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Danielle de Carvalho Mendes
Federal University of Para
Carla Paracampo
Federal University of Para
Fernando Rocha
rochaf@ufpa.br

Federal University of Para

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Caregiver Burden and Associated Factors Among Caregivers of Children and Adolescents with Type 1 Diabetes Mellitus

Danielle Castelo de Carvalho Mendes[1], Carla Cristina Paiva Paracampo[1], Fernando Allan de Farias Rocha[1]

Affiliations

1 Federal University of Pará (UFPA), Postgraduate Program in Neuroscience and Behavior, Belém, Pará, Brazil

Corresponding Author:

Fernando Allan de Farias Rocha

Federal University of Pará

Address: Núcleo de Teoria e Pesquisa, Building 2, Room 23. Guamá University Campus

Rua Augusto Corrêa, 01. Belém, Pará, Brazil – ZIP Code 66075-110

Phone: +55 (91) 3201-7949

E-mail: rochaf@ufpa.br

Abstract

Background: Type 1 diabetes mellitus (T1DM) diagnosed in childhood and adolescence requires continuous management and intensive daily care, often placing substantial demands on caregivers. These demands may contribute to caregiver burden, which can negatively affect both caregiver well-being and patient management. To evaluate caregiving behaviors and identify factors associated with caregiver burden among caregivers of children and adolescents with T1DM. **Methods:** A cross-sectional online survey was conducted in Brazil with 71 caregivers of children and adolescents with T1DM. Participants completed a sociodemographic questionnaire and the Zarit Burden Interview (ZBI). Descriptive statistics were calculated, and associations between sociodemographic variables and caregiver burden were examined using ordinal logistic regression in R software. **Results:** Most caregivers were female (81.7%) and parents of the patient (85.9%). Mild to moderate burden was reported by 56.3% of caregivers, while 25.3% presented moderate to severe burden. Higher caregiver burden was significantly associated with longer working hours (31–40 h/week: OR = 10.59, $p = 0.026$; >40 h/week: OR = 20.91, $p = 0.016$) and having children (OR = 52.45, $p = 0.018$). Married or cohabiting caregivers were less likely to experience higher burden compared with single caregivers (OR = 0.08, $p = 0.0017$). A good or very good caregiver–patient relationship was also associated with lower burden levels ($p < 0.001$). **Conclusions:** Caregiver burden among caregivers of children and adolescents with T1DM is influenced by work demands, family structure, and the quality of the caregiver–patient relationship. Strategies aimed at strengthening social and family support systems may help reduce caregiver burden and improve disease management outcomes.

Keywords:

Caregivers; Caregiver Burden; Type 1 Diabetes Mellitus; Child; Adolescent; Family Caregivers.

Introduction

Type 1 diabetes mellitus (T1DM) is a chronic metabolic disorder commonly diagnosed in childhood and adolescence and is characterized by persistent hyperglycemia resulting from the body's inability to produce sufficient insulin in the pancreas [1]. Worldwide, the number of individuals living with T1DM has increased substantially in recent decades. In 2022, approximately 8.75 million people were estimated to be living with the disease, with nearly 1.9 million residing in low- and middle-income countries. In Brazil alone, about 588.8 thousand individuals were living with T1DM, including more than 112 thousand children and adolescents under 20 years of age [2].

The management of T1DM requires continuous monitoring and complex daily care. Patients must regularly monitor blood glucose levels and administer insulin, in addition to maintaining appropriate dietary habits and engaging in regular physical activity. Effective disease management therefore depends not only on the patient's adherence but also on adequate education, guidance, and support from family members and health professionals [3].

In this context, social support plays a crucial role in both metabolic control and psychosocial well-being. Caregivers often represent the main source of such support, particularly in childhood and adolescence, when patients may have limited autonomy in managing their condition. Previous studies have shown that the patient's social support network and socioeconomic characteristics may significantly influence treatment adherence and health outcomes [4–8]. The term caregiver refers to an individual who provides assistance to another person who requires support due to physical or cognitive limitations. Caregivers may assist with daily activities and disease management tasks that the patient cannot perform independently, regardless of whether this assistance is provided with or without financial compensation [9]. In the case of pediatric chronic illnesses such as T1DM, caregivers are frequently family members who must balance caregiving responsibilities with work, household duties, and other personal obligations.

These demands may lead to caregiver burden, a multidimensional construct that encompasses

emotional, physical, social, and financial strain resulting from the caregiving role. Caregiver burden is typically assessed through psychological and behavioral evaluations that examine caregivers' perceptions, attitudes, and responses to caregiving responsibilities [10,11]. Identifying caregiver burden is important because excessive burden may negatively affect caregivers' well-being and, consequently, the quality of care provided to patients. One of the most widely used instruments for assessing caregiver burden is the Zarit Burden Interview (ZBI), originally developed to evaluate caregivers of patients with dementia but later applied to caregivers of individuals with various chronic conditions [11,12]. Previous studies using the ZBI have demonstrated associations between caregiver burden and several sociodemographic characteristics, including marital status, employment conditions, and family structure [10,13,14].

Despite the growing body of research on caregiver burden, studies specifically focusing on caregivers of children and adolescents with T1DM remain relatively limited, particularly in developing countries. Considering that T1DM treatment is complex and often costly, caregivers play a fundamental role in ensuring adherence to treatment and supporting the emotional well-being of patients [15].

Therefore, the objectives of the present study were: (a) to describe caregiving behaviors among caregivers of children and adolescents with T1DM during treatment and to evaluate their perceptions of caregiver burden; and (b) to investigate possible associations between caregivers' sociodemographic characteristics and levels of perceived burden.

