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Assessment of the burden on caregivers of children with type 1 diabetes mellitus in Baghdad, Iraq, 2023

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Abstract

Background: Diabetes is a major global health emergency, with Type 1 diabetes being prevalent among children. Caregiver burden for managing this chronic condition is influenced by the community's context and culture. This descriptive study aims to assess the burden on caregivers of patients with Type 1 diabetes mellitus, identifying various burden types and examining the impact of socio-demographic and clinical characteristics on caregiver burden.

Method: A descriptive cross-sectional study was conducted among caregivers of children with Type 1 diabetes mellitus at the Children's Welfare Teaching Hospital in Baghdad, Iraq, over four months. Data was collected via socio-demographic questionnaires and the Zarit burden questionnaire through direct face-to-face interviews. Statistical analyses included Pearson, Chi-square, and Fisher Exact tests.

Results: This study included 300 caregivers of children with Type 1 diabetes, with 97.3% being the patient's mothers and an average age of 34.30 ± 5.82 years. Caregiver burden was prevalent in all participants: 4.7% had mild, 42.3% had moderate, and 53% had severe burden. Severe burden was higher in mothers aged 30-34 years, housewives, low-educated parents, and low-income families. Patient factors significantly associated with severe burden included female sex, recent diagnosis, frequent hospital admissions for Diabetic Ketoacidosis, comorbidities, monthly doctor visits, uncontrolled diabetes, insulin administration difficulties, and dietary requirements.

Conclusion: Parents of children with T1DM face significant caregiver burden. These findings can guide medical professionals in creating comprehensive, family-centered care plans that address burden-raising factors and highlight the importance of community-based programs and ongoing family interventions to improve care quality.

Keywords: Assessment, burden, caregivers, children, type 1, diabetes mellitus, Baghdad

Introduction

Diabetes is one of the biggest global health crises of the twenty-first century, ranking among the top ten causes of mortality worldwide. Alongside other major non-communicable diseases (NCDs) such as cancer, respiratory illness, and cardiovascular disease, diabetes accounts for over 80% of premature NCD fatalities. In 2015, NCDs were responsible for 39.5 million out of 56.4 million deaths globally [1]. Despite a noted decrease in diabetes-related deaths in several countries over recent decades, the excess risk of death remains higher in the diabetic population, particularly among younger age groups [2]. According to the Global Burden of Diseases, Injuries, and Risk Factors Study (GBD) 2019, diabetes was the eighth most common cause of death and disability worldwide, affecting around 460 million people across all age groups [3]. Type 1 and type 2 diabetes are the most prevalent forms of the disease, diagnosed with specific criteria [4]. Type 1 diabetes mellitus (T1DM) is one of the most common chronic diseases in children [5], with its incidence rising globally [6]. The Middle East has reported increases of 2-5 percent per year [7], and a recent study highlighted variations in T1DM incidence and prevalence among Arabs [8]. In Iraq, the prevalence of diabetes in primary school children in Baghdad was 159 per 100,000, higher than the 87 per 100,000 rate in Basrah [9]. The annual increase in T1DM cases, especially in children under 15, is about 3%, with an estimated 96,100 new cases yearly in 2017 [10]. The etiology of T1DM involves the autoimmune destruction of β -cells in 70-90% of patients, known as autoimmune T1DM or type 1a diabetes mellitus. A smaller subset has idiopathic T1DM (type 1b diabetes mellitus), where β -cell destruction is not linked to immune responses or autoantibodies and has a strong genetic component [11]. T1DM typically presents with symptoms such as polyuria, polydipsia, weight loss, and diabetic ketoacidosis (DKA) in children [12].

