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Caregiver Burden and Associated Socioeconomic and Clinical Factors Among Parents of Pediatric Type 1 Diabetes Patients in Sulaymaniyah, Iraq

Dyari Saleem Ismael Ali
Dept. of Pediatric Nursing, College of Nursing, University of Sulaimani, Sulaimaniyah City, Iraq,
dyari.ismael@univsul.edu.iq

Bahar Nasradeen Majeed
Dept. of Pediatric Nursing, College of Nursing, University of Sulaimani, Sulaimaniyah City, Iraq,
baharped@gmail.com

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ORIGINAL STUDY

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Caregiver Burden and Associated Socioeconomic and Clinical Factors Among Parents of Pediatric Type 1 Diabetes Patients in Sulaymaniyah, Iraq

Dyari Saleem Ismael Ali *, Bahar Nasradeen Majeed

Dept. of Pediatric Nursing, College of Nursing, University of Sulaimani, Sulaimaniyah City, Iraq

Abstract

Background: Type 1 Diabetes Mellitus (T1DM) in children imposes a significant caregiving burden on parents, affecting their psychological and social well-being. Understanding this burden and its associated factors is crucial for improving family-cantered diabetes care.

Objectives: This study aimed to assess the level of caregiver burden among parents of children with type 1 diabetes mellitus (T1DM) and explore its association with sociodemographic, clinical, and management-related factors.

Methods: A quantitative cross-sectional study was conducted at Dr. Jamal Ahmad Rashid Pediatric Teaching Hospital in Sulaymaniyah, Iraq, between November 2024 and February 2025. A total of 160 parents of children with T1DM were recruited through convenience sampling. Data were collected using a structured questionnaire, including the Zarit Burden Interview (ZBI), and analyzed using descriptive statistics, as well as Chi-square and Fisher's exact tests, with a significance level of $p < 0.05$.

Results: The mean ZBI score was 42.51 ± 14.47 (range: 5–83). Most caregivers experienced mild-to-moderate (41.9%) or moderate-to-severe (38.8%) burden, while 13.1% reported severe burden. Burden levels were significantly associated with caregiver education (P-value 0.001), employment (P-value 0.034), economic status (P-value < 0.0001), child age (P-value 0.003), disease duration (P-value 0.003), and insulin administration responsibility (P-value 0.005).

Conclusion: Caregivers of children with T1DM experience a considerable burden influenced by socioeconomic, educational, and disease-related factors. Targeted psychosocial support, structured diabetes education, and community-based interventions are essential to reduce caregiver stress and enhance family well-being.

Keywords: Type 1 Diabetes mellitus, Caregiver burden, Parents, Pediatric diabetes, Sulaymaniyah governorate

1. Introduction

Type 1 Diabetes Mellitus (T1DM) is a chronic autoimmune endocrine disorder in which the immune system attacks and destroys insulin-producing beta cells in the pancreas, resulting in insulin deficiency and hyperglycemia [1]. Genetic predisposition, along with environmental factors such as enteroviral infections (especially coxsackie B virus), may trigger autoimmune responses that contribute to the onset of T1DM [2]. Several pathophysiological mechanisms have been implicated in disease development, including gut microbiome dysbiosis, mitochondrial dysfunction in pancreatic β-cells, and activation of cytotoxic CD8+ T cells [3]. The factors that increase the risk for early-onset T1DM include childhood infections, younger maternal age, older paternal age, Caesarean delivery, and a parental history of diabetes [4]. The classical clinical presentation of T1DM in children typically includes severe polyuria, polydipsia, weight loss, and ketonemia [5].

Globally, the prevalence of T1DM is rising. It is projected that by 2025, there will be approximately 9.5 million individuals living with T1DM, with

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* Corresponding author.
E-mail addresses: dyari.ismael@univsul.edu.iq (D. S. Ismael Ali), baharped@gmail.com (B. N. Majeed).

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significantly higher increase rates in low-income countries [6]. T1DM accounts for about 10% of all diabetes cases, with an annual incidence increase estimated at 3% to 4% [7, 8]. In Iraq, the incidence among children under 15 years of age increased markedly—from 7.8 cases per 100,000 in 1995 to 24.7 cases in 2014—highlighting a concerning trend [9, 10].

The disease is associated with both acute and long-term complications. Diabetic ketoacidosis (DKA) and severe hypoglycemia are among the most common acute events [11]. Long-term complications include both microvascular and macrovascular pathologies [12]. Microvascular complications encompass diabetic retinopathy, nephropathy, and neuropathy, while macrovascular consequences include cardiovascular disease, cerebrovascular events, and peripheral arterial disease [13].

Notably, cardiovascular disease remains the leading cause of mortality in individuals with T1DM [14]. Other serious complications include diabetic retinopathy, which impairs vision over time [15] and diabetic peripheral neuropathy, the most prevalent neurodegenerative complication in diabetes [16]. Furthermore, diabetic cardiomyopathy and diabetic myopathy, including early-onset sarcopenia and reduced physical activity, further exacerbate the disease burden [17, 18].

