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# Influence of the informal primary caretaker on glycemic control among prepubertal pediatric patients with type 1 diabetes mellitus $^{\pm}$

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Abstract **KEYWORDS** Objectives: In prepubertal type 1 diabetic patients (DM1), the availability of an informal pri-Type 1 diabetes; mary caregiver (ICP) is critical to making management decisions; in this study, the ICP-related Caregiver; risk factors associated with glycemic control were identified. **Pediatrics** Patients, materials, and methods: A comparative cross-sectional study was performed. Fiftyfive patients with DM1 under the age of 11 years were included. The patient-related factors associated with glycemic control evaluated were physical activity, DM1 time of evolution, and adherence to medical indications. The ICP-related factors evaluated were education, employment aspects, depressive traits (Beck questionnaire), family functionality (family APGAR), support of another person in patient care, stress (Perceived Stress Scale), and socioeconomic status (Bronfman questionnaire). Multivariate logistic and linear regression analyses were performed. Results: The patients' median age was 8 years; 29 patients had good glycemic control, and 26 were uncontrolled. The main risk factor associated with glycemic dyscontrol was stress in the ICP (OR 24.8; 95% CI 4.06–151.9, p=0.001). While, according to the linear regression analysis it was found that lower level of education ( $\beta$  0.991, 95% CI 0.238–1.743, p = 0.011) and stress ( $\beta$  1.918, 95% CI 1.10–2.736, p=0.001) in the ICP, as well as family dysfunction ( $\beta$  1.256, 95% CI 0.336–2.177, p = 0.008) were associated with higher levels of glycated hemoglobin.

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*Conclusions*: Level of education and stress in the ICP, as well as family dysfunction, are factors that influence the lack of controlled blood glucose levels among prepubertal DM1 patients. © 2016 Sociedade Brasileira de Pediatria. Published by Elsevier Editora Ltda. This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/).

Influência do cuidador familiar principal sobre o controle glicêmico entre pacientes pediátricos pré-púberes com diabetes mellitus tipo 1

#### Resumo

*Objetivos*: Em pacientes pré-púberes com diabetes tipo 1 (DM1), a disponibilidade de um cuidador familiar principal (CFP) é fundamental para tomar decisões de administração; neste estudo, foram identificados os fatores de risco relacionados a CFPs associados ao controle glicêmico.

Pacientes, materiais e métodos: Foi realizado um estudo transversal comparativo. Foram incluídos 55 pacientes com DM1 menores de 11 anos de idade. Os fatores relacionados aos pacientes associados ao controle glicêmico avaliados foram atividade física, tempo de evolução da DM1 e adesão às indicações médicas. Os fatores relacionados a CFPs avaliados foram escolaridade, aspectos profissionais, traços de depressão (questionário de Beck), funcionalidade familiar (APGAR familiar), ajuda de outra pessoa no cuidado do paciente, estresse (Escala de Estresse Percebido) e situação socioeconômica (questionário de Bronfman). Foram realizadas análises de regressão logística multivariada e de regressão linear.

*Resultados*: A idade média dos pacientes era de 8 anos; 29 pacientes apresentavam bom controle glicêmico e 26 não tinham controle. O principal fator de risco associado ao descontrole glicêmico foi o estresse no CFP (RC 24,8; IC de 95% 4,06–151,9, p=0,001). Ao passo que, de acordo com a análise de regressão linear, constatamos que: o menor nível de escolaridade ( $\beta$  0,991, IC de 95% 0,238–1,743, p=0,011) e estresse ( $\beta$  1,918, IC de 95% 1,10–2,736, p=0,001) do CFP, bem como a disfunção familiar ( $\beta$  1,256, IC de 95% 0,336-2,177, p=0,008), foram associados a níveis maiores de hemoglobina glicosilada.

*Conclusões*: O nível de escolaridade e o estresse do CFP e a disfunção familiar são fatores que influenciam a falta de níveis glicêmicos controlados entre pacientes pré-púberes com DM1.

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#### Introduction

Type 1 diabetes mellitus (DM1) is one of the most common chronic diseases of childhood and adolescence. It is characterized by chronic hyperglycemia and impaired metabolism of carbohydrates, proteins, and lipids. The physiopathology of this type of diabetes is autoimmune destruction of pancreatic  $\beta$  cells accompanied by deficiency of insulin production.<sup>1</sup>

Maintaining the best glycemic control possible, avoiding complications in the short, medium and long term, and allowing adequate psychological and emotional development are the main objectives of treatment of DM1.<sup>2</sup> To reach these objectives, DM1 patients require the use of insulin, control of their diet, and exercise.<sup>3</sup> Usually, these patients are actively involved in their treatment on a daily basis, which includes performing various procedures and analyzing information to make decisions for insulin administration, diet, and physical activity. However, glycemic control may be complicated and challenging, even for those patients with a good understanding of their illness and complications. In pediatric patients with DM1, the participation of an informal primary caregiver (IPC) is needed in the decision-making process because their mental and physical capacity is not optimal, particularly in younger children.  $\!\!\!^4$ 

An IPC is a person in the environment of a patient who is voluntarily responsible for the patient without any remuneration. Interventions that IPC must provide when they are caring for children with DM1 include: application and adjustment of the dose of insulin, properly providing the type and amount of food, exercise supervision, monitoring capillary blood glucose, and managing hypoglycemia and hyperglycemia.<sup>5</sup> IPC activities are often very demanding; the more time spent in the care of a diabetic child, the more she/he sacrifices her/his own resources, which can alter her/his health and welfare.<sup>6</sup> The caregiver may experience anger, fear, emotional ambivalence, social isolation, pathological grief, anxiety, or stress.<sup>7–9</sup>

DM1 itself creates a crisis situation, with abrupt changes in lifestyle, both for the patient and his/her family from the time of diagnosis, during treatment and complications.<sup>10</sup> In this context, glycemic control may be affected when there is no appropriate adaptation process, leading to abnormal behavior, such as lack of treatment adherence.<sup>11</sup> In particular, it has been described that when the IPC participates in treatment, her/his own emotional characteristics may affect the maintenance of optimal glycemic control for

PALAVRAS-CHAVE Diabetes tipo 1:

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