

Unravelling the Struggles and the Multifaceted Challenges among the Caregivers of Type 1 Diabetes Children in a Tertiary Care Hospital

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Abstract:

Background: Type 1 diabetes mellitus imposes significant challenges for both diagnosed children and their caregivers worldwide, affecting their well-being and family dynamics. This study aims to explore the experiences of caregivers managing Type 1 diabetes in pediatric patients.

Methods: The study was conducted at St. John's Medical College Hospital in Bangalore over 12 months (August 2019 to August 2020).

Our mixed-methods approach integrates qualitative and quantitative techniques. In-depth interviews with caregivers of children aged 1-18 diagnosed with Type 1 diabetes uncover unique challenges and coping strategies. Additionally, a modified questionnaire is administered to 80 caregivers, assessing knowledge, attitudes, and practices related to pediatric diabetes.

Results: The diverse study cohort (n=80) spans ages 1 to 18, with 82% falling in the 6-15 age range. Gender distribution includes 37 males and 43 females, and residence comprises 41 from rural and 39 from urban areas. Caregivers exhibit varied educational backgrounds, adding richness to the demographic snapshot. Quantitative analysis of the questionnaire offers insights into caregivers' knowledge, attitudes, and practices regarding Type 1 diabetes management. Qualitative analysis of in-depth interviews uncovers nuanced challenges and coping strategies, enriching our understanding of the caregiving experience.

Conclusion: This comprehensive study contributes vital insights into pediatric diabetes care, emphasizing the need for tailored support and education for caregivers. The mixed-methods approach provides a holistic understanding of caregiver perspectives, laying the foundation for targeted interventions that enhance caregiver competence and well-being. Improving the support system for caregivers is crucial for the holistic management of Type 1 diabetes in pediatric patients.

Keywords: Type 1 diabetes mellitus, Caregiver burden, challenges, experiences.

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Introduction

Children diagnosed with type 1 diabetes mellitus (T1DM) require homecare assistance from their caregiver. Individuals should be provided with therapy and thorough psychological assistance during their developmental stage. Elevated blood glucose levels that deviate from the norm are a characteristic feature of T1DM, a persistent medical illness [1]. According to projections made by the World Health Organization, 366 million children globally are expected to develop type 1 diabetes by 2030, affecting about one million children by the year 2020 [2]. It is challenging for caregivers to manage and treat children with type 1 diabetes when they lack specialized training. According to a study by [3], parenting children with T1DM presents

difficulties for caregivers in the majority of developing nations. Among these problems include limiting the children's physical activity, creating and adhering to a balanced meal plan, and regularly checking their blood sugar levels. [4]

As mentioned in [5], caregivers experience a tremendous deal of discomfort when caring for a kid with T1DM at home. These include temperament issues and stubborn children who, despite being warned against it, may be persuaded by their companions to immediately consume things that are banned. Unfortunately, this behaviour usually has a negative effect on their health and education. [6] High blood sugar can cause diabetic ketoacidosis (DKA), which impairs a child's ability to learn and

necessitates hospitalization. However, [7] emphasizes the importance of behavioural support and education, which can assist by giving parents the knowledge and skills necessary to handle any challenges they may encounter when caring for their T1DM children. Apart from that, people could struggle with nutrition, consistent exercise, lifestyle modifications, and following a daily drug schedule. [8]

The Middle East and North Africa have the highest rate of diabetes globally, with a frequency of 10.9%. Between 2005 and 2011, the percentage of adult Iranians with diabetes rose by 35% to 11.37% [9]. Polyuria, polydipsia, weight loss, and diabetic ketoacidosis are characteristics of children with type 1 diabetes [10, 11]. This type of diabetes primarily affects children and teenagers [12]. When parents learn that their kid has diabetes, they often experience severe anxiety. In addition to a rigorous and intricate treatment plan, caregivers, particularly mothers, must offer round-the-clock care and supervision [13]. The mother, who is the primary caregiver, can find this demanding care regimen too much to handle, particularly if it aggravates the already negative effects of diabetes on relationships within the family. The environment and traditions of the population being cared for have a major impact on the complex idea of caregiver burden [14, 15].