Parents of children with T1DM are responsible not only for supporting their children's mental, physical, and emotional development but also for monitoring diet, supervising exercise, administering insulin, and preventing hypoglycemia [19, 20]. These responsibilities often disrupt normal family routines and impose significant psychological and logistical challenges [21, 22].

The intensity and constancy required in daily management mean that any oversight can lead to serious acute events, underscoring the need for continuous vigilance [23]. As a result, many caregivers experience a considerable burden stemming from the conflict between caregiving demands and other familial, professional, or personal roles [24]. This caregiver burden encompasses physical, emotional, social, financial, and spiritual stressors [25, 26].

Despite the rising prevalence of T1DM in Iraq—particularly in the Sulaymaniyah Governorate—there is limited research on the caregiver burden experienced by parents of children with T1DM in this region. Given the disease's lifelong nature and early onset, understanding the specific challenges faced by caregivers is essential to formulating effective, context-specific support programs. The present study seeks to fill this gap by assessing the caregiver burden among parents of children with T1DM at Dr. Jamal Ahmad Rashid Pediatric Teaching Hospital in Sulaymaniyah.

Aim of the research: This study aimed to evaluate the level of caregiver burden among parents of children with Type 1 Diabetes Mellitus and to examine its association with sociodemographic, clinical, and management-related factors at Dr. Jamal Ahmad Rashid Pediatric Teaching Hospital in Sulaymaniyah, Iraq.

2. Materials and methods

2.1. *Study design and setting*

This quantitative cross-sectional study was conducted to describe the burden of Type 1 Diabetes Mellitus (T1DM) on children's caregivers at Dr. Jamal Ahmad Rashid Pediatric Teaching Hospital in Sulaymaniyah Governorate, Kurdistan Region of Iraq. Data collection was carried out between November 1, 2024, and February 1, 2025.

2.2. *Study population and sampling*

The study included 160 parents through a non-probability convenience sampling method of children with T1DM. Data collection was specifically conducted in the Chronic Disease Unit, which provides ongoing management and follow-up care for children with chronic conditions, including T1DM. The sample size was determined based on patient flow records at the hospital and guided by similar studies assessing caregiver burden in pediatric diabetes populations.

The study included the parent or primary caregiver of a child diagnosed with T1DM and registered at the hospital, provided the child had no additional chronic conditions. In addition, parents of children with Type 2 Diabetes Mellitus, children with special needs, or those unwilling to participate were excluded from the study.

2.3. *Data collection and instruments*

A structured questionnaire was developed for data collection, sourced from previous studies on the same topic and adapted to reflect relevant cultural and geographical characteristics. Data were collected through face-to-face interviews with caregivers in a private consultation room within the Chronic Disease Unit during morning hours (09:00–12:30). In addition to the interviews, medical records were reviewed to extract relevant clinical data.

The questionnaire consisted of three main sections. The first section gathered socio-demographic information, including the child's ages and gender, as well as the parents' age, educational level, and socioeconomic status. The second section focused on the child's medical history, covering details such as age at diagnosis, disease duration, and the frequency of blood glucose monitoring. The third section assessed the caregiving burden using the Zarit Burden Interview (ZBI), a validated and widely utilized tool designed to measure caregiver stress.

The ZBI comprises 22 items rated on a 5-point Likert scale, yielding a total score ranging from 0 to 88, with higher scores indicating greater perceived burden. The scores are classified into four levels: 0–20 (little or no burden), 21–40 (mild-to-moderate burden), 41–60 (moderate-to-severe burden), and 61–88 (severe burden). Previous research has shown the ZBI to have strong internal consistency, with Cronbach's alpha values ranging from 0.85 to 0.92 [27, 28].

2.4. Validity, reliability, and pilot testing

The questionnaire underwent content validation by a panel of 14 experts in pediatric nursing, pediatric endocrinology, community nursing, pediatric medicine, community medicine, and diabetes education, leading to minor refinements in the disease-related section. A pilot study with 20 parents (1–15 December 2024) assessed clarity and feasibility, with an average completion time of 25–35 minutes.

2.5. Data analysis

Data were entered into Microsoft Excel for initial cleaning and subsequently exported to SPSS (Statistical Package for the Social Sciences) for analysis. Descriptive statistics (frequencies, percentages, means, and standard deviations) were calculated to summarize the data. Chi-square tests were used to determine the difference between categorical variables. However, Fisher's exact test was applied in cases where the expected cell frequency was less than five, considering A P-value of <0.05 as statistically significant.

2.6. Ethical considerations

Ethical approval was obtained from the Scientific Committee of the College of Nursing and the Ethical Committee of Nursing Colleges at the University of Sulaimani, following the institutional review board (IRB) guidelines. Permissions were granted by the Department of Health and Dr. Jamal Ahmad Rashid Pediatric Teaching Hospital. All participants were fully informed about the study's purpose and procedures, assured of confidentiality, and notified of their right to withdraw at any time without consequence. Verbal informed consent was obtained before participation [29].