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T1DM complications vary geographically and ethnically. The youngest age groups (0-4 years) have the highest rates of DKA, with almost 30% in the USA [13]. DKA, a potentially life-threatening condition, is characterized by hyperglycemia, ketonaemia, and acidaemia due to decreased insulin and elevated counter-regulatory hormones [14]. The probability of DKA at diabetes onset varies significantly across countries [15]. Managing DKA imposes a significant economic burden on patients and families, particularly in developing countries [16]. Hypoglycemia, a common complication of insulin treatment, is determined by factors like glucose fall rate, hypoglycemia duration, and child's age, with safe blood glucose levels typically at 65-70 mg/dl (3.6-3.9mmol/L) [17]. Severe hypoglycemia can lead to unconsciousness, seizures, or death and often requires hospitalization [18]. Chronic diabetes complications include microvascular (nephropathy, neuropathy, retinopathy) and macrovascular issues (coronary heart disease, heart failure, cerebrovascular disease, peripheral artery disease, cognitive impairment) [19]. Caregiving for T1DM involves substantial physical, psychological, emotional, social, and financial burdens [20]. Primary caregivers, especially mothers, experience significant stress, anxiety, and depression [21]. In pediatrics, T1DM is considered a "family disease" due to the crucial role families play in treatment [22]. Parental involvement often disrupts daily family functioning and leads to feelings of shame, guilt, anxiety, and poor quality of life [23]. The management of T1DM is complex, involving diet regulation, exercise, insulin injections, and blood glucose monitoring [24]. The International Society for Pediatric and Adolescent Diabetes (ISPAD) guidelines emphasize maintaining HbA1c <7% and family-centered interventions to delay complications and promote health [25]. The rigorous care required can significantly burden caregivers, heavily influenced by community context and culture [26]. Studies have found that mothers experience more anxiety than fathers and feel overwhelmed by diabetes care demands, with perceived care burden linked to anxiety and depression [27].

Objectives of the Study: Identify the rate of burden on caregivers of T1DM patients at Children's Welfare Teaching Hospital in Baghdad, Iraq. Identify the types of burden experienced by caregivers. Assess the severity of burden using the Zarit Burden Questionnaire. Determine the impact of socio-demographic and clinical characteristics of children with T1DM on caregiver burden.

Method

A cross-sectional study was conducted from March 2023 to July 2023 at the Endocrinology consultation clinic at Children's Welfare Teaching Hospital, Baghdad, Iraq, Medical City, Directorate of Health. The study included a sample of 300 caregivers of children diagnosed with Type 1 Diabetes Mellitus (T1DM) aged ≤15 years, who attended the clinic during the data collection period. Caregivers aged 18+ years with at least six months of caregiving and willing to participate were included. Children with severe diseases that impeded parental questionnaire response were excluded. Data were collected via a questionnaire divided into three parts: socio-demographic data of children and caregivers, the child's diabetes history, and the Zarit Burden questionnaire. The socio-demographic section included

questions on caregiver identity (father, mother, others), parental age groups (<25, 25–29, 30–34, 35–39, and ≥ 40 years), education level (illiterate, primary, secondary, higher education), employment status (employed, unemployed), number of children (1–2, 3–4, ≥5), monthly income (<500, 500–1 million, >1 million Iraqi dinars), and treatment costs. Questions included child's age (≤5, 6–10, 11–15 years), sex, BMI percentile (underweight, normal, overweight, obesity), age at diabetes diagnosis (<5, 5–9, ≥10 years), duration since diagnosis (<3, 3–5, >5 years), DKA incidents, DKA-related hospital admissions (1–3, 4–6, ≥7 times), comorbidities, follow-up visit frequency (monthly, every 3 months, every 6 months), blood glucose control (controlled, uncontrolled), insulin administration (child or caregiver), insulin injection difficulty, and number of meals/snacks (3, 6, or 8). The Zarit Burden Interview (ZBI) developed by Zarit et al. (1980) and validated in Arabic was used to assess caregiver burden [66-69]. The ZBI includes 22 items across five domains: burden on the relationship, loss of control over life, finance, social and family life, and emotional well-being, rated on a 4-point Likert scale from 0 (never) to 4 (always). Scores range from 0-88, categorized as no to mild burden (0-20), mild to moderate burden (21-40), moderate to severe burden (41-60), and severe burden (≥61) [28]. A pilot study was conducted with ten caregivers to evaluate the questionnaire's clarity, understanding, and completion time, which was about 15-20 minutes. Ethical approval was obtained from the Iraqi Council of Medical Specializations/Family Medicine, and administrative approval from the Children's Welfare Teaching Hospital, Baghdad, Iraq. Participants were informed of the study's aim, and confidentiality was ensured. Statistical Analysis: Data were analyzed using SPSS-25. Results were presented as frequencies, percentages, means, standard deviations, and ranges. Differences in percentages were tested using Pearson Chi-square, Yate's correction, or Fisher Exact test where applicable. Logistic regression adjusted for factors associated with caregiver burden, with statistical significance set at $P \leq 0.05$.