Methods

Study design and ethical approval

This was a cross-sectional descriptive and analytical study conducted in Brazil between January and March 2023. The study protocol was approved by the Research Ethics Committee of the Institute of Health Sciences at the Federal University of Pará, Brazil (protocol no. 5.842.096 - CEP/ICS), in

accordance with the ethical standards of the Declaration of Helsinki and the Brazilian National Health Council Resolutions nº 466/12 and 510/16. All participants provided informed consent prior to participation.

Participants

The participation in the study was voluntary. The participants were recruited using a non-probabilistic convenience sampling strategy through online diabetes support groups and social media platforms.

The sample consisted of 71 adult caregivers of children and adolescents diagnosed with Type 1 Diabetes Mellitus (T1DM). Eligible participants were individuals aged 18 years or older who had completed at least five years of elementary education and were unpaid caregivers responsible for the care of children (5–12 years) or adolescents (13–17 years) diagnosed with T1DM for at least one year and undergoing treatment prescribed by a healthcare team [16]. Exclusion criteria included caregivers who did not meet these requirements, as well as caregivers of children or adolescents with additional chronic diseases requiring ongoing care, those considered neuroatypical, and caregivers of patients using advanced diabetes management technologies such as continuous glucose monitoring systems (e.g., flash glucose monitoring) or insulin pumps. These exclusions were applied to maintain greater homogeneity in treatment management demands among participants.

Data collection procedures

Data were collected online using Google Forms®. Recruitment was conducted through email invitations and social media platforms, including WhatsApp®, Instagram®, and Facebook®.

Initially, potential participants were identified in online support communities for individuals living with diabetes. Invitations were sent individually to caregivers who met the eligibility criteria. After agreeing to participate, a date and time were scheduled for questionnaire completion. On the

scheduled day, participants received a link containing the informed consent form. Once consent was provided electronically, participants were redirected to the study questionnaires. Participants first completed the Sociodemographic and Perceptions of T1DM Questionnaire, followed by the Zarit Burden Interview (ZBI). The total time required to complete the instruments was approximately 30 minutes. The researcher remained available online throughout the data collection process to clarify questions if necessary. Online data collection was adopted to facilitate access to caregivers from different regions of Brazil and to increase participation among individuals involved in online diabetes support communities.

Instruments

Two instruments were administered in this study.

Sociodemographic and Perceptions of T1DM Questionnaire

This questionnaire was developed for the purposes of the study and consisted of 38 items organized into nine dimensions addressing caregivers' sociodemographic characteristics, caregiving responsibilities, and perceptions related to the management of T1DM.

Zarit Burden Interview (ZBI)

Caregiver burden was assessed using the Brazilian Portuguese version of the Zarit Burden Interview. The ZBI is composed of 22 items evaluating the impact of caregiving on several domains, including health, social and personal life, financial situation, emotional state, and interpersonal relationships [17]. Each item is rated on a five-point Likert scale ranging from 0 (never) to 4 (always), resulting in total scores ranging from 0 to 88. Higher scores indicate greater caregiver burden, classified as follows:

- No burden (0–20)
- Mild to moderate burden (21–40)

- Moderate to severe burden (41–60)
- Severe burden (61–88)

Statistical analysis

Data were tabulated using Microsoft Excel 2016 and analyzed with R software (version 4.2.2) [18]. Descriptive statistics were calculated for all variables, including means, medians, standard deviations, and frequency distributions.

Associations between caregiver burden levels and sociodemographic variables were examined using ordinal logistic regression, since caregiver burden was categorized into ordered levels according to ZBI scores. The regression models generated estimates of regression coefficients, odds ratios (OR), and corresponding confidence intervals. Prior to model estimation, the Variance Inflation Factor (VIF) was calculated to assess potential multicollinearity among predictor variables. Variables with VIF values greater than 5 were excluded from the model. A significance level of 5% ($p < 0.05$) was adopted. Odds ratios were interpreted as follows: values greater than 1 indicated an increased probability of higher caregiver burden relative to the reference category, whereas values below 1 indicated a reduced probability of higher burden [19].

Results

Sociodemographic characteristics of caregivers

A total of 71 caregivers participated in the study. Most participants were female (81.7%), with a mean age of 39 years (SD = 9.21). The largest proportion of caregivers was aged 31–40 years (32.4%). Regarding geographic distribution, 39.4% of participants resided in the Southeast region of Brazil, followed by the South (29.6%).

Most caregivers were married or living in a stable union (67.6%), and 31.0% had completed

higher education. In terms of income, 59.2% reported monthly family income between one and three minimum wages, while 40.9% reported working between 31 and 40 hours per week. The detailed sociodemographic characteristics are presented in Table 1.

Table 1. Sociodemographic characteristics of caregivers of children and adolescents with Type 1 Diabetes Mellitus (T1DM).

Variable	N (%)	Mean	SD	Min	Max
Sex					
Female	58 (81.7)	39.36	9.21	21	63
Male	13 (18.3)	38.00	6.78	24	45
Age group (years)					
20–30	11 (15.5)	–	–	–	–
31–40	23 (32.4)	–	–	–	–
41–50	19 (26.8)	–	–	–	–
51–60	6 (8.5)	–	–	–	–
>61	1 (1.4)	–	–	–	–
Region					
North	11 (15.5)	–	–	–	–
Northeast	5 (7.0)	–	–	–	–
Midwest	6 (8.5)	–	–	–	–
Southeast	28 (39.4)	–	–	–	–
South	21 (29.6)	–	–	–	–
Marital status					
Single	15 (21.1)	–	–	–	–
Married / Cohabiting	48 (67.6)	–	–	–	–
Divorced	6 (8.5)	–	–	–	–
Widowed	2 (2.8)	–	–	–	–
Education					
Incomplete elementary	2 (2.8)	–	–	–	–
Completed elementary	1 (1.4)	–	–	–	–
Incomplete high school	8 (11.3)	–	–	–	–
Completed high school	20 (28.2)	–	–	–	–

