The mean age of onset of SLE was 9.97 ± 1.15 years, and the mean disease duration was 50.44 ± 45.88 months. The mean SLE disease activity score was 4.19 ± 4.01 (0–16). Eight (23.5%) patients with SLE had a chronic comorbid disease. Six (17.6%) caregivers in the patient group and four (11.8%) in the control group had chronic diseases. Two caregivers had a known psychiatric disease in the patient group; there were no caregivers with psychiatric disease in the control group. Eight caregivers (23.5%) in the patient group and seven (20.6%) in the control group reported having financial difficulties. There was no statistically significant difference between the patient and control groups in terms of age, sex, caregiver's kinship to the child, age of the caregiver, educational status of the caregiver, and financial difficulties. The sociodemographic and clinical characteristics are shown in Table 1.

The mean ZBI scores were evaluated across the groups. Although there was a trend towards a higher mean score of caregiver burden in the SLE group, no statistically significant difference was found between the patient and control groups ($p = 0.288$) (Table 2). The mean scores of depression, anxiety, and patient's psychological difficulties were also evaluated across the groups (Table 2). Similar to caregiver burden, there was no significant difference between the groups regarding the depression and anxiety scores of the caregivers. Also, there was no significant difference between the SDQ-total score and subscales of children and adolescents between the patient and control groups.

Relationships between demographic–clinical variables and psychological tests

The correlation between demographic–clinical variables such as age, SLE severity, age of onset of SLE, duration of illness, number of outpatient clinic visits and hospitalizations, and psychological test scores such as ZBI, BDI, BAI, and SDQ were calculated in the patient group. These intercorrelations are shown in Table 3. SLE severity was not correlated either with caregiver burden or with other psychological total test scores. The ZBI score was positively correlated with scores of caregivers' BDI ($r = 0.648$, $p < 0.001$), BAI ($r = 0.396$, $p = 0.03$), and patients' SDQ hyperactivity/inattention ($r = 0.353$, $p = 0.04$), conduct problems ($r = 0.383$, $p = 0.025$), peer relationship problems ($r = 0.394$, $p < 0.05$), and total subscale scores ($r = 0.446$, $p = 0.008$), indicating higher levels of caregivers' depression and anxiety, and the children's psychological difficulties were related with greater caregiver burden. The ZBI score was moderately

Table 1 Clinical and demographic features of the patient and control groups

	Patients (<i>n</i> = 34) <i>N</i> (%) or mean ± SD	Controls (<i>n</i> = 34) <i>N</i> (%) or mean ± SD	<i>Z</i> / <i>X</i> ²	<i>p</i>
Characteristics of children				
Age, years	14.35 ± 2.83	15.62 ± 1.46	− 1.455	0.146
Female	28 (82.4)	27 (79.4)	0.095	0.758
Education level, years	8.12 ± 2.78	10.03 ± 1.19	− 2.787	0.005
Age of onset of SLE, years	9.97 ± 1.15	-		
Duration of illness, months	50.44 ± 45.88	-		
Characteristics of caregivers				
Age, years	39.91 ± 5.19	42.44 ± 7.12	− 1.139	0.255
Kinship with the child				
Mother	29 (85.3)	30 (88.2)	0.128	1
Father	4 (11.8)	4 (11.8)		
Other	1 (2.9)	0 (0)		
Education level, years	7.53 ± 3.51	6.74 ± 2.87	− 0.662	0.508
Work				
Yes	7 (20.6)	11 (32.4)	1.209	0.272
No	27 (79.4)	23 (67.6)		
Financial difficulties				
Yes	8 (23.5)	7 (20.6)	0.086	0.770
No	26 (76.5)	27 (79.4)		

positively correlated with the number of outpatient clinic follow-ups in the past year ($r = 0.362$, $p < 0.05$) and the number of hospitalizations in the past year ($r = 0.396$, $p < 0.05$).

The number of hospitalizations was moderately positively correlated with patients' SDQ-conduct problems ($r = 0.52$, $p < 0.01$), emotional problems ($r = 0.5$, $p < 0.01$), and total subscale scores ($r = 0.46$, $p < 0.01$). There was no significant correlation between BDI and BAI scores and demographic-clinical variables. In addition, the prosocial subscale score of SDQ was negatively correlated with ZBI ($r = -0.473$, $p = 0.005$) and BDI

($r = -0.380$, $p < 0.05$) scores, indicating higher levels of patient strength were related with both better caregivers' mental health and lighter burden of care. There was no significant correlation between caregiver anxiety scores and SDQ subscale and total scores.