Results

This study included 300 caregivers of children with type 1 diabetes. Of the 300 participant caregivers, 292 (97.3%) were the patient's mother, 3 (1%) were the patient's father, and 5 (1.7%) were the patient's relatives. The mean age of caregivers was 34.30 ± 5.82 years, with a range of (20 – 53) years. The highest proportion of caregivers, 96 (32%), were found in the age group of (30 – 34) years, followed by 85 (28.3%) who belonged to the age group of (35 – 39) years. About 90% (268) of mothers were housewives, and 142 (47.3%) had a secondary school level of education. The mean age of participants' husbands was 38.10 ± 6.30 years, and 127 (42.3%) were ≥40 years. Secondary school was the most common level of education attained by participants' husbands; 140 (46.6%) and 183 (61%) were unemployed. Monthly family income of (500,000- 1 million) Iraqi Dinars was reported by more than half of the participants 161 (53.7%). About two-thirds of participants, 197(65.7%), reported that they spent (150,000-250,000) Iraqi dinars/month on treatment of their children. As illustrated in (Table 1).

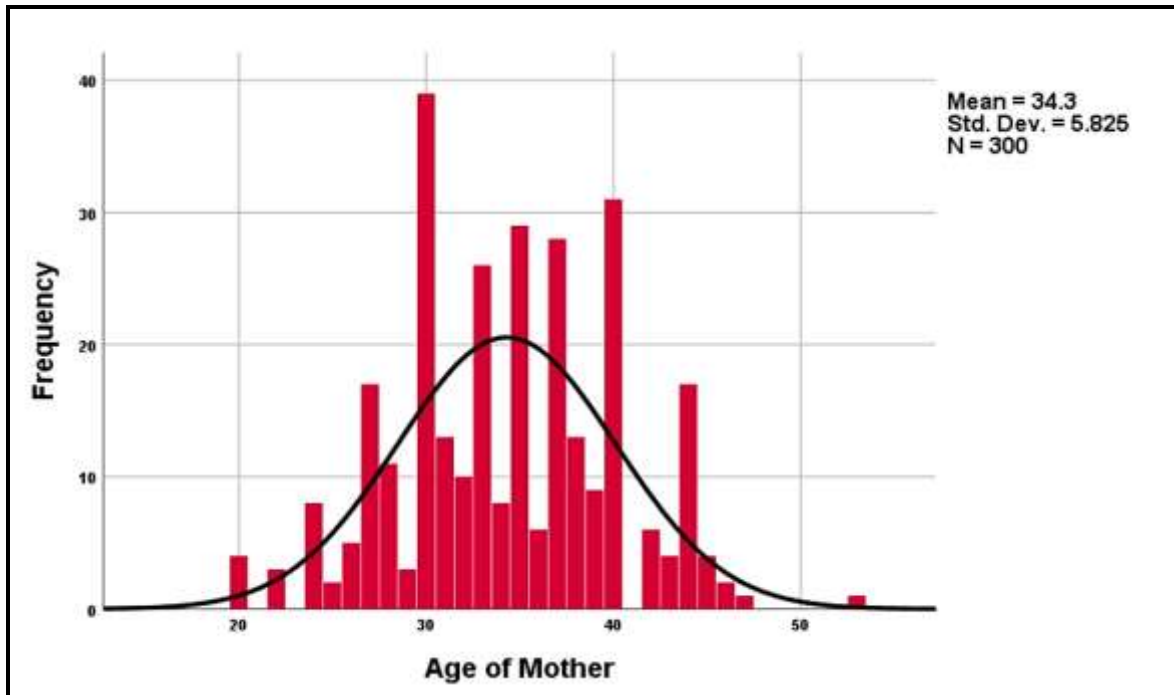


Fig 1: Distribution of the participant caregivers according to age.