3. Results

3.1. Patient's demographic characteristics

The study included 160 patients with Type 1 Diabetes mellitus with a mean age of 10.28 ± 3.62 years (ranging from 2 to 17 years). The age group distribution revealed that 12 (7.5%) children were younger than 5 years, 61 (38.1%) were between 5 to 10 years, and 87 (54.4%) were older than 10 years. The sample consisted of an equal number of females and males, with 80 (50%) in each group. Regarding the children's birth order, 56 (35%) were first-born, 43 (26.9%) were second-born, 31 (19.4%) were third-born, 14 (8.8%) were fourth-born, 10 (6.3%) were fifth-born, 2 (1.3%) were sixth-born, and 4 (2.5%) were seventh-born. For the educational status, 21 (13.1%) had not yet enrolled in school, 1 (0.6%) attended nursery, 8 (5%) attended kindergarten, and most of them 130 (81.3%) were in school grades from first to tenth. (Table 1).

Table 1. Sociodemographic characteristics of the study population.

Variables and groups	Frequency	%
Age groups		
Less than 5 years	12	7.5
5–10 years	61	38.1
More than 10 years	87	54.4
Child's Gender		
Female	80	50
Male	80	50
Child's order in the family		
1	56	35
2	43	26.9
3	31	19.4
4	14	8.8
5	10	6.3
6	2	1.3
7	4	2.5
Child's Schooling		
Null class	21	13.1
Nursery	1	0.6
Kindergarten	8	5
School grades (1st–10th)	130	81.3

3.2. Patients' family characteristics

Most caregivers 131(81.9%) were mothers, while 29 (18.1%) were fathers. Age distribution showed that 6 (3.8%) caregivers were younger than 30 years, 74 (46.3%) were between 30–39 years, 59 (36.9%) were between 40–49 years, and 21 (13.1%) were aged 50 years or older. The caregivers had a mean age of 40.15 ± 7.69 years, ranging from 21 to 72 years. The majority of the patients' families 52 (95%) were married, while a minority 8 (5%) were divorced. Regarding the caregivers' educational level, 9 (5.6%) caregivers were illiterate, 46 (28.7%) completed basic school, 45 (28.1%) had secondary education, 56 (35%) held an institute or university degree, and 4 (2.5%) had a master's degree or higher.

About caregivers' occupational status, 66 (41.3%) were public employees, 14 (8.8%) were private employees, 14 (8.8%) were self-employed, and 66 (41.3%) were out of work or housewives. Concerning families' economic status, 30 (18.8%) families reported sufficient income, 83 (51.9%) barely sufficient income, and 47 (29.4%) insufficient income. Furthermore, family size was small (2–3 members) in 6 (3.8%) households, medium (4–5 members) in 100 (62.5%), and large (6–10 members) in 54 (33.8%). Most families were nuclear 147 (91.9%), with 9 (5.6%) extended families and 4 (2.5%) single-parent households. Finally, most of the patients' families lived inside the city 100 (62.5%) while 60 (37.5%) resided outside the city. (Table 2).

Table 2. Sociodemographic characteristics of patients' caregivers.

Variables and groups	Frequency	%
Who is the caregiver		
Mother	131	81.9
Father	29	18.1
Caregiver age groups		
<30 years (younger caregivers)	6	3.8
30–39 years (early-middle caregivers)	74	46.3
40–49 years (mid-age caregivers)	59	36.9
50+ years (older caregivers)	21	13.1
Marital status		
Married	152	95
Divorced	8	5
Educational Level (caregiver)		
Illiterate	9	5.6
Basic School	46	28.7
Secondary School	45	28.1
Institute / University degree	56	35
Master's or Higher degree	4	2.5
Caregiver Occupational Status		
Public Employee	66	41.3
Private Employee	14	8.8
Self-Employee	14	8.8
Out of work/ Housewife	66	41.3
Economic Status		
Sufficient	30	18.8
Barely sufficient	83	51.9
Insufficient	47	29.4
Family Size		
Small (2–3)	6	3.8
Medium (4–5)	100	62.5
Large (6–10)	54	33.8
Family Type		
Nuclear	147	91.9
Extended (grandfather or grandmother)	9	5.6
Single parent	4	2.5
Residential Areas		
Inside the city	100	62.5
Outside the city	60	37.5

3.3. *Patients' BMI categories*

The patients' Body Mass Index (BMI) categories showed that the majority 90 (58.8%) of participants were of healthy weight, followed by the obese category, 24 (15.7%), underweight 22 (14.4%), and overweight 17 (11.1%) respectively. The overall BMI score ranged from 5 to 87.34 with a mean of 18.46 (SD 6.97). (Fig. 1)

3.4. *Distribution of last recorded HbA1c levels among children*

Fig. 2A and 2B show the distribution of the most recent HbA1c levels. The values ranged from 4.58 to 15, with a mean of 9.18 and a median of 9. Fig. 2B presents the proportion of patients within three glycemic control categories. A minority of the children, 14 (10.3%) had controlled HbA1c levels (<7%) while the majority of children, 79 (58.1%) were in the moderately controlled range (7–9%), and 63 children (46.3%) had uncontrolled levels (>9%).