Variable	N (%)	Mean	SD	Min	Max
Incomplete higher education	16 (22.5)	–	–	–	–
Completed higher education	22 (31.0)	–	–	–	–
Other	2 (2.8)	–	–	–	–
Monthly family income					
≤1 minimum wage	7 (9.9)	–	–	–	–
1–3 minimum wages	42 (59.2)	–	–	–	–
3–6 minimum wages	16 (22.5)	–	–	–	–
6–9 minimum wages	4 (5.6)	–	–	–	–
>9 minimum wages	2 (2.8)	–	–	–	–
Weekly working hours					
No fixed schedule / up to 10h	20 (28.2)	–	–	–	–
11–20h	7 (9.9)	–	–	–	–
21–30h	7 (9.9)	–	–	–	–
31–40h	29 (40.9)	–	–	–	–
>40h	8 (11.3)	–	–	–	–

Characteristics of patients and caregiver–patient relationship

Among the children and adolescents receiving care, 50.7% were male, with a mean age of 10.53 years (SD = 3.56), while females had a mean age of 9.49 years (SD = 3.86). Most caregivers were parents of the patient (85.9%), and the majority reported a very good relationship with the child or adolescent (71.8%). Additionally, 56.3% of participants reported being the sole caregiver responsible for daily care, while 67.6% reported having no caregiving responsibilities for other individuals.

Regarding treatment-related aspects, 84.5% of caregivers reported that the patient had experienced hyperglycemic episodes during the previous year, and 57.8% reported that patients had difficulties following dietary recommendations. Furthermore, 64.8% of patients self-administered insulin, whereas 64.8% did not independently monitor their blood glucose levels. These characteristics are summarized in Table 2.

Table 2. Sociodemographic and treatment-related characteristics of patients with Type 1 Diabetes Mellitus (T1DM) and their relationship with caregivers.

Variable	N (%)	Mean	SD	Min	Max
Sex					
Male	36 (50.7)	10.53	3.56	5	17
Female	35 (49.3)	9.49	3.86	5	17
Age group					
Children – Male	26 (36.6)	–	–	–	–
Adolescents – Male	10 (14.1)	–	–	–	–
Children – Female	24 (33.8)	–	–	–	–
Adolescents – Female	11 (15.5)	–	–	–	–
Kinship with caregiver					
Son/Daughter	61 (85.9)	–	–	–	–
Grandchild	4 (5.6)	–	–	–	–
Nephew/Niece	3 (4.2)	–	–	–	–
Other	3 (4.2)	–	–	–	–
Quality of relationship with patient					
Very good	51 (71.8)	–	–	–	–
Good	18 (25.4)	–	–	–	–
Reasonable	2 (2.8)	–	–	–	–
Sole daily caregiver	Yes = 40 (56.3)	–	–	–	–
Has caregiving responsibilities for others	No = 48 (67.6)	–	–	–	–
Perceived general health of child/adolescent					
Very good	20 (28.2)	–	–	–	–
Good	30 (42.3)	–	–	–	–
Fair	14 (19.7)	–	–	–	–
Poor	7 (9.9)	–	–	–	–
Difficulty assisting in treatment	No = 39 (54.9)	–	–	–	–
Patient has difficulties following diet prescription	Yes = 41 (57.8)	–	–	–	–
Hyperglycemic episodes in the past year	Yes = 60	–	–	–	–

Variable	N (%)	Mean	SD	Min	Max
	(84.5)				
Patient self-injects insulin	Yes = 46 (64.8)	–	–	–	–
Patient independently monitors glucose	No = 46 (64.8)	–	–	–	–
Patient practices physical activity	Yes = 59 (83.1)	–	–	–	–

Caregiving behaviors

Caregiving activities were primarily related to treatment management. The most frequently reported activities included accompanying patients to medical appointments (17.8%), assisting with glycemic monitoring (16.5%), and supporting medication administration (15.2%). Overall, caregivers reported a higher number of caregiving activities directed toward children (n = 314) compared with adolescents (n = 62). Other activities included assistance with eating, participation in physical activities, school-related support, and involvement in leisure activities. The distribution of caregiving behaviors is presented in Table 3 and illustrated in Fig1.

Table 3. Caregiving behaviors provided by caregivers of children and adolescents with Type 1 Diabetes Mellitus (T1DM).

Type of assistance provided	N (Total)	Children (n)	Adolescents (n)	%
Assistance with self-care				
Eating	31	26	5	8.24
Bathing	12	11	1	3.19
Dressing/undressing	9	9	0	2.39
Glycemic control	62	48	14	16.50
Medication administration/intake	57	49	8	15.16
Toileting (physiological needs)	8	8	0	2.13
Physical activity practice	19	18	1	5.05
Accompanying patient in activities outside home				
Medical appointments	67	48	19	17.82

Type of assistance provided	N (Total)	Children (n)	Adolescents (n)	%
Physical activity	27	23	4	7.18
School	36	34	2	9.57
Leisure activities	48	40	8	12.77
Total	376	314	62	100