Table 1: Socio-demographic characteristics of the studied caregivers

Participants' characteristics	No. (n= 300)	Percentage (%)
Mother Occupation		
Housewives	268	89.3
Employed	32	10.7
Mother Education		
Primary School	108	36.0
Secondary School	142	47.3
Higher Education	50	16.7
Father Age (Years)		
< 25	2	0.7
25 – 29	25	8.3
30 – 34	53	17.7
35 – 39	93	31.0
≥ 40	127	42.3
Father Occupation		
Employed	117	39.0
Unemployed	183	61.0
Father Education		
Illiterate	2	0.7
Primary School	110	36.7
Secondary School	140	46.6
Higher Education	48	16.0
Number of Children		
1 – 2	86	28.7
3 – 4	149	49.7
≥ 5	65	21.6
Monthly family Income (Iraqi Dinar)		
< 500	91	30.3
500 – 1 million	161	53.7
> Million	48	16.0

The study involved 300 children with Type 1 Diabetes Mellitus, with a mean age of 8.81 ± 3.47 years. Most children (45%) were aged 6-10 years. Gender distribution was nearly equal, with 147 males (49%) and 153 females (51%). Half of the children had a normal BMI. The age at diagnosis ranged from 1 to 13 years, with 47.3% diagnosed between 5-9 years. The disease duration was mostly ≥ 5 years (84.3%). All children required hospitalization, with

half needing 1-3 admissions. Diabetic ketoacidosis occurred in 77.7% of children, with 37.7% hospitalized ≤ 3 times. Comorbidities were present in 38.3% of children. Monthly doctor visits were reported by 58.3% of participants, and 75.7% had uncontrolled diabetes. Insulin was administered by caregivers in 74.3% of cases, with 56% reporting difficulty. Most children (64.7%) had six meals per day. As in table 2.

Table 2: Socio-demographic and clinical characteristics of the studied children.

Children's characteristics	No. (n= 300)	Percentage (%)
Age (Years)		
≤ 5	50	16.7
6 – 10	135	45.0
≥ 11	115	38.3
Gender		
Male	147	49.0
Female	153	51.0
BMI (Percentile)		
Underweight (< 5 th)	22	7.3
Normal (5 – 84 th)	150	50.0
Overweight (85 – 94 th)	91	30.4
Obesity (≥ 95 th)	37	12.3
Age At Diagnosis (Years)		
< 5	117	39.0
5 – 9	142	47.3
≥ 10	41	13.7
Duration of Diabetes (Years)		
< 3	133	44.3
3 – 5	120	40.0
> 5	47	15.7
Diabetic Ketoacidosis (DKA)		
Yes	233	77.7
No	67	22.3
Frequency of Admission due to DKA n= 233		
1 – 3	88	37.7
4 – 6	68	29.2
≥ 7	77	33.1
Comorbidity		
Yes	115	38.3
No	185	61.7
Follow-up Visit		
Monthly	175	58.3
Every 3 Months	99	33.0
Every 6 Months	26	9.7
Control of Diabetes		
Controlled	73	24.3
Uncontrolled	227	75.7
Insulin injection by		
Child	77	25.7
Caregivers	223	74.3
Difficulty of insulin injection		
Yes	168	56.0
No	132	44.0
Number of Meals and snack		
3	64	21.3
6	194	64.7
8	42	14.0