Materials and Methods

Study design: This cross-sectional observational study was conducted in the Department of Paediatrics (Paediatric endocrinology clinic) and Endocrinology at St. John's Medical College Hospital in Bangalore. While well-established and validated questionnaires such as Michigan's Diabetes Knowledge Scale exist for type 2 diabetes, there is a notable absence of specific, validated questionnaires tailored for type 1 diabetes, except for a study from SG PGI that has a validated questionnaire on knowledge. Previous paediatric studies often employed questions drawn from adult questionnaires. In our study, we aimed to address this gap by incorporating questions from both adult questionnaires and those available for paediatric populations.

Study design: A cross sectional clinical study

Place of study-Paediatric inpatient and outpatient department and Paediatric endocrinology clinic at St. John's Medical College and Hospital, Bangalore.

Sample size: 80

Inclusion Criteria: Children (1-18 years) diagnosed with Type 1 Diabetes mellitus.

Exclusion Criteria: Secondary causes of diabetic mellitus like a chronic recurrent pancreatic disease/Drug-induced (steroid induced).

Statistical Analysis: The statistical analysis encompassed a cohort of 80 caregivers participating in the study at St. John's Medical College Hospital, focusing on Type 1 diabetes in children aged 1-18. Using a modified questionnaire with domains for Knowledge, Attitude, and Practice, mean scores and standard deviations were calculated to quantify caregivers' perspectives. T-tests or non-parametric tests were employed for comparative analysis, revealing potential variations based on education level, rural/urban residence, and gender. Correlation analysis explored interrelationships between knowledge, attitudes, and practices. If applicable, factor analysis was performed to identify underlying structures within the questionnaire. This robust statistical approach provided a quantitative foundation, complementing the qualitative insights, to comprehensively understand caregivers' perspectives on managing Type 1 diabetes in the paediatric context.

Ethical Approval: The approval for the study was obtained from the Institutional Ethical Committee and a written informed consent was taken from the caretakers prior to the interview.

Results

The age distribution in the study cohort spans 1 to 18 years, with 9 participants aged 1-5, 33 aged 6-10, 33 aged 11-15, and 5 aged 16-18. Notably, 82% of the participants fall within the age range of 6-15 years. The overall mean age is 10.36 years, with a standard deviation of 3.73. This diverse age distribution, emphasizing a significant proportion in the 6-15 age groups, showcases the inclusion of a broad spectrum of paediatric participants in the study, as listed in Table 1.

Table 1: Age distribution of Children studied

Age in years	No. of Children	%
1-5	9	11.25
6-10	33	41.25
11-15	33	41.25
16-18	5	6.25
Total	80	100

The gender distribution, illustrated in Figure 1, comprised 37 males and 43 females. In terms of residence, 41 participants were from rural areas, and 39 were from urban areas.