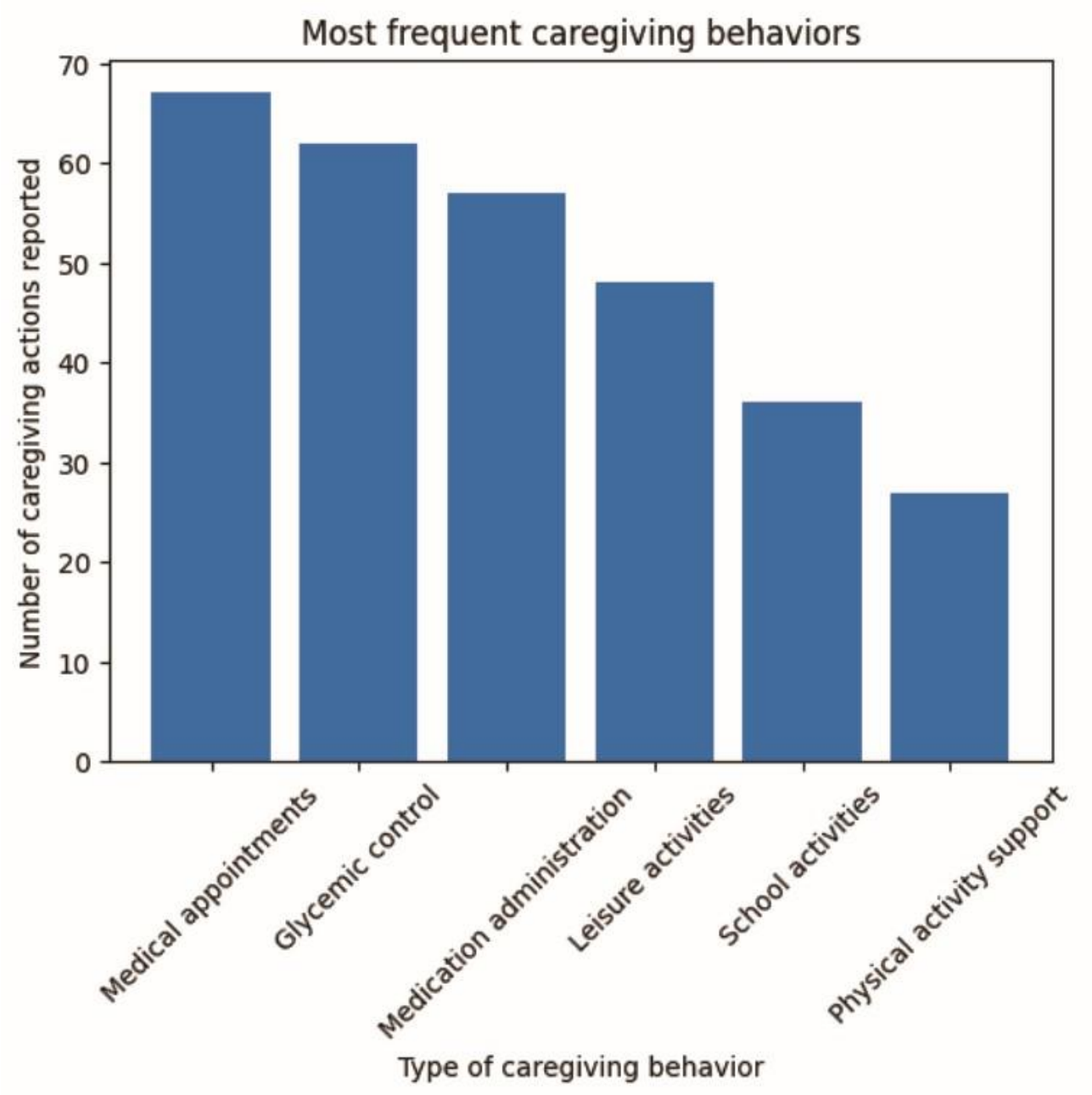


Fig1. Most frequent caregiving behaviors reported by caregivers of children and adolescents with type 1 diabetes mellitus.

Caregiver burden levels

According to the Zarit Burden Interview (ZBI), 56.3% of caregivers presented mild to moderate burden, 25.3% reported moderate to severe burden, and 18.3% reported no burden. No participants reported severe burden. The distribution of caregiver burden levels is summarized in Table 4 and illustrated in Figure 2.

Table 4. Perceived burden level of caregivers according to the Zarit Burden Interview (ZBI).

Burden level	N	%
No burden	13	18.31
Mild to moderate	40	56.34
Moderate to severe	18	25.35
Severe	0	0.00