3.5. *Patients' disease history and follow-up*

For the patients' follow-up, the majority of children 110 (68.8%) attended regular follow-up visits, whereas 50 (31.3%) did not. The mean age at diagnosis was 4.06 ± 3.10 years, with most children diagnosed in infancy or toddlerhood (<5 years) 108 (67.5%), followed by early childhood (5–9 years) 39 (24.4%) and late childhood (10–14 years) 13 (8.1%). The mean duration of type 1 diabetes mellitus (T1DM) was 6.31 ± 3.67 years, with 71 (44.4%) having a long duration (>6 years), 45 (28.1%) a moderate duration (4–6 years), 42 (26.3%) a short duration (1–3 years), and only 2 (1.3%) being newly diagnosed (<1 year). A strong majority 147 (91.9%) reported having no other children with T1DM in the family, while 13 (8.1%) did.

Regarding insulin administration, 92 (57.5%) children were injected by their parents, 37 (23.1%) shared the task with their parents, 29 (18.1%) self-administered, and 2 (1.3%) received injections from others. The predominant method of insulin delivery was by insulin pen, 140 (87.5%), followed by syringes 18 (11.3%) and pumps 2 (1.3%). Difficulties with insulin injections were reported by 69 (43.1%) children, while 88 (55.0%) sometimes experienced such difficulties, and only 3 (1.9%) reported no issues. (Table 3).

3.6. *The children's insulin management and lifestyle*

Among the studied children with Type 1 Diabetes Mellitus, the frequency of daytime blood sugar testing was high (≥4/day) in 80 (50%), moderate

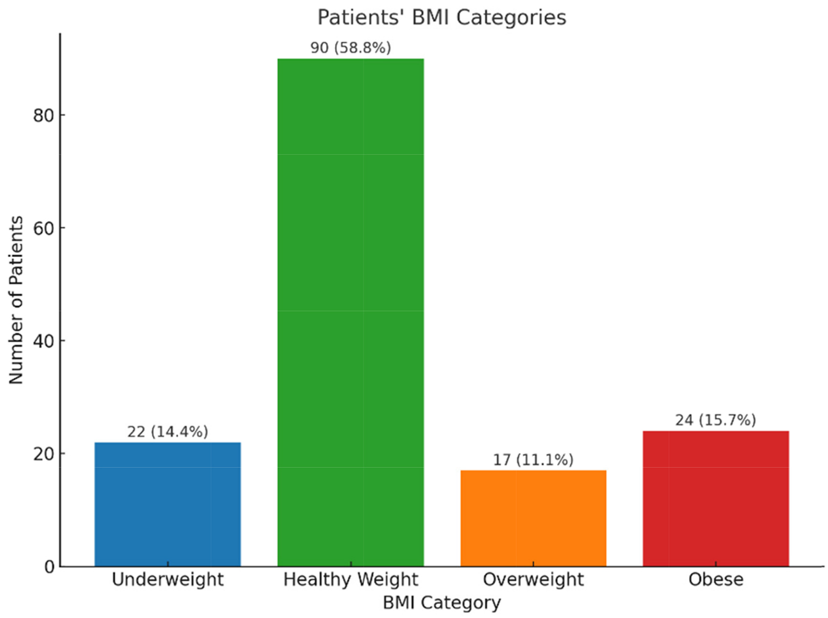

Fig. 1. The distribution of the patients' BMI categories.

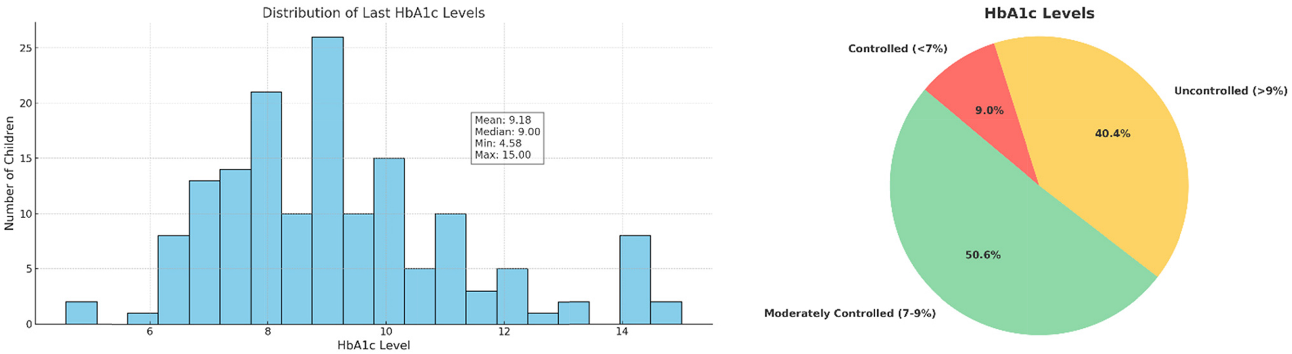

Fig. 2. A and B: Distribution of last recorded HbA1c levels in children.

(2–3/day) in 63 (39.4%), and low (≤1/day) in 17 (10.6%) of cases. Regarding recent hypoglycemic episodes, 87 (54.4%) experienced mild episodes (1–2), 19 (11.9%) had frequent episodes (≥3), while 54 (33.8%) reported none. In terms of diabetes management (DM) education, 106 (66.3%) received information from healthcare providers, 26 (16.3%) through online resources, 3 (1.9%) from family or friends, 1 (0.6%) from books or printed materials, and 1 (0.6%) through workshops or seminars, while 23 (14.4%) had not participated in any form of DM education (Table 4).