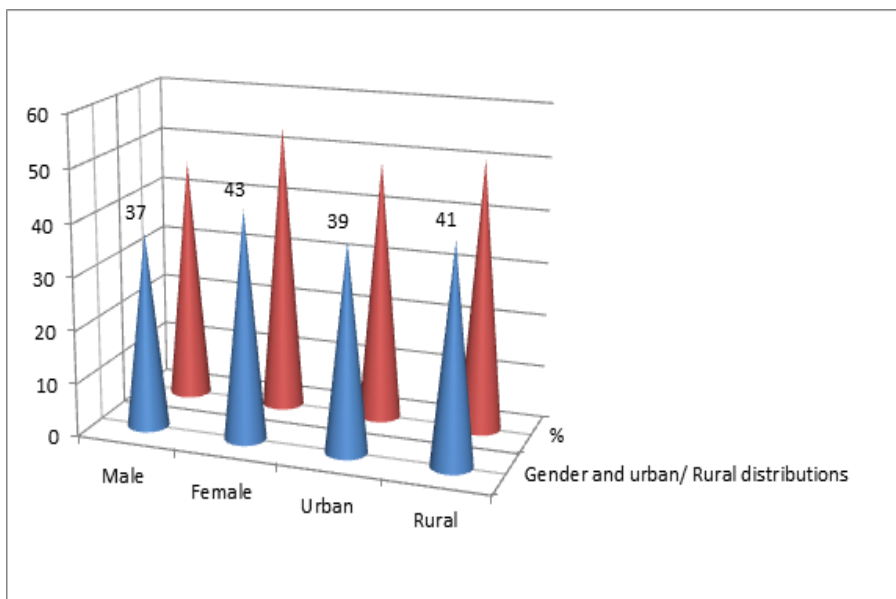


Figure 1: Gender and Urban / Rural distributions

The education of the caregivers of the children in the study varied, with 5 having completed primary school, 7 middle school, 31 high school and 13 with a pre-university education, 8 holding degrees, 9 completed a diploma, and 7 being graduates as discussed in Fig. 2. This diverse educational

background among the caregivers reflects a range of educational experiences within the study cohort. Understanding the educational status of the caregivers is essential for contextualizing the support and comprehension available to children with Type 1 Diabetes mellitus.

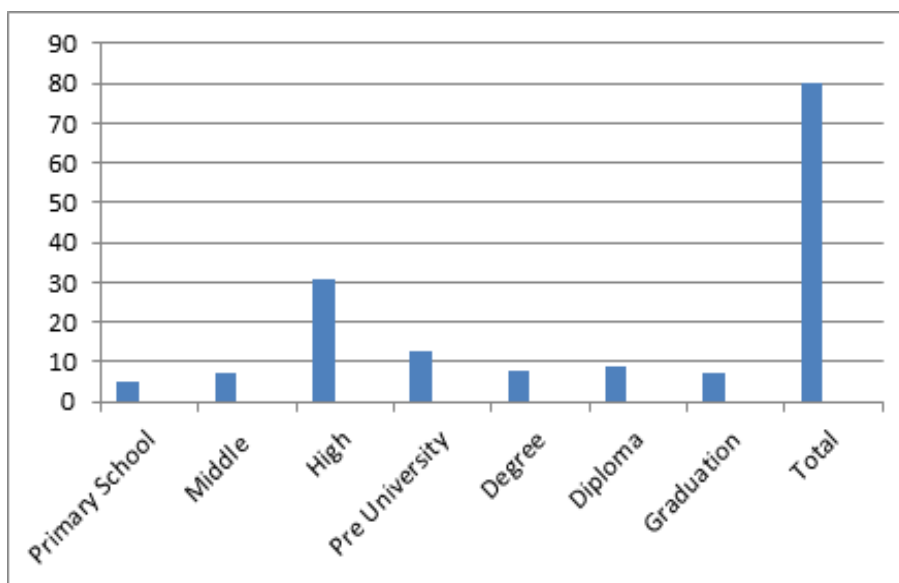


Figure 2: Education Status of caregiver of the children studied

In the study on caregivers of children with Type 1 Diabetes Mellitus, the distribution of responsibilities among various caregivers was examined. Among the caregivers, 61 were mothers, 8 were fathers, 9 represented the children themselves who took on the responsibility of self-care, and 2 were siblings. The inclusion of a group labelled "Self" indicates a notable aspect of the study, signifying the children with Type 1 Diabetes actively manage and care for

themselves. This finding suggests a level of independence and self-reliance among a segment of the study population. Further exploration of the role and challenges faced by each caregiver group, particularly the children engaged in self-care, could provide valuable insights into the dynamics of managing Type 1 Diabetes in a familial context, as illustrated in Fig. 3.

