Original Article

Big Feelings in a Small Syringe: Exploring Parental Distress in Type 1 Diabetes and the Buffering Role of Child Life Specialists

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ABSTRACT

Background: Caring for a child or adolescent with Type 1 Diabetes (T1D) requires sustained emotional, relational, and behavioural involvement from parents and may lead to psychological distress. Although parental diabetes-related distress has gained increasing recognition globally, evidence from Indian paediatric care settings remains limited, where psychosocial services are not routinely integrated into diabetes management. A clearer understanding of the psychological dimensions of parental distress is essential for developing family-centred interventions. **Materials and methods:** This pilot cross-sectional exploratory study was conducted during a Diabetes Awareness Camp at Aster CMI Hospital, Bangalore. Thirteen parents (eight fathers and five mothers) of children and adolescents with T1D attending a multidisciplinary clinic participated. Parental distress was assessed using the Parent Diabetes Distress Scale (Parent-DDS), a validated psychological instrument evaluating four domains: Teen Management Distress, Parent–Teen Relationship Distress, Personal Distress, and Healthcare Team Distress. Data were analysed using descriptive and exploratory statistical methods. **Results:** Parents reported a moderate level of overall psychological distress (mean score = 2.60). Distress related to parent–teen interactions was the most prominent domain (mean = 2.73), indicating substantial relational strain associated with diabetes management. The Healthcare Team Distress domain demonstrated the greatest variability (SD = 1.09), reflecting differences in perceived quality of medical communication and support. Approximately 25% of participants had distress scores in the high range (≥ 3.20), indicating clinically meaningful emotional burden. Fathers tended to report higher distress levels than mothers across several domains; however, these differences were not statistically significant. **Conclusion:** A considerable proportion of parents of children with T1D experience elevated psychological distress, primarily influenced by relational challenges and perceptions of professional support rather than medical factors alone.

Key words: Type 1 diabetes, Parents, Stress, Psychological, Paediatrics

Type 1 diabetes mellitus (T1D) in childhood and adolescence requires continuous and complex daily management, including insulin therapy, regular blood glucose monitoring, dietary regulation, and adjustment of physical activity. Because children and adolescents are not fully capable of performing these tasks independently, parents assume primary responsibility for disease management and treatment-related decisions [1, 2]. The period following diagnosis has been associated with intense emotional responses among caregivers, including fear of hypoglycaemia, concerns about long-term complications, and uncertainty regarding the child's future health [3].

Over time, the persistent demands of vigilance and problem-solving contribute to psychological strain, which may manifest as anxiety, depressive symptoms, and diabetes-specific distress [4]. Parental distress has been shown to vary across the disease course, with higher levels reported during early diagnosis and during adolescence, when challenges related to autonomy, adherence, and risk-taking behaviours become more prominent [5].

Research indicates that parental distress differs by caregiver role and family context. Mothers often report greater emotional fatigue related to daily caregiving responsibilities, whereas fathers experience stress associated with responsibility for treatment decisions and perceived accountability for clinical outcomes [6]. Increased levels of parental distress have been linked to poorer glycaemic control, reduced adherence to prescribed regimens, and heightened family conflict, suggesting that psychosocial factors influence both parental wellbeing and child health outcomes [2, 7]. Difficulties in communication with healthcare providers and

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perceptions of inadequate professional support further contribute to caregiver burden [4, 8]. In the Indian healthcare context, these challenges may be intensified by variable access to structured psychosocial services, differences in health literacy, and constraints within healthcare delivery systems. Although advances in medical management of paediatric T1D have improved metabolic outcomes, psychosocial and family-focused interventions are not consistently incorporated into routine care in many tertiary centres [1, 9].

Parental distress can be quantified using validated instruments such as the Parent Diabetes Distress Scale (Parent-DDS), a standardised questionnaire developed to assess diabetes-related emotional strain among caregivers of young individuals with T1D, which assesses burden related to treatment management, parent–child relationships, personal emotional strain, and interactions with the healthcare team [8]. Child Life Specialists support children and families through developmentally appropriate education, facilitation of coping strategies, and family-centred interventions, and their involvement has been associated with improved treatment engagement and reduced caregiver burden in paediatric chronic illness settings [9,10].