3.7. ZBI assessment total burden score and categories

The Zarit Burden Interview (ZBI) scores among caregivers showed a mean of 42.51 and SD ± 14.47, with scores ranging from 5 to 83. The categorization of the score in Fig. 3 demonstrated that most caregiver participants experienced a mild to moderate burden 67(41.9%) or a moderate to severe burden 62(38.8%). In addition, a smaller proportion reported a severe burden 21(13.1%), while only 10 (6.3%) indicated no to mild burden.

3.8. Burden level among demographic variables

The distribution of Zarit Burden Interview (ZBI) levels varied significantly across several demographic and contextual variables. The caregiver burden was highest among children aged more than 10 years, with 43 (69.4%) experiencing moderate-to-severe burden and 8 (38.1%) severe burden, compared to 2 (3.2%) and 4 (19.0%) respectively, in children under 5 years, with a highly significant difference (P-value 0.003). Child schooling showed a significant difference

Table 3. The distribution of the Patients' disease history and follow-up.

Variables and groups	Frequency	%
Does your child attend regular follow-up visits?		
No	50	31.3
Yes	110	68.8
Child's Age at Diagnosis (4.06 ± 3.10)		
Infant & Toddler (<5)	108	67.5
Early Childhood (5–9)	39	24.4
Late Childhood (10–14)	13	8.1
Duration of T1DM groups (6.31 ± 3.67)		
Newly Diagnosed (<1 yr)	2	1.3
Short Duration (1–3 yrs)	42	26.3
Moderate Duration (4–6 yrs)	45	28.1
Long Duration (>6 yrs)	71	44.4
Do you have other children in the family with TDM1		
No	147	91.9
Yes	13	8.1
Insulin injection by		
Child him/herself	29	18.1
Parent	92	57.5
Parent & Child	37	23.1
Others	2	1.3
Method of administration of insulin		
Insulin syringe	18	11.3
Insulin pen	140	87.5
Insulin pump	2	1.3
Does your child experience difficulties with insulin injection?		
Yes	69	43.1
No	3	1.9
Sometimes	88	55.0

Table 4. Characteristics of insulin management and lifestyle in children with Type 1 diabetes mellitus.

Variables and groups	Frequency	%
How often does your child have blood sugar tests during the daytime? (3.43 ± 1.56)		
Low (≤1/day)	17	10.6
Moderate (2–3/day)	63	39.4
High (≥4/day)	80	50
How often has your child experienced hypoglycemic episodes recently?		
None	54	33.8
Mild (1–2)	87	54.4
Frequent (≥3)	19	11.9
Have you received diabetes management (DM) education before?		
Not participated	23	14.4
Healthcare providers	106	66.3
Online resources	26	16.3
Books or printed materials	1	0.6
Family members or friends	3	1.9
Workshop or seminars	1	0.6

with burden (P-value 0.009), where caregivers of children in null classes had a higher severe burden 8 (38.1%) compared to those in school grades 12 (57.1%). Educational level of caregivers also differed significantly (P-value 0.001), with severe burden more frequent among those with only basic schooling 9 (42.9%), compared to 5 (23.8%) among those with institute/university education.

Occupational status significantly affected burden (P-value 0.034), with severe burden reported most among out-of-work caregivers 13 (61.9%). Economic status strongly correlated with burden (P-value < 0.0001), as 12 (57.1%) of those with insufficient income experienced severe burden compared to only 2 (9.5%) in the sufficient group. Residential areas also showed significance (P-value 0.025), with those living outside cities reporting more moderate-to-severe and severe burdens 30 (48.4%) and 9 (42.9%) than urban residents. Other variables, including the child's gender (P-value 0.551), caregiver identity (P-value 0.376),

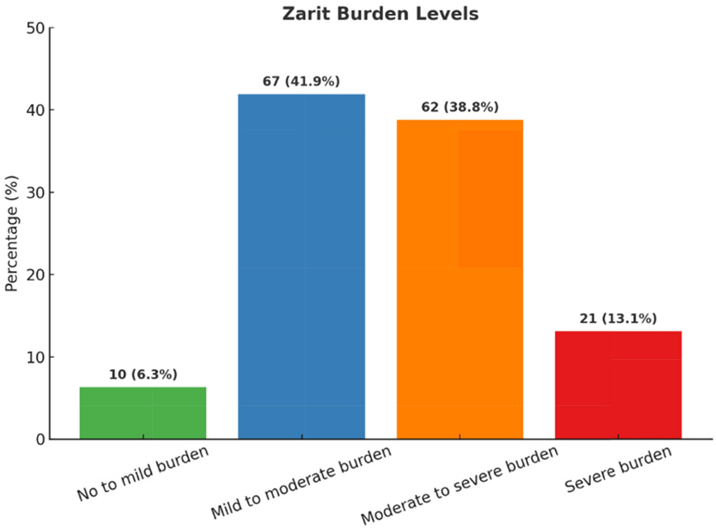

Fig. 3. Distribution of caregiver burden levels.

caregiver age (P-value 0.220), marital status (P-value 0.515), and family type (P-value 0.148), were not statistically significant (Table 5).