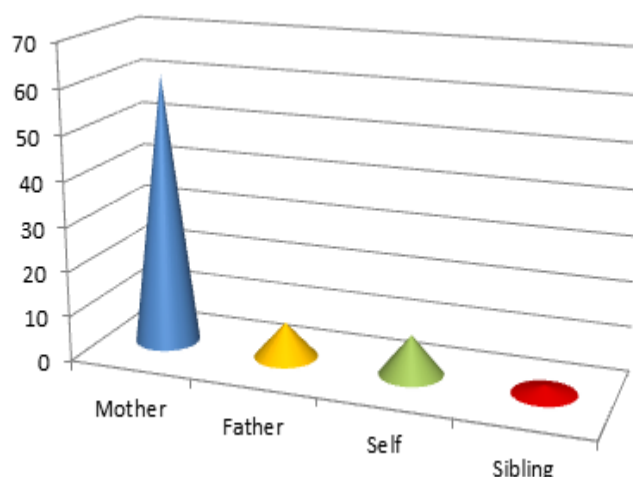


Figure 3: Caregivers of Children with Type 1 Diabetes

The study evaluates knowledge, practice, and attitude scores across age groups and socioeconomic statuses (SES) Fig.4 and Table. 1. For ages 1-5, participants exhibit high knowledge (88.88±11.11), moderate practice (75.16±14.03), and attitude (58.88±20.88) scores. In the 6-10 age group, knowledge decreases (73.40±20.21), while practice increases (78.60±12.46), and attitude remains moderate (71.51±16.41). Age's 11-15 show stable knowledge (73.06±19.84) and practice

(72.37±13.35) scores, with a notable increase in attitude (76.33±24.45). Participants aged 16-18 exhibit high knowledge (86.66±9.29) and practice (82.35±17.64) scores, with a moderate attitude (60.00±18.70). Overall, the cohort demonstrates moderate knowledge (75.83±19.34), practice (75.88±13.48), and attitude (66.00±20.90) scores. Socioeconomic status influences scores, with higher SES associated with elevated knowledge, practice, and attitude scores.

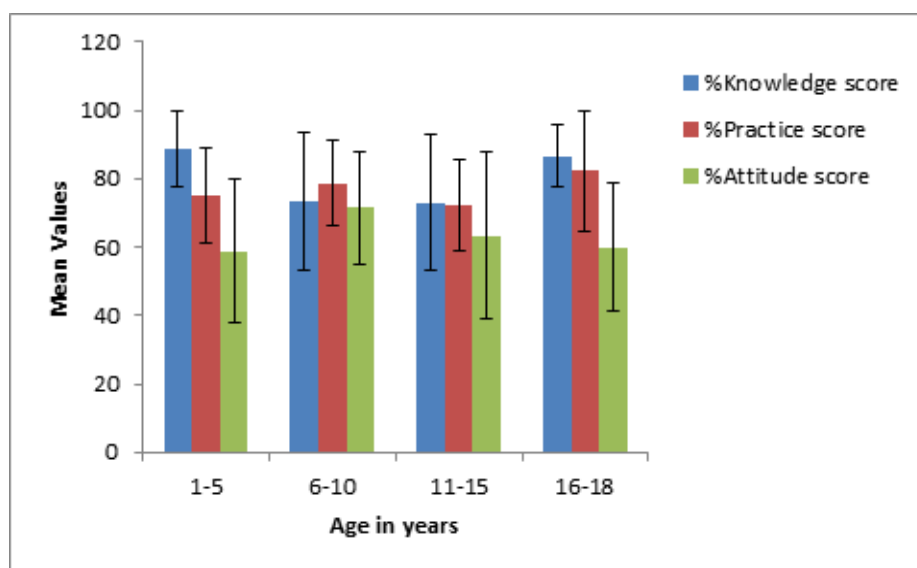


Figure 4: Knowledge score, Practice score and Attitude score according to age in years

Table 2: Comparison of Knowledge score, Practice score and Attitude score according to SES Category

SES	Knowledge score	Practice score	Attitude score
Upper	8.75±0.50	12.00±1.41	5.00±1.70
Upper Middle	8.09±0.83	13.04±2.35	7.33±3.11
Lower Middle	6.76±1.67	13.42±2.31	6.23±2.25
Upper Lower	6.26±1.72	13.10±2.42	6.73±1.59
Lower	5.33±1.39	12.06±2.43	5.86±1.64
Overall score	6.82±1.74	12.92±2.34	6.67±2.30
P Value	<0.001**	0.445	0.186

