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# Evaluation of psychological stress in primary caregivers of patients with juvenile idiopathic arthritis

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**Abstract**

**Objective:** To assess psychological stress in primary caregivers of juvenile idiopathic arthritis (JIA) pediatric patients.

**Methods:** Uncontrolled cross-sectional analytical study of 40 caregivers of JIA patients. Caregivers were evaluated using the Caregiver Burden Scale, which analyzes five domains of stress on a scale of 1 to 4: general strain, isolation, disappointment, emotional involvement and strain caused by environmental barriers. The data were subjected to statistical analysis.

**Results:** Caregivers of JIA patients were mainly female (87.5%), married (92.1%) and close relatives (90%). Stress levels were higher in caregivers of polyarticular JIA patients (p = 0.006), single caregivers (p = 0.019) and female caregivers (p = 0.017). Environment-related difficulties were reported as the most stressful category by caregivers.

**Conclusion:** Caregivers of JIA patients are usually married female relatives. Caring for polyarticular JIA patients is more stressful than caring for oligoarticular JIA patients. Strain caused by environmental barriers accounts for the highest levels of stress among the caregivers included in this study.

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## Introduction

Juvenile idiopathic arthritis (JIA) is a chronic inflammatory systemic disease of unknown etiology. It causes damage to the joints and other connective tissues.[1] It affects children of both sexes before the age of 16. Full remission is observed in only approximately 75% of patients.[1-3]

Children with JIA are usually cared for by family members, who usually face two types of emotional burden: objective and subjective.[4] Objective stress is related to the disruptions caused by financial turmoil, performance of social roles, overseeing patients and interpersonal relations.[4] Subjective stress, on the other hand, encompasses feelings of being burdened, loss of control, embarrassment, helplessness, resentment and isolation.[4] When faced with these problems, caregivers may develop depression, irritability, loss of self-esteem, sleep deprivation, changes in eating habits, higher likelihood of accidents and diseases, self-victimization, exaggerated responses and hostility.[4] Lederberg classifies caregivers as second order patients[5] who also require medical care and attention.

Therefore, the objective of this study was to assess psychological stress and quality of life in primary caregivers of JIA patients and to describe the profile of individuals performing this role in a Brazilian community.

## Methods

An uncontrolled cross-sectional analytical study was carried out in the pediatric outpatient unit at Hospital Universitário Evangélico de Curitiba (HUEC), in the Brazilian state of

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Paraná. The study was approved by the hospital's Research Ethics Committee under protocol no. 3243/05.

A total of 53 JIA patients were followed at the hospital during the study period and all received care through the public health care system (SUS). The sample included caregivers who agreed to participate in the study and who fulfilled the following inclusion criteria: caring for the patient at least four days a week, regardless of whether they lived with the patient or not, having performed the role of primary caregiver for at least 2 months, and not receiving any financial compensation. Forty caregivers of JIA patients served by the HUEC pediatric outpatient clinic with appointments between April 1, 2005 and August 1, 2006 were included.

After signing an informed consent form, caregivers filled out an identification form with demographic data (sex, age, schooling, employment, relationship with patient, time as caregiver) and type of JIA. Next, the participants were interviewed using the Caregiver Burden Scale (CBS). The CBS measures the subjective impact on caregivers of patients with chronic diseases.[6] The original Swedish version of the CBS was proposed by Oremark, and later adapted by Elmasthal et al.[6] The questionnaire has been validated for Brazilian Portuguese. Its objective is to analyze the level of stress to which caregivers are subjected. It divides stress into four domains: general strain, isolation, disappointment, emotional involvement and environment.[6] The answers receive scores from 0 to 4: 0 – Never, 1 – Rarely, 2 – Sometimes, 3 – Frequently, 4- Nearly always. The mean for each domain was considered for the analysis. Thus, the higher domain mean, the higher the degree of difficulty faced by the caregiver in that particular domain.

Results were analyzed through frequency table using the Kruskal-Wallis, Mann-Whitney and ANOVA tests, with a significance level of 0.05. All statistical tests were performed using the GraphPad Prism program, version 4.0.

## Results

The age of caregivers ranged between 24 and 60 years (mean 37.5±8.7 years). They cared for 23 polyarticular JIA patients and 17 oligoarticular JIA patients. The mean time caring for the patient was 48.7±38.3 months. The demographic data for the caregivers can be found in Table 1.