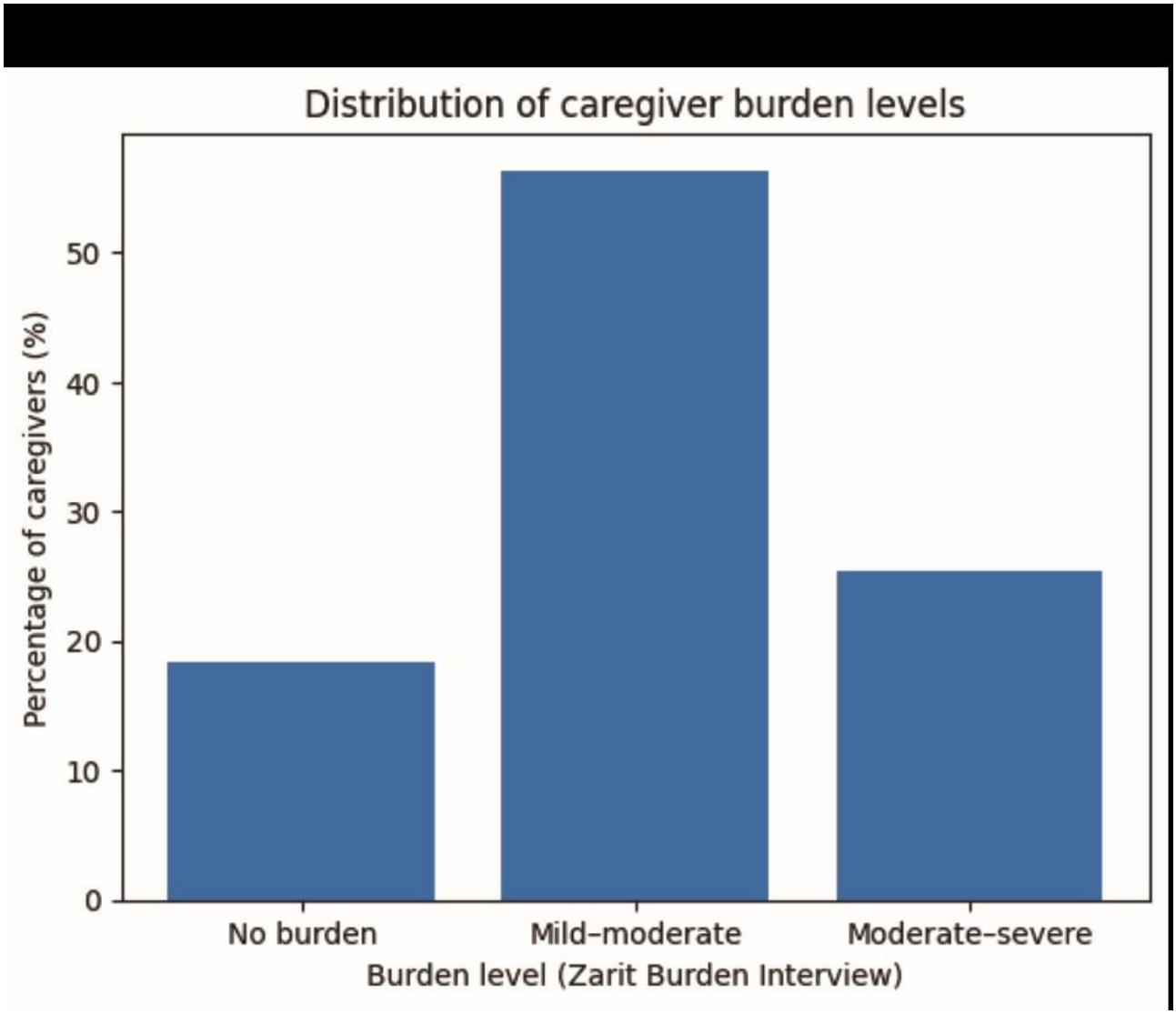


Figure 2. Distribution of caregiver burden levels among caregivers of children and adolescents with type 1 diabetes mellitus according to the Zarit Burden Interview (ZBI).

Factors associated with caregiver burden

Ordinal logistic regression analysis was performed to examine the association between caregiver burden and sociodemographic variables. Working hours were significantly associated with caregiver burden. Caregivers working 31–40 hours per week were more likely to experience higher burden compared with those working 11–20 hours per week (OR = 10.59, p = 0.026). Similarly, caregivers working more than 40 hours per week had an even greater likelihood of increased burden (OR = 20.91, p = 0.016). Caregivers with irregular working hours or ≤10 hours per week also showed

higher burden levels (OR = 8.94, p = 0.042).

Marital status was another significant factor. Married or cohabiting caregivers were significantly less likely to experience higher burden compared with single caregivers (OR = 0.08, p = 0.0017). Additionally, caregivers who reported having children were more likely to present higher burden compared with those without children (OR = 52.45, p = 0.018).

Finally, the quality of the caregiver–patient relationship showed a strong association with burden levels. Caregivers who reported a good or very good relationship with the patient were significantly less likely to experience higher burden compared with those reporting a reasonable relationship ($p < 0.001$). The complete regression model is presented in Table 5, and the main associations are illustrated in Figure 3.

Table 5. Estimates of the ordinal regression model for caregiver burden.

Variable	Estimate	Odds Ratio	% Change	Std. Error	p-value
Working hours					
11–20 h/week (ref.)	—	—	—	—	—
21–30 h/week	0.789	2.20	+120%	1.15	0.4985
31–40 h/week	2.36	10.59	+959%	1.03	0.0264*
>40 h/week	3.04	20.91	+1991%	1.22	0.0163*
Irregular / ≤10 h/week	2.19	8.94	+794%	1.05	0.0425*
Marital status					
Single (ref.)	—	—	—	—	—
Divorced	-0.999	0.37	-63%	1.38	0.4752
Widowed	-1.356	0.25	-75%	1.57	0.3915
Married / stable union	-2.503	0.08	-92%	0.76	0.0017*
Having children					
No (ref.)	—	—	—	—	—
Yes	3.963	52.45	+5145%	1.63	0.0183*
Relationship with patient					
Reasonable (ref.)	—	—	—	—	—
Good	-16.37	0.00	-100%	0.668	<0.0001*

Variable	Estimate	Odds Ratio	% Change	Std. Error	p-value
Very good	-17.14	0.00	-100%	0.426	<0.0001*
Lives with patient					
Yes (ref.)	—	—	—	—	—
No	4.80	121.51	+12051%	2.41	0.0513
Other covariates (Region, Sex, Education, Household size, Income, Degree of kinship, Sole caregiver, Duration of care)	ns	ns	ns	ns	ns

Notes:

- Positive estimates indicate increased burden; negative estimates indicate reduced burden.
- Odds Ratio (OR): values >1 indicate higher probability of burden; values <1 indicate lower probability.
- % Change = (OR – 1) × 100%.
- Only statistically significant associations ($p < 0.05$) were observed for: working hours, marital status, having children, and relationship with patient.