Discussion

Managing the needs of individuals with type 1 diabetes poses significant challenges, necessitating additional assistance. Caregivers can optimize their caregiving efforts by collaborating with healthcare professionals, fostering a more effective and comprehensive approach to address the unique demands of diabetes care [16]. However, caregivers who routinely attend check-up sessions may receive assistance in comprehending and gaining sufficient knowledge about how to care for ill children [17]. It appears that caretakers had no intention of responding at this time, as evidenced by the fact that they only got involved after a T1DM medical issue became obvious. There is little question that the secondary caregivers greatly influence the T1DM patients' worsening circumstances. In a perfect world, caregivers would frequently be aware that issues could worsen to the point that patients might require more medical care.

In our study involving 80 caregivers of children diagnosed with Type 1 Diabetes Mellitus, we found that the mean age of the type 1 diabetic children was 10.36 ± 3.73 years, with 82% falling within the age range of 6-15 years. Caregivers, predominantly mothers (76.26%), were from both rural (51.25%) and urban (48.75%) areas, with 55% having completed high school and pre-university college education. The age of initial presentation of illness was 7.48 ± 3.70 years, and 31.25% of children presented with Diabetic Ketoacidosis. About 60% required admission to critical care, with 61 children experiencing at least one readmission. While 97.5% had a diet plan, knowledge gaps existed regarding hypoglycemia symptoms and complications. [18, 19] Caregivers expressed positive attitudes toward their child's education, but almost 1/3 denied family support. Urban caregivers exhibited higher knowledge scores (80.34 ± 19.98 vs. 71.54 ± 17.92 , $p=0.041$), as did those with higher education and socio-economic status. However, as per our study, good knowledge did not necessarily translate to good attitude and practice. Approximately 12.5% of participants were children with diabetes involved in their care, suggesting the potential for self-care training, especially among older children and adolescents.

Diabetes, like other chronic illnesses, portends serious consequences for the whole family. Chronic illness, the need for insulin shots, and consequences that could be fatal or highly incapacitating can all significantly raise maternal anxiety. If you remember the previously mentioned elements, it will become simpler to comprehend why mothers go through periods of helplessness and crisis. The need for continuous care and concern over potentially negative effects contribute to the high expense of healthcare. T1D is one of the illnesses that require caretakers the most [20]. Numerous studies [21–23]

have shown that having a child with diabetes severely lowers a mother's quality of life. Severe sleep disturbances are reported by parents of diabetic children [24]. Our research also showed how the severe effects of diabetes on caregivers could trigger a family crisis. According to a study by Commissariat, Harrington [17], diabetes is associated with two types of suffering: the psychological toll that the disease puts on parents and their children and the difficulty of locating, screening, and putting the trust in reliable backup caregivers. Parents considered themselves to be their kids' pancreas. [25] Our research also revealed similar changes in how people seek out and maintain their health.

Conclusion

The present study underscores the imperative for enhanced knowledge and awareness among caregivers of children with diabetes mellitus. While attitudes and practices exhibited improvement compared to knowledge levels despite difference in education level, socio economic strata and the area of residence. However, certain specific areas demand focused attention. These include the necessity for regular daily monitoring of blood glucose levels, recognition of symptoms associated with hypoglycemia though the admissions related to hypoglycemia were minimal, reinforcement of avoidance of injection administration in the arms, and the active involvement of close family members beyond parents in the care of diabetic individuals. It is noteworthy that self-care by diabetic children was almost similar to the primary care takers and the need of the hour to train the children above 10 years of age in graded manner under the supervision of primary care taker thus enforce self-reliance among the children and reduce the stress burden among the primary caretakers as well.

Limitation

Validated questions from adult questionnaire modified to the pediatric population which was not validated itself Since it was a question based study, the recall by caregiver may be inaccurate. Study is from a small population, single centre and majority were from lower and middle socioeconomic strata

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