According to the caregivers' responses to the Zarit burden questionnaire, caregiver burden was found in all participants; 14 (4.7%) had mild burden, 127 (42.3%) had moderate burden, and 159 (53%) had severe burden (Figure 2). Since the number of mild ones is small, we classified the caregiver burden into mild/moderate into a group and the severe burden into another group. This study found a statistically significant association between the caregiver burden and the mother's age, occupation, education, father's education, and monthly family income. The rates of severe caregiver burden were significantly higher in mothers aged 30 – 34 years (39%, P = 0.031), housewife mothers (96.2%, P = 0.001), low-educated mothers (47.2%), low-educated fathers (46.5%), and caregivers with a monthly family income of <500.000 Iraq Dinars (44%, P =0.001). Other variables showed no significant association ($p \geq 0.05$) with caregiver burden score. As shown in (Table 3).

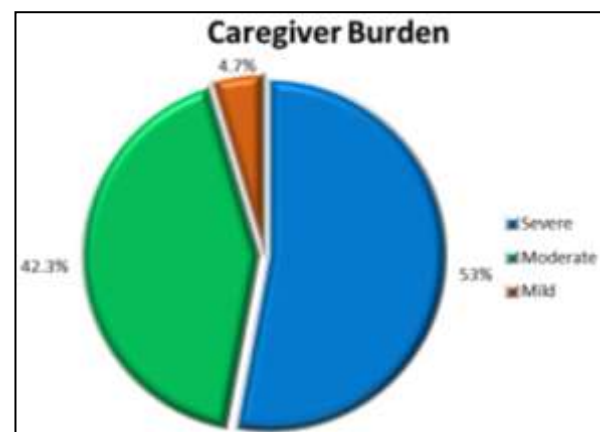


Fig 2: Distribution of the participant caregivers' burden based on the score of the Zarit scale.

Table 3: Distribution of the participant caregivers' burden by socio-demographic characteristics

Participants characteristics	Caregiver Burden		P- Value
	Mild / Moderate (%) n= 141	Severe (%) n= 159	
Mother Age (Years)			
< 25	9 (6.4)	6 (3.8)	0.031
25 – 29	24 (17.0)	14 (8.8)	
30 – 34	34 (24.1)	62 (39.0)	
35 – 39	43 (30.5)	42 (26.4)	
≥ 40	31 (22.0)	35 (22.0)	
Mother Occupation			
Housewives	115 (81.6)	153 (96.2)	0.001
Employed	26 (18.4)	6 (3.8)	
Mother Education			
Primary School	33 (23.4)	75 (47.2)	0.001
Secondary School	69 (48.9)	73 (45.9)	
Higher Education	39 (27.7)	11 (6.9)	
Father Age			
< 25	17 (12.1)	10 (6.3)	0.053
25 – 29	17 (12.1)	36 (22.6)	
30 – 34	45 (31.9)	48 (30.2)	
35 – 39	62 (44.0)	65 (40.9)	
Father Occupation			
Employed	63 (44.7)	54 (34.0)	0.057
Unemployed	78 (55.3)	105 (66.0)	
Father Education			
Illiterate or Primary School	38 (27.0)	74 (46.5)	0.001
Secondary School	67 (47.5)	73 (45.9)	
Higher Education	36 (25.5)	12 (7.6)	
Number of Children			
1 – 2	42 (29.8)	44 (27.7)	0.762
3 – 4	71 (50.4)	78 (49.1)	
≥ 5	28 (19.8)	37 (23.2)	
Monthly family Income (Iraqi Dinar)			
< 500	21 (14.9)	70 (44.0)	0.001
500 – 1 million	93 (66.0)	68 (42.8)	
> Million	27 (19.1)	21 (13.2)	

In the present study, patients characteristics that significantly associated with severe caregivers' burden were: female sex (57.9%, $P = 0.012$), diagnosis of type 1 diabetes since <5 years (54.9%, $P = 0.030$), less than three years duration of disease (48.4%, $P = 0.007$), having DKA (90.6%, $P = 0.001$) and \geq seven admission to the hospital due to DKA (45.1%, $P = 0.001$), comorbidities (52.2%, $P = 0.001$), monthly doctor visits (58.6%, $P = 0.006$), uncontrolled diabetes (93.8%, $P = 0.001$), insulin injection by caregivers (81.8%, $P = 0.002$), difficulty of administration of the insulin (69.2%, $P = 0.001$), and having

six meals (70.4%, $P = 0.003$). The age of the child was not significantly associated with the caregiver burden. As illustrated in (Table 4).