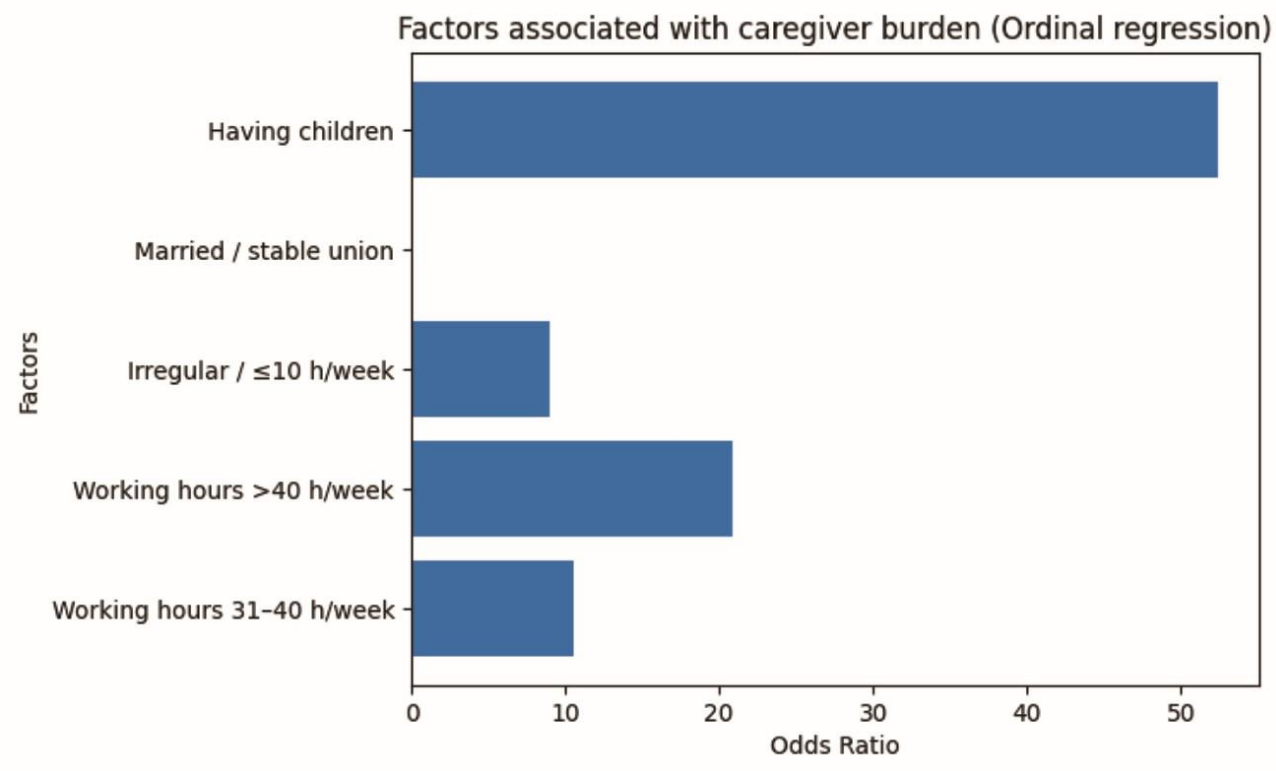


Figure 3. Factors associated with caregiver burden according to ordinal logistic regression analysis. Odds ratios represent the likelihood of higher caregiver burden relative to reference categories.

Discussion

This study examined caregiving behaviors and factors associated with caregiver burden among caregivers of children and adolescents with Type 1 Diabetes Mellitus (T1DM). Overall, the findings indicate that caregiver burden is influenced by contextual factors such as work demands, family structure, and the quality of the caregiver–patient relationship.

The predominance of female caregivers, particularly mothers, observed in this study is consistent with previous research on pediatric chronic diseases. Caregiving for children with T1DM often falls primarily on mothers, who typically assume responsibility for daily disease management and coordination of treatment activities. Similar caregiving patterns have been reported in recent studies investigating the psychosocial impact of pediatric T1DM on families [20–22,31]. Most caregivers in the present study reported mild to moderate levels of burden, a finding consistent with recent literature describing the multidimensional nature of caregiver burden in T1DM. Caregivers frequently experience emotional, social, and practical challenges related to continuous disease management, including glucose monitoring, insulin administration, and vigilance regarding potential complications. These ongoing responsibilities may lead to psychological stress and fatigue over time [32].

Working hours were significantly associated with caregiver burden in the present study. Caregivers working longer hours were more likely to report higher burden levels, suggesting that balancing professional responsibilities with intensive caregiving tasks may increase stress and time constraints. Similar associations between employment demands and caregiver strain have been reported in recent studies involving families managing pediatric T1DM [33]. Marital status also appeared to influence caregiver burden. Caregivers living with a partner were less likely to report higher burden compared with single caregivers, suggesting that the presence of additional family support may help distribute caregiving responsibilities and reduce emotional and practical strain.

Family support networks have been identified as protective factors that facilitate adaptation to chronic disease management within households affected by T1DM [34].

Another relevant finding was the association between having children and increased caregiver burden, which may reflect the cumulative demands of managing childcare responsibilities alongside intensive diabetes care. Previous research has shown that parents of children with T1DM frequently experience persistent stress related to treatment management, fear of hypoglycemia, and the need to balance disease control with promoting the child's autonomy [35]. The quality of the caregiver–patient relationship was also associated with burden levels. Caregivers who reported a positive relationship with the child or adolescent were less likely to experience higher burden. Emotional closeness and supportive family dynamics may facilitate coping strategies and resilience when managing chronic illness, whereas family conflict may intensify caregiver stress [36].

Regarding caregiving behaviors, the most frequently reported activities were directly related to treatment management, particularly glycemic monitoring, medication administration, and accompanying patients to medical appointments. These findings reinforce the central role caregivers play in the daily management of pediatric T1DM, especially during childhood, when patients often have limited autonomy in performing these tasks independently. Despite its contributions, this study has some limitations. The relatively small sample size and the use of online recruitment may limit the generalizability of the findings. In addition, caregivers of patients using advanced diabetes management technologies were excluded, which may restrict the applicability of the results to families using newer treatment approaches. Future studies should include larger samples and explore additional psychosocial variables, as well as the potential impact of emerging diabetes technologies on caregiver burden.