Multiple linear regression analyses were used to evaluate the independent relationships of caregiver's psychological symptoms, child's psychological symptoms, and clinical variables related to SLE with caregiver burden in the patient group. We included psychological test scores (BDI, BAI, SDQ-HA/inattention, SDQ-conduct problems, SDQ-peer relationships, and SDQ-prosocial behavior

Table 2 Comparison of psychological test scores of patient and control groups

	Patients (<i>n</i> = 34)	Controls (<i>n</i> = 34)	<i>Z</i>	<i>p</i>
Caregiver burden	15.0 (7.75–22.75)	12.5 (5.75–19.5)	− 1.062	0.288
Beck depression	4 (2–11.5)	5 (2–12)	− 0.126	0.900
Beck anxiety	6 (3–12)	6.5 (2–13)	− 0.311	0.756
SDQ				
Total score	8 (5–13.25)	8 (5–12.25)	− 0.160	0.873
Hyperactivity/inattention	2 (1–4.75)	2.5 (1–5)	− 0.467	0.640
Conduct problems	2 (0–3)	1 (0–2)	− 1.185	0.236
Emotional symptoms	2 (1–4)	2 (0–3.25)	− 0.430	0.667
Peer relationship problems	2 (1–3.25)	3 (1–3.25)	− 0.526	0.599
Prosocial behavior	9 (7–10)	9 (8–10)	− 0.256	0.798
Impact score	0 (0–0)	0 (0–0)	− 0.297	0.767

Median (IQR 25–75)

Table 3 Intercorrelations among study variables

	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1. Caregiver burden	0.65***	0.40*	0.45**	0.35*	0.38*	0.21	0.39*	-0.47**	0.11	-0.21	0.36*	0.40*	-0.12	0.02
2. Beck depression		0.49**	0.31	0.29	0.24	0.26	0.11	-0.38*	0.14	0.08	0.18	0.28	0.05	0.14
3. Beck anxiety			0.14	0.33	-0.22	0.19	0.25	-0.26	0.09	-0.09	0.22	0.13	-0.15	0.09
4. SDQ-total score				0.69***	0.74***	0.71***	0.44*	-0.49**	-0.14	0.07	0.29	0.46**	-0.18	-0.23
5. SDQ-HA/inattention					0.36*	0.40*	0.08	-0.42*	0.03	-0.01	0.24	0.29	-0.38*	-0.26
6. SDQ-conduct problems						0.45**	0.31	-0.32	0.09	-0.01	0.34*	0.52**	-0.10	-0.28
7. SDQ- emotional problems							0.08	-0.34	0.05	0.34*	-0.05	0.50**	-0.10	-0.12
8. SDQ- relationships problems								-0.30	-0.38*	-0.10	0.31	-0.07	0.20	0.01
9. SDQ-prosocial behavior									0.18	-0.15	0.01	-0.25	0.11	0.17
10. SLE severity										-0.05	0.17	0.19	-0.06	-0.04
11. Duration of illness (months)											-0.61***	-0.25	0.14	0.08
12. Number of medical visits												0.26	0.11	0.01
13. Number of hospitalizations													-0.40*	-0.13
14. Age (years)														0.44**
15. Caregiver age (years)														

N=34

SDQ, Strengths and Difficulties Questionnaire-Parent form; SLE, systemic lupus erythematosus

* P < 0.05

** P < 0.01

*** P < 0.001

Table 4 Results of linear regression (forward conditional) determinating caregiver burden scores of children with SLE

	<i>B</i>	SE	β	<i>t</i>	<i>p</i>	Confidence interval (%95)
Log-BDI	0.423	0.094	0.587	4.490	<0.001	0.231–0.615
Log-SDQ- peer relationships	0.335	0.155	0.284	2.167	0.038	0.020–0.650

$R^2=0.488$, adjusted $R^2=0.455$, $F=14.767$, $p<0.001$

BDI, Beck Depression Inventory; *SDQ*, Strenghs and Difficulties Questionarie-Parent form

scores) and clinical factors (number of medical visits and number of hospitalizations) that significantly correlated with caregiver burden as independent variables. The analyses showed that BDI and SDQ-peer relationships scores had positive effects on the caregiver burden (Table 4).

Discussion

To the best of our knowledge, this is the first report on psychological status and caregiver burden data in patients with childhood-onset SLE and their caregivers compared with a healthy control group. There are very limited data available regarding the association between childhood chronic diseases and caregiver burden in the scientific literature [24–28]. The present study revealed that the caregiver burden, depression, and anxiety levels of the caregivers were not worse than those of the control group. In addition, the psychological status of patients with SLE was similar to the control group. The caregiver burden scores were correlated to the levels of psychological symptoms and the number of medical visits and hospitalizations. However, according to the regression analysis, only levels of difficulty in peer relationships of patients and depression levels of the caregivers have roles in determining the caregiver burden of caregivers.