Using logistic regression analysis of the factors associated with the severe caregiver burden, seven factors were found to be the statistically significant determinants of caregiver burden. These factors were the mother's age, mother's education, DKA, comorbidity, frequent doctor visits, uncontrolled diabetes, difficulty with insulin administration, and frequent meals. As illustrated in (Table 5).

Table 4: Distribution of the studied sample by caregivers' burden and children's sociodemographic and clinical characteristics

Children characteristics	Caregiver Burden		P- Value
	Mild / Moderate (%) n= 141	Severe (%) n= 159	
Age (Years)			
≤ 5	17 (12.1)	33 (20.8)	0.115
6 – 10	65 (46.1)	70 (44.0)	
≥ 11	59 (41.8)	56 (35.2)	
Gender			
Male	80 (56.7)	67 (42.1)	0.012
Female	61 (43.3)	92 (57.9)	
BMI (Percentile)			
Underweight (< 5 th)	14 (9.9)	8 (5.0)	0.216
Normal (5 – 84 th)	63 (44.7)	87 (54.7)	
Overweight (85 – 94 th)	46 (32.6)	45 (28.4)	
Obesity (≥ 95 th)	18 (12.8)	19 (11.9)	
Age At Diagnosis (Years)			
< 5	44 (31.2)	73 (45.9)	0.030
5 – 9	74 (52.5)	68 (42.8)	
≥ 10	23 (16.3)	18 (11.3)	
Duration of Diabetes (Years)			
< 3	56 (39.7)	77 (48.4)	0.007
3 – 5	69 (48.9)	51 (32.1)	
> 5	16 (11.3)	31 (19.5)	
Diabetic Ketoacidosis (DKA)			
Yes	89 (63.1)	144 (90.6)	0.001
No	52 (36.9)	15 (9.4)	
Frequency of Admission due to (DKA)			
1 – 3	44 (49.4)	44 (30.6)	0.001
4 – 6	32 (36.0)	35 (24.3)	
≥ 7	13 (14.6)	65 (45.1)	
Comorbidity			
Yes	32 (22.7)	83 (52.2)	0.001
No	109 (77.3)	76 (47.8)	
Follow-up Visit			
Monthly	66 (46.8)	109 (68.6)	0.006
Every 3 Months	59 (41.8)	40 (25.2)	
Every 6 Months	16 (11.4)	10 (6.2)	
Control of Diabetes			
Controlled	63 (44.7)	10 (6.2)	0.001
Uncontrolled	78 (55.3)	149 (93.8)	
Insulin injection by			
Child	48 (34.0)	29 (18.2)	0.002
Caregivers	93 (66.0)	130 (81.8)	
Difficulty of insulin injection			
Yes	58 (41.1)	110 (69.2)	0.001
No	83 (58.9)	49 (30.8)	
Number of Meals and snack			
3	42 (29.8)	22 (13.8)	0.003
6	82 (58.2)	112 (70.4)	
8	17 (12.0)	25 (15.8)	

Table 5: Logistic regression analysis of the factors associated with severe caregiver burden

Determinants of Caregiver Burden	Odds ratio	95% C.I.		P - Value
		lower	Upper	
Age of Mother	2.038	1.427	2.913	0.001
Education of Mother	1.848	1.066	3.205	0.029
DKA	2.361	1.214	3.982	0.001
Comorbidity	2.032	1.026	4.016	0.042
Frequent Doctor visit	1.631	1.023	2.597	0.039
Uncontrolled Diabetes	9.861	3.814	21.499	0.001
Difficulty of Insulin Administration	2.785	1.314	5.882	0.007
Frequent Meals	1.993	1.018	3.899	0.044