Conclusion

This study identified important factors associated with caregiver burden among caregivers of

children and adolescents with Type 1 Diabetes Mellitus (T1DM). Longer working hours were associated with increased levels of burden, whereas married or cohabiting caregivers were less likely to experience higher burden compared with single caregivers. Additionally, caregivers who reported having children were more likely to experience higher burden, while a positive caregiver–patient relationship was associated with lower burden levels.

These findings highlight the multifactorial nature of caregiver burden and emphasize the importance of social and family support in the management of pediatric T1DM. Healthcare professionals and public health policies should consider the needs of caregivers when designing interventions aimed at improving diabetes management and patient well-being. Given the limited number of studies addressing caregiver burden in families of children and adolescents with T1DM, further research with larger and more diverse samples is necessary. Such studies may help to better understand the psychosocial challenges faced by caregivers and support the development of targeted interventions to reduce caregiver burden and improve quality of life for both caregivers and patients.

References

1. Sociedade Brasileira de Diabetes. Diretriz oficial: classificação do diabetes [Internet]. São Paulo: Sociedade Brasileira de Diabetes; 2022. Available from: https://doi.org/10.29327/557753.2022-1

2. International Diabetes Federation. IDF Diabetes Atlas 2022 Reports [Internet]. Brussels: International Diabetes Federation; 2022. Available from: https://diabetesatlas.org/2022-reports/

3. Sociedade Brasileira de Diabetes. Diretrizes da Sociedade Brasileira de Diabetes 2019–2020 [Internet]. São Paulo: Sociedade Brasileira de Diabetes; 2019. Available from: https://edisciplinas.usp.br/pluginfile.php/5730478/mod_resource/content/0/Diretrizes-SBD-2019-2020.pdf

4. Correia Júnior PCT, Pereira SMPD, Almeida VCF, Saraiva ARB, Alencar AMPG. Understanding the impact of diabetes mellitus in children from the mothers' perspective. Rev Rene. 2014;15(1):60–69.

5. Pellizzaro AO, Belini GF, Santos EL, Formentão K, Liz RG. Social support in the treatment and prevention of complications of type 1 diabetes mellitus in young patients. Rev Ciên Saúde. 2021;6(2):1–6.

6. Pérez-Marín M, Gómez-Rico I, Montoya-Castilla I. Type 1 diabetes mellitus: psychosocial factors and adjustment of the pediatric patient and his/her family. Arch Argent Pediatr. 2015;113(2):158–162. https://doi.org/10.5546/aap.2015.eng.158

7. Soares NS, Rocha TK, Carvalho GP, Viegas K, Geremia C, Canabarro ST. Knowledge of relatives of children with type 1 diabetes mellitus treated at a reference center. Res Soc Dev. 2018;7(7). https://doi.org/10.17648/rsd-v7i7.294

8. Zurita-Cruz JN, Nishimura-Meguro E, Villasís-Keever MA, Hernández-Méndez ME, Garrido-Magaña E, Rivera-Hernández AD. Influence of the informal primary caretaker on glycemic control among prepubertal pediatric patients with type 1 diabetes mellitus. J Pediatr (Rio J). 2017;93(2):136–141. https://doi.org/10.1016/j.jped.2016.05.009

9. Boaventura LC, Borges HC, Ozaki AH. Caregiver burden among adult wheelchair-bound neurological patients. Cien Saude Colet. 2016;21(10):3193–3202. https://doi.org/10.1590/1413-812320152110.15202016

10. Flesch LD, Batistoni SST, Neri AL, Cachioni M. Psychological aspects of quality of life of elderly caregivers: an integrative review. Geriatr Gerontol Aging. 2017;11(3):138–149. https://doi.org/10.5327/Z2447-211520171700041

11. Bianchi M, Flesch LD, Alves EV, Batistoni SST, Neri AL. Zarit Burden Interview psychometric indicators applied in older people caregivers of other elderly. Rev Latino-Am Enfermagem. 2016;24:e2835. https://doi.org/10.1590/1518-8345.1379.2835

12. Barroso SM, Santos LP, Silva LFE. Assessment instruments for caregiver burden: an integrative review. Aval Psicol. 2017;16(4):498–504. https://doi.org/10.15689/ap.2017.1604.13726

13. Domínguez-Guedea MT, Garcia AO. Sociocultural and familial influences on the well-being of Mexican older adults' family caregivers. Res Gerontol Nurs. 2015;8(4):188–196. https://doi.org/10.3928/19404921-20150219-02

14. McConaghy R, Caltabiano ML. Caring for a person with dementia: exploring relationships between perceived burden, depression, coping and well-being. Nurs Health Sci. 2005;7(2):81–91. https://doi.org/10.1111/j.1442-2018.2005.00213.x

15. Moreira AA. Effects of instructions and feedback on treatment adherence in adolescents with type 1 diabetes [dissertation]. Belém (PA): Federal University of Pará; 2019.

16. Brasil. Lei nº 8.069, de 13 de julho de 1990. Estatuto da Criança e do Adolescente. Diário Oficial da União. 1990 Jul 16. Available from: http://www.planalto.gov.br/ccivil_03/leis/l8069.htm

17. Amendola F. Quality of life of caregivers of patients with functional loss and dependence treated at home by the family health program of São Paulo [master's thesis]. São Paulo: University of São Paulo; 2007.