We found a trend towards increased levels of caregiver burden in the caregivers of patients with SLE, although the difference in levels of caregiver burden between the patients and controls was not statistically significant. In addition, the psychological symptom levels of patients with SLE and their caregivers were not worse than those of the control group. According to the previous scientific literature on childhood, the caregivers of patients with chronic conditions such as Down syndrome, mitochondrial disease, cerebral palsy (CP), and diabetes are at an increased risk of caregiver burden and psychological symptom levels [24–28]. This difference between our findings and the scientific literature may be due to the difference in study designs. There are also studies showing higher caregiver stress and depression in the early period after diagnosis [9, 29]. As time passes after the diagnosis, mothers' social adaptation increases and their anxiety decreases [30]. Cognitive and emotional processing of the subjective experiences of parents and children after medical

trauma and the adaptation potential of the families can provide post-traumatic growth (PTG) [31, 32]. Many families find ways to endure trauma, which may be influenced by personal characteristics such as maturity, resilience, and optimism. Cognitive and emotional processing of traumatic events may be facilitated by social support networks [32]. This may explain why caregiver burden and psychological symptom levels did not differ between groups.

A positive correlation has been reported between disease severity and caregiver burden [26, 33]. However, in our study, there was no relationship between SLE severity and caregiver burden, caregiver's depression, and anxiety scores. The subjective experience of a traumatic event may be more impactful than its objective reality, as has been demonstrated in perceived treatment risks of medical illness [32]. In our study, we evaluated disease severity using an objective severity index; we did not evaluate the subjective perception of patients or caregivers about the disease, which may explain why we found no relationship between caregiver burden and disease severity.

In the literature, a consistent relationship has been found between caregiver burden and caregivers' psychological state (depression and anxiety) [9, 11, 26, 34, 35]. The results of our study were compatible with the literature. The presence of psychiatric symptoms in caregivers affects their perceptions about caregiver burden [25]. Although the relationship between caregiver burden and depression and anxiety has been shown in studies, data on the cause–effect relationship are lacking. Therefore, prospective studies are needed to follow patients and caregivers from the onset of disease symptoms in terms of caregiver burden and psychopathology development.

In studies conducted with different disease groups, it has been shown that there is a relationship between caregiver burden and child-related factors such as more frequent hospital visits, attention-deficit/hyperactivity disorder (ADHD) comorbidity, and the behavioral and cognitive symptoms of the child [36, 37]. In accordance with this, in our study, caregiver burden was positively correlated with the number of medical visits and hospitalizations in the last year, hyperactivity, behavioral problems, and peer problems. Also, the number of hospitalizations was moderately positively correlated with patients' conduct problems and emotional

problems. Frequent medical visits and hospitalizations may affect caregiver burden and patients' psychological status because it can disrupt both caregivers' and patients' daily life (i.e., work, school, and social). In contrast to behavioral problems, there was a moderately negative correlation between children's prosocial behavior and caregiver burden. Children's effective use of coping strategies and social adaptations may reduce caregiver burden.

We also evaluated the distribution of possible clinical and psychological determinants of caregiver burden and the association between these determinants and caregiver burden in the patient group using multiple linear regression analyses. The data showed that the caregivers' depression and difficulties of patients' peer relationships had negative effects on caregiver burden. Our results regarding the negative impacts of depression and difficulties of peer relationships on caregiver burden are consistent with the above scientific literature.

The most important limitation of our study was the small sample size. At the same time, because it was a case-control study, we could not give a cause-effect relationship between caregiver burden and psychological problems. Also, we did not evaluate some factors that could affect caregivers' burden, such as the child's adaptation skills, parent's social support, and problem-solving skills.

In conclusion, the psychological state of the child and parent seems to be more influential than the clinical characteristics of the disease in the caregiver burden of the parents of SLE patients. So, physicians should be alert to the presence of psychological symptoms in patients with childhood-onset SLE and their caregivers because it can affect caregiver burden and the caregiver's psychological state. The psychological status of children with SLE and their caregivers should be evaluated periodically during the diagnosis and follow-up process, and at-risk caregivers and their children should be referred to mental health professionals. For these children, it would be helpful for mental health professionals to focus on improving problem-solving, communication, and emotion regulation skills. Longitudinal studies examining the coping strategies and social supports of caregivers will be useful to reveal the cause-effect relationship and to identify social strategies that will reduce caregiver burden.

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Declarations

Ethical approval The study was reviewed and approved by the local ethical committee.

Disclosures None

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