3.9. Distribution of burden categories across clinical and diabetes management variables

The distribution of Zarit Burden Interview (ZBI) categories across clinical and diabetes management variables showed notable patterns. Most caregivers of children with a healthy weight reported moderate-to-severe burden 37 (60.7%) and severe burden 12 (66.7%), with no significant difference between ZBI categories and BMI groups (P-value 0.841). The severe burden was more frequent among those who did not attend follow-up visits 10 (47.6%) compared to regular attendees, though the difference was not statistically significant (P-value 0.064). Caregiver burden did not differ significantly (P-value 0.311) by child age at diagnosis, with the highest severe burden observed among those diagnosed in infancy or toddlerhood 13 (61.9%).

There was a significant difference between ZBI burden categories and diabetes duration (P-value 0.003), with severe burden reported most frequently among caregivers of children with short disease duration (1–3 years) 10 (47.6%). A significant difference was observed between ZBI burden categories and insulin administration responsibility (P-value 0.005), with severe burden most common among caregivers administering insulin themselves 18 (85.7%). The method of insulin administration (syringe, pen, pump) did not show a significant association with burden (P-value 0.108). (Table 6)

4. Discussion

4.1. Patient demographic profile

The present study involved 160 pediatric patients with Type 1 Diabetes Mellitus, with a mean age slightly above ten years, spanning early childhood to late adolescence. The largest proportion was over ten years old, followed by those aged five to ten, and a smaller group under five. This distribution reflects epidemiological trends, as Hummel [30] stated that the annual incidence of newly diagnosed Type 1 Diabetes Mellitus cases among youth rose by 5.71% during 15 years, with the most significant increase observed in the 5–9-year age group. Our slightly older cohort may reflect local patterns of delayed diagnosis or referral within Iraq's healthcare system, possibly due to gaps in early screening, cultural perceptions of childhood illness, or access barriers in rural areas. The equal distribution of males and females in the current sample differs from Tatti & Pavandeep's [31] report that males exhibit a higher incidence rate relative to females in specific populations. This disparity may be attributable to regional variations, differing environmental exposures, or genetic factors influencing disease risk in this cohort. This difference could be due to Iraq's relatively equal healthcare-seeking behavior between genders in pediatric cases, where parents typically prioritize medical care for children irrespective of sex.

More than one-third of the participants were firstborn, which is consistent with Cardwell's study [32] who reported reduced diabetes risk in later-born children. The link between birth order and autoimmune disease susceptibility remains

Table 5. Distribution of burden categories across demographic and socioeconomic variables.

	Burden Level								
	No to mild burden		Mild to moderate burden		Moderate to severe burden		Severe burden		
Variables and groups	N	%	N	%	N	%	N	%	P-value
Age groups									
Less than 5 years	3	30	3	4.5	2	3.2	4	19	0.003
5–10	3	30	32	47.8	17	27.4	9	42.9	
More than 10 years	4	40	32	47.8	43	69.4	8	38.1	
Child's Gender									
Female	6	60	37	55.2	28	45.2	9	42.9	0.551
Male	4	40	30	44.8	34	54.8	12	57.1	
Child's Schooling									
Null class	3	30	6	9	4	6.5	8	38.1	0.009
Nursery	0	0	0	0	1	1.6	0	0	
Kindergarten	0	0	5	7.5	2	3.2	1	4.8	
School grades (1st-10th)	7	70	56	83.6	55	88.7	12	57.1	
Who is the caregiver									
Mother	8	80	53	79.1	50	80.6	20	95.2	0.376
Father	2	20	14	20.9	12	19.4	1	4.8	
Caregiver age groups									
<30 years (younger caregivers)	1	10	3	4.5	1	1.6	1	4.8	0.220
30–39 years (early-middle caregivers)	5	50	36	53.7	24	38.7	9	42.9	
40–49 years (mid-age caregivers)	2	20	21	31.3	30	48.4	6	28.6	
50+ years (older caregivers)	2	20	7	10.4	7	11.3	5	23.8	
Marital status									
Married	9	90	63	94	59	95.2	21	100	0.515
Divorced	1	10	4	6	3	4.8	0	0	
Educational Level (caregiver)									
Illiterate	0	0	4	6	2	3.2	3	14.3	0.001
Basic School	2	20	8	11.9	27	43.5	9	42.9	
Secondary School	0	0	25	37.3	16	25.8	4	19	
Institute/University degree	7	70	28	41.8	16	25.8	5	23.8	
Master's or Higher degree	1	10	2	3.0	1	1.6	0	0	
Caregiver Occupational Status									
Public Employee	5	50	31	46.3	25	40.3	5	23.8	0.034
Private Employee	1	10	11	16.4	2	3.2	0	0	
Self-Employee	1	10	5	7.5	5	8.1	3	14.3	
Out of work/Housewife	3	30	20	29.9	30	48.4	13	61.9	
Economic Status									
Sufficient	7	70	16	23.9	5	8.1	2	9.5	0.0001
Barely sufficient	3	30	39	58.2	34	54.8	7	33.3	
Insufficient	0	0	12	17.9	23	37.1	12	57.1	
Family Type									
Nuclear	9	90	61	91.0	56	90.3	21	100	0.148
Extended (grandfather or grandmother)	1	10	6	9.0	2	3.2	0	0	
Single parent	0	0	0	0.0	4	6.5	0	0	
Residential Areas									
Inside the city	5	50	51	76.1	32	51.6	12	57.1	0.025
Outside the city	5	50	16	23.9	30	48.4	9	42.9	

inconclusive. The firstborn children often receive more parental attention, particularly within the Iraqi context, which may contribute to earlier detection and hospital presentation but could also heighten parental anxiety and perceived disease burden.