18. R Core Team. R: A language and environment for statistical computing [Internet]. Vienna: R Foundation for Statistical Computing; 2023. Available from: https://www.R-project.org/

19. Leão ALMS, Moritz GO. Applied statistics: numerical methods in R. Rio de Janeiro: Elsevier; 2018.

20. Borsoi S, Scheidt IV, Cordeiro GR, Mascarenhas LPG. Quality of life among caregivers of children and adolescents with type 1 diabetes. Multitemas. 2018;23(55):25–39. https://doi.org/10.20435/multi.v23i55.1743

21. Abreu Paiva LM, Gandolfi L, Pratesi R, Uenishi RH, Puppin Zandonadi R, Nakano EY, et al. Measuring quality of life in parents or caregivers of children and adolescents with celiac disease. Nutrients. 2019;11(10):2302. https://doi.org/10.3390/nu11102302

22. Jewell VD, Lee G, Harmon K, Gallegos E. Correlations between burden and quality of life for caregivers of children living with type 1 diabetes. Diabetes. 2021;70(Suppl 1):508-P. https://doi.org/10.2337/db21-508-P

23. Piran P, Khademi Z, Tayari N, Mansouri N. Caregiving burden of children with chronic diseases. Electron Physician. 2017;9(9):5380–5387. https://doi.org/10.19082/5380

24. Davis AO, Olagbegi OM, Orekoya K, Adekunle M, Oyewole OO, Adepoju M, et al. Caregiver burden and quality of life of informal caregivers of children with cerebral palsy. Rev Rene. 2021;22:e61752. https://doi.org/10.15253/2175-6783.20212261752

25. Guimarães G, Moraes J, Christoffel M, Silva L, Pacheco S, Rodrigues E. Burden of primary caregivers of children with congenital heart disease. Rev Enferm UERJ. 2022;30:e70344. https://doi.org/10.12957/reuerj.2022.70344

26. Barros ALO, Barros AO, Barros GLM, Santos MTBR. Burden of caregivers of children and adolescents with Down syndrome. Cien Saude Colet. 2017;22(11):3625–3634. https://doi.org/10.1590/1413-812320172211.31102016

27. Warschburger P, Kühne D. Psychosocial determinants of quality of life in parents of obese children seeking inpatient treatment. Qual Life Res. 2014;23(7):1985–1995. https://doi.org/10.1007/s11136-014-0659-y

28. Ortiz Claro YG, Lindarte Clavijo AA, Jiménez Sepúlveda MA, Vega Angarita OM. Sociodemographic characteristics associated with the burden of caregivers of diabetic patients in Cúcuta. Rev Cuidarte. 2013;4(1):36–44. https://doi.org/10.15649/cuidarte.v4i1.5

29. Barbosa DC, De Sousa FGM, Silva ACO, Silva ÍR, Da Silva TP, Paiva MCM. Maternal

burden in caring for children with chronic conditions. Cogitare Enferm. 2012;17(3):530–536. https://doi.org/10.5380/ce.v17i3.25830

30. Maulais SMC. Impact of psychoeducational group interventions on the burden of informal caregivers of children and adolescents with type 1 diabetes mellitus [master's thesis]. Belo Horizonte: Santa Casa de BH; 2014.

31. Young MT, Lord JH, Patel NJ, Gruhn MA, Jaser SS. Mothers' experiences caring for young children with type 1 diabetes: a qualitative study. BMJ Open. 2025;15:e103981. https://doi.org/10.1136/bmjopen-2024-103981

32. Alshammari M, Alanazi A, Alharbi A. Caregiver burden and psychological distress among parents of children with type 1 diabetes mellitus: a cross-sectional study. Heliyon. 2024;10:e35709. https://doi.org/10.1016/j.heliyon.2024.e35709

33. Sundberg F, Forsander G, Samuelsson U. Parental stress and work–life balance among caregivers of children with type 1 diabetes. Pediatr Diabetes. 2023;24:1252–1260. https://doi.org/10.1111/pedi.13554

34. AlBuhairan F, Alosaimi F, AlAteeq D. Family support and psychosocial adjustment among children with type 1 diabetes mellitus. BMC Endocr Disord. 2024;24:310. https://doi.org/10.1186/s12902-024-01310-2

35. Patton SR, Clements MA, Dolan LM, Powers SW. Fear of hypoglycemia and parental stress in families of children with type 1 diabetes. J Pediatr Psychol. 2025;50:880–889. https://doi.org/10.1093/jpepsy/jsae045

36. Hood KK, Hilliard ME, Piatt GA, Ievers-Landis CE. Effective family-based behavioral interventions in pediatric type 1 diabetes. Curr Diab Rep. 2023;23:145–153. https://doi.org/10.1007/s11892-023-01519-8

Ethics approval and consent to participate

This study involving human participants was reviewed and approved by the Research Ethics Committee of the Institute of Health Sciences at the Federal University of Pará (CEP/ICS/UFPA), Brazil (protocol no. 5.842.096). All procedures were conducted in accordance with the ethical standards of the Declaration of Helsinki and the Brazilian National Health Council Resolutions No. 466/2012 and 510/2016. Informed consent was obtained electronically from all participants prior to data collection.

Consent for publication

Not applicable. All data presented in this manuscript are anonymized and do not contain any information that could identify individual participants.

Availability of data and materials

The datasets generated and/or analyzed during the current study are available from the corresponding author (Fernando Allan de Farias Rocha, e-mail: rochaf@ufpa.br) upon reasonable request.

Competing interests

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Authors' contributions

D.C.C.M. contributed to study design, data collection, data organization, and drafting of the manuscript.

C.C.P.P. contributed to data collection, data verification, and manuscript revision.

F.A.F.R. supervised the study design, performed statistical analysis, interpreted the data,

critically revised the manuscript, and approved the final version for publication.

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Authors' information

Not applicable.