As shown in Table 1, most caregivers were middle-aged female relatives, married, with little schooling.

The mean scores for each domain were: general strain, 1.75±0.6; isolation, 1.35±0.53; disappointment, 2.0±0.6; emotional involvement, 1.1±0.39; and strain caused by environmental barriers, 2.4±0.8. The highest burden levels were

**Table 1** - Caregivers of JIA patients

| Variable | Sample size |
|---|---|
| Sex | |
| Female | n = 35 (87.5%) |
| Male | n = 5 (12.5%) |
| Marital status | |
| Married | n = 37 (92.5%) |
| Single | n = 3 (7.5%) |
| Employment status | |
| Formal | n = 14 (35%) |
| Informal | n = 6 (15%) |
| Unemployed | n = 20 (50%) |
| Schooling | |
| Incomplete primary education | n = 21 (52.5%) |
| Complete primary education | n = 8 (20%) |
| Secondary education | n = 10 (25%) |
| Higher education | n = 1 (2.5%) |
| Kinship | |
| Direct | n = 36 (90%) |
| Indirect | n = 4 (10%) |

n = sample size.

observed in the environmental category, followed by disappointment and general strain.

The mean overall score for each individual caregiver according to JIA type revealed that caregivers of polyarticular JIA patients are subject to more stress than caregivers of patients suffering from oligoarticular JIA (p = 0.0062; Mann-Whitney).

Analyzing the mean burden scores in terms of gender revealed that female caregivers were more stress-prone than male caregivers (p = 0.017; Mann-Whitney). However, males were underrepresented in the study (n = 5).

The following correlations were not significant: caregiver schooling and burden scores (p = 0.23, Kruskal-Wallis); JIA duration and caregiver burden score (p = 0.53; ANOVA); and employment (formal, informal, unemployment) and burden score (p = 0.073; Kruskal-Wallis).

## Discussion

The study of psychological stress in primary caregivers of JIA patients is a pioneering effort in Brazil. There are few studies in the literature on caregivers of children suffering from rheumatoid diseases.[7-9] However, the number of studies focused on caregivers of patients with chronic diseases in general is increasing.[10-12]

The profile of the caregivers in this study is in accordance with previous studies, which show that 60-70% of them are middle-aged women.[4] Our study found that women, as well as being more frequent caregivers of JIA patients, are subject to higher stress levels than men. A possible explanation for this finding is that women tend to accumulate roles in our society, which can include homemaking, family obligations and child-rearing, among others. However, our sample differs from most of the literature regarding employment status. Studies show that most caregivers are employed outside the home and have their own health problems,[4] but only half (50%) of the caregivers in our sample work outside the home. This might be related to the fact that most of the patients whose caregivers were analyzed received care through the public health system. People who are dependent on free healthcare programs tend to have low income, and thus the present sample may not be representative of the general population.

The present results showing that caregivers of patients with polyarticular JIA are under higher stress levels differ from the findings of Buskila et al.,[13] who studied 28 caregivers and found that mothers of patients with oligoarticular JIA are under more stress. Buskila et al. suggest new analyses, with larger sample sizes, to validate their claims. Since our study has a larger sample size, it suggests a possible bias in that study. Polyarticular JIA burdens caregivers more than other types of JIA because it leads to greater pain, disability and deformity for the child.

Unmarried caregivers presented higher stress levels than married caregivers. This aspect, which is possibly relevant in this situation, may be explained by division of labor and responsibilities within couples. However, due to the low number of single caregivers in the sample (n = 3), we suggest further research to validate this finding.

Hostile environments were identified as the main factor affecting psychological stress among caregivers of JIA patients. The environmental indicator had the highest scores in the CBS and was widely mentioned by interviewees. Several caregivers complained about the lack of infrastructure in their cities regarding healthcare; about drug shortages in the public healthcare system; and about architectural obstacles or barriers in public spaces. We suggest that special attention should be paid to this aspect, since it relates to issues of public health policy which can and should be remedied.

Recognizing the caregiver as a potential second order patient is crucial when caring for the JIA patient himself. This study shows that single female caregivers of polyarticular JIA patients are under the highest stress levels. Physicians should ensure that these particular caregivers receive extra emotional support. It is also crucial that society as a whole become more aware of how oppressive environments can affect the care of JIA patients, and act to improve this situation.

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