Most children were enrolled in formal education, with only a small proportion in pre-school or not yet attending. This result is supported by Fleming's study, which concluded that children with Type 1 Diabetes Mellitus exhibit a higher propensity for hospital admissions, mortality, school absenteeism, and learning impairments in comparison to their peers [33], emphasizing the need for educational support systems to mitigate the disease's impact on academic engagement. In Iraq, where public school systems have limited resources for chronic illness support, these risks could translate into disrupted schooling and academic underachievement, underlining the need for school-based diabetes education programs and nurse-led monitoring.

Table 6. Distribution of burden categories across clinical and diabetes management variables.

	Burden Level								
	No to mild burden		Mild to moderate burden		Moderate to severe burden		Severe burden		
Variables and groups	N	%	N	%	N	%	N	%	P-value
BMI categories									
Underweight (severely wasted)	1	10	12	18.8	8	13.1	1	5.6	0.841
Healthy Weight	8	80	33	51.6	37	60.7	12	66.7	
Overweight	0	0	7	10.9	7	11.5	3	16.7	
Obese	1	10	12	18.8	9	14.8	2	11.1	
Does your child attend regular follow-up visits?									
No	1	10	16	23.9	23	37.1	10	47.6	0.064
Yes	9	90	51	76.1	39	62.9	11	52.4	
Child's Age at Diagnosis									
Infant & Toddler (<5)	8	80	43	64.2	44	71.0	13	61.9	0.311
Early Childhood (5–9)	2	20	22	32.8	9	14.5	6	28.6	
Late Childhood (10–14)	0	0	2	3	9	14.5	2	9.5	
Duration of T1DM groups									
Newly Diagnosed (<1 yr)	1	10	0	0	0	0	1	4.8	0.003
Short Duration (1–3 yrs)	3	30	20	29.9	9	14.5	10	47.6	
Moderate Duration (4–6 yrs)	0	0	21	31.3	20	32.3	4	19.0	
Long Duration (>6 yrs)	6	60	26	38.8	33	53.2	6	28.6	
Insulin injection by									
Child him/herself	1	10	11	16.4	17	27.4	0	0	0.005
Parent	6	60	42	62.7	26	41.9	18	85.7	
Parent & Child	3	30	13	19.4	19	30.6	2	9.5	
Others	0	0	1	1.5	0	0.0	1	4.8	
Method of administration of insulin									
Insulin syringe	2	20	3	4.5	9	14.5	4	19	0.108
Insulin pen	8	80	62	92.5	53	85.5	17	81	
Insulin pump	0	0	2	3	0	0	0	0	

4.2. Caregiver socioeconomic and educational background

Caregiving responsibilities were primarily assumed by mothers, consistent with Zamarlik's [34] reports, which found that mothers predominantly assume the psychological load and obligation for the care of children with Type 1 Diabetes Mellitus. Most caregivers were in their thirties or forties, reflecting the common age range of parents for children in this cohort, and supporting Harjutsalo's [35] evidence, which concluded that the level of maternal engagement does not change regardless of the age at which diabetes begins, although the level of paternal involvement can fluctuate.

The majority of caregivers were married, though Jubber's literature warns that the caregiving responsibilities of both parents are strongly correlated with marital conflict [36], highlighting the potential for family dynamics to influence disease management. In the Iraqi context, where extended family systems are common, relatives may provide some respite, but stigma around chronic illness can still amplify emotional stress and limit help-seeking. Lower educational levels were associated with increased caregiver burden in our study. This is in line with Baharvand [37] study, who observed that parental education impacts both perceived support and metabolic control in adolescents. In the local context, parents with limited schooling may face difficulties in understanding diabetes management instructions or interpreting blood glucose trends, resulting in greater stress. This highlights the importance of simplifying educational materials and offering culturally appropriate caregiver training sessions.

In addition to education, employment patterns revealed that many caregivers were out of work or housewives, which is consistent with Karakus' [38] findings that unemployment rose markedly among mothers within a year following the child's diagnosis. Financially, most households reported barely sufficient or insufficient income, consistent with Eshtehardi's evidence, which stated that Parents make financial sacrifices to pay for diabetes-related costs [39]. Given Iraq's out-of-pocket health financing system and limited insurance coverage, this economic strain likely magnifies caregiver stress and reduces capacity to afford optimal supplies (e.g., CGM devices, insulin pens). Residence was predominantly urban, which provides better access to specialized care compared with rural areas. Similar results were observed in the Grudziąż-Sękowska study, which found that living outside of cities makes it harder to get specialized medical care and go to school [40]. However, rural caregivers face longer travel times and higher indirect costs, which may compound their burden and lead to poorer glycemic outcomes.