Discussion

Diabetes in children significantly impacts every aspect of life, requiring continuous monitoring and regulation of blood glucose levels, dietary adjustments, and activity management. This study aimed to assess the burden on caregivers of children with Type 1 Diabetes Mellitus (T1DM) at Children's Welfare Teaching Hospital in Baghdad, Iraq, revealing that most caregivers were mothers who experienced a severe burden (53%). A recent study in Turkey reported that 68.9% of mothers of children with T1DM had a moderate burden [28]. Similarly, a study in Iran indicated that parents of diabetic children experienced a high level of burden [29]. The current study found that severe caregiver burden was significantly higher in mothers aged 30–34 years (39%), likely due to the added responsibilities of childbearing and caring for other young children. In contrast, a Turkish study found no significant correlation between caregiver age and burden [28]. Housewife mothers also showed a significant association with caregiver burden (96.2%), consistent with studies in Poland and India [30], as unemployment increases the impact of care and reduces financial and community resources, exacerbating the burden on parents with diabetic children. Low-educated mothers (47.2%) and fathers (46.5%) were significantly associated with caregiver burden, echoing findings from Poland where less educated women felt more burdened by their diabetic children [30]. Higher education levels in parents can improve metabolic control and meal planning in children with T1DM, highlighting the importance of family-centered care training for adolescents with low-educated parents to prevent complications and promote optimal metabolic control [31]. Family income was also a significant factor, with caregivers from families earning less than 500,000 Iraqi dinars per month (44%) experiencing higher burdens. This aligns with research from North India [32], which found that chronic illnesses impose significant financial strains due to the need for long-term care, monitoring, and follow-up [33]. T1DM's economic burden on patients, healthcare systems, and society is significant due to lifelong insulin therapy, high hospitalization risks, and childcare expenses [34]. The study also showed that female children were significantly associated with higher caregiver burden (57.9%), contrasting with studies in Mexico and Turkey that found no association [35]. Gender disparities in clinical outcomes like glycemic control, BMI, insulin dose, and quality of life suggest a less favorable clinical profile for female adolescents [36]. Additionally, the age at diagnosis (<5 years) was significantly associated with caregiver burden (54.9%) due to the complexity of managing T1DM in younger children, requiring continuous monitoring and frequent insulin administration. Diabetic ketoacidosis (DKA) was a significant factor, with 90.6% of children experiencing DKA and 45.1% having \geq seven hospital admissions due to DKA, indicating a higher burden on caregivers. This is consistent with research showing that DKA requires urgent medical care, frequent hospitalizations, and is more common in children with T1DM [37]. Chronic cognitive problems and poor glycemic outcomes are closely linked to DKA [38]. Comorbidities (52.2%) were also significantly associated with caregiver burden, consistent with a study in Turkey [28], as additional diseases increase the effort and financial costs for parents. The frequency of doctor visits (58.6%) was another significant factor, with families making frequent checkups

to control blood sugar, adding to the caregiver's burden, similar to findings in Sweden [39]. Poorly controlled diabetes (93.8%) was significantly associated with caregiver burden, consistent with a Turkish study [40], as managing hypoglycemia and hyperglycemia requires numerous daily insulin injections, challenging for parents and increasing their burden. The study found significant associations between caregiver-administered insulin injections (81.8%), difficulty in insulin administration (69.2%), and caregiver burden. Consistent with a Turkish study, children's fear and resistance to insulin injections pressure parents, increasing their burden [28].

Conclusion

Most of the caregivers of children with T1DM have a severe burden. Mother's age and education, having DKA, comorbidity, frequent doctor visits, uncontrolled diabetes, difficulty with insulin administration, and frequent meals were the significant unconfounded variables affecting the severity of the burden.

Conflict of Interest

Not available

Financial Support

Not available

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