4.3. Clinical characteristics and disease management

Nutritional status varied among the children, with most maintaining a healthy BMI, while smaller proportions were classified as obese, underweight, or overweight. The underweight group is of particular concern because Jung's study found that people with T1D who are underweight have a much higher risk of dying from any cause [41].

The average HbA1c level in this study exceeded recommended targets, with only a small minority achieving optimal glycemic control. This is consistent with the Poobalan [42] literature showing that the majority of people with Type 1 Diabetes Mellitus did not reach their glycosylated blood goals, and that glycemic trends vary by age; this finding is consistent with the Miller [43] study, which found a decline during childhood and a rise during teenage years. This finding suggests that despite regular insulin administration, psychosocial barriers, dietary patterns, and erratic glucose monitoring may undermine metabolic control. In Iraq, the limited availability of diabetes educators and structured follow-up clinics may contribute to suboptimal outcomes.

The current study concluded that insulin administration was largely managed by parents, and insulin pens were the predominant delivery method. These results are consistent with the Zuberi [44] study, which stated that young children require parental supervision for diabetes management, including insulin administration and glucose monitoring. While vials and syringes are effective, they are invasive and less user-friendly. Insulin pens offer greater accuracy, ease of use, and reduced discomfort. Frequent blood glucose monitoring was common, which supports the Formosa [45] evidence that stated that monitoring four times daily considerably enhances HbA1c levels. The patterns mostly reflect good adherence behaviors; however, the high HbA1c levels suggest that frequency alone may not ensure optimal control, possibly due to other factors such as diet, insulin timing, or psychosocial barriers.

4.4. Determinants of caregiver burden

Caregiver burden emerged as a central finding of this study. Most caregivers experienced mild-to-moderate or moderate-to-severe burden, with a substantial minority reporting severe burden. In the Iraqi context, stigma surrounding mental health often prevents caregivers from seeking psychosocial support, potentially worsening the emotional toll. These findings are consistent with Balcázar [46] study, which identified a strong association between high caregiver burden and psychological distress, including depression. Such emotional strain is further supported by Capistrant's study [47], which observed that caregivers with high burden scores had a 41% likelihood of experiencing clinical depression. These insights underscore the psychological vulnerabilities inherent in caregiving for children with chronic illnesses.

Significant associations emerged between burden and factors such as child age, caregiver education, employment, income, and place of residence. This aligns with Kobos & Imiela's study [48], stating that the degree of load correlates with the child's age, as well as the parents' occupational standing and educational attainment, and Kobos's [49] study found that financial instability correlates with increased caregiver strain. Socioeconomic inequities in Iraq, such as unemployment, inflation, and limited social safety nets, may exacerbate these associations. However, Family caregivers who lived in traditional village communities were more likely than those who lived in private housing estates to feel emotional and total caregiver burden [50].

Caregiver burden was significantly higher during the early years following a child's T1DM diagnosis. Cornelius' study [51] similarly reports of heightened anxiety in recently diagnosed families. This may reflect the psychological shock, lack of experience in managing insulin regimens, and fear of acute complications such as hypoglycemia. In Sulaymaniyah, where structured diabetes education and counseling services are scarce, families often rely on informal networks or internet resources, which may be inconsistent or incomplete. Early, structured interventions—such as home visits by trained diabetes educators, peer support groups, and telephone follow-up—could significantly reduce caregiver stress during this critical adjustment period.

4.5. Limitations of the study

While this study offers valuable insight into the caregiver burden associated with managing children with T1DM in Sulaymaniyah, several limitations must be acknowledged. First, the cross-sectional design prevents any inference of causality between caregiver burden and associated variables such as socioeconomic status or disease duration. Longitudinal studies are needed to explore how caregiver burden evolves over time. Second, data collection relied primarily on self-reported measures, which are subject to recall bias and social desirability bias. Third, the use of a convenience sampling method and restriction to a single-centre setting (Dr. Jamal Ahmad Rashid Pediatric Teaching Hospital) limits the generalizability of the findings to broader or rural populations across Iraq or the Kurdistan Region. Lastly, the study did not explore psychosocial comorbidities such as caregiver depression, anxiety, or sleep disturbances, which are known to influence burden levels and may confound the reported results.

5. Conclusion

This study demonstrated that caregivers of children with Type 1 Diabetes Mellitus experience a substantial burden, with most reporting mild-to-severe levels of stress. The burden was significantly associated with socioeconomic status, caregiver education, employment, child age, disease duration, and responsibility for insulin administration. These findings emphasise the complex challenges faced by caregivers and the need for comprehensive strategies to address their psychological, social, and educational needs. Healthcare providers should implement structured diabetes education programs and psychosocial support services tailored to caregivers, especially for caregivers with limited resources or lower educational attainment.

Conflict of interest

The authors declare that there are no conflicts of interest.

Ethical approval

This study was conducted in accordance with the principles of the Declaration of Helsinki. Ethical approval was obtained from the Ethics Committee of the University of Sulaimani, College of Medicine (Date: 3 November 2024; Approval No. 1490).

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