However, empirical evidence describing parental distress and the role of Child Life Services in paediatric diabetes care in India remains limited [11]. The rationale of the present study was to generate preliminary evidence on diabetes-related parental distress in an Indian clinical setting. This pilot study aimed to assess levels and patterns of parental distress using the Parent-DDS. The objectives were to evaluate domain-specific distress, compare distress between mothers and fathers, and identify areas in which Child Life Specialist interventions may enhance psychosocial support within paediatric diabetes care.

MATERIALS AND METHODS

2.1. Study design and location

A cross-sectional observational study was undertaken during a Diabetes Awareness Camp conducted at Aster Hospital, Bengaluru, India. Information was gathered at a single time point during the camp as part of a service-focused evaluation conducted in a hospital setting.

2.2. Study participants

The study included 13 parents of children and adolescents diagnosed with T1D, comprising 8 fathers and 5 mothers. Participants were enrolled based on their availability and willingness to participate in the study while attending the camp with their children.

Parents were considered eligible if they were the main caregiver of a child or adolescent with a confirmed diagnosis of T1D and agreed to participate. Parents were not included if their child had a diagnosis other than T1D or if the questionnaire was returned with unanswered items. Written informed consent was obtained from all respondents before participation.

2.3. Measurement of parental distress

Parental distress was measured using the Parent-DDS. The tool evaluates four domains: stress related to daily disease management, difficulties in parent–child interactions, individual emotional burden, and distress associated with communication with healthcare professionals. These 4 domains are:

1. Teen Management Distress – distress related to the child's daily diabetes management tasks (e.g., glucose monitoring, insulin administration, dietary regulation).
2. Parent–Teen Relationship Distress – distress associated with conflict, tension, or difficulties in parent–adolescent interactions around diabetes care.
3. Personal Distress – emotional burden experienced by the parent, including feelings of worry, frustration, and exhaustion related to caregiving.
4. Healthcare Team Distress – distress related to communication with and support from healthcare professionals.

Each item is scored on a six-point Likert scale ranging from 1 = "Not a problem" to 6 = "A very serious problem." Higher scores indicate greater levels of diabetes-related distress. Domain scores are obtained by calculating the mean of the items within each domain. An overall distress score is calculated as the mean of all items (Table 1) [8].

Table 1. Parent-DDS Domain scores

No.	Scores	Interpretation
1	1.0–1.9	Low distress
2	2.0–2.9	Moderate distress
3	3.0–3.9	High distress
4	≥ 4.0	Very high distress

2.4. Data collection and ethical considerations

Questionnaires were administered in a single session during the camp. Participation was optional and did not influence the clinical care of the children. No personal identifiers were collected. The study procedures conformed to institutional ethical standards and internationally accepted principles for research involving human participants, including the Declaration of Helsinki [12]. Only de-identified data obtained from service evaluation activities were used for analysis.

2.5. Statistical analysis

Distress scores were summarised using descriptive statistical techniques [13]. Relationships between domain scores were examined using correlation coefficients [14]. Multiple linear regression analysis was applied to explore factors associated with overall parental distress [15]. Comparisons between mothers and fathers were performed using t-tests for independent samples, and the magnitude of group differences was estimated using effect size measures [16]. Participants

were further ordered according to total distress scores to identify caregivers who might benefit from additional psychosocial support.

RESULTS

A total of 13 parents completed the Parent-DDS during the camp-based data collection period. Data were obtained at a single time point, and no follow-up assessments were conducted. The findings are presented as exploratory and descriptive because of the small sample size.

3.1 Overall Pattern of Parental Distress

The overall pattern of parental distress, measured by the Parent-DDS Response scale, is shown in Table 2.

Table 2. Distribution of Parents by Overall Distress Category (N = 13)

Distress	Score Range	n (%)
Low distress	1.0–1.9	2 (15.4%)
Moderate distress	2.0–2.9	7 (53.8%)
High distress	3.0–3.9	4 (30.8%)
Very high distress	≥ 4.0	0 (0%)

Descriptive statistics for the four Parent-DDS domains and overall distress are shown in Table 3.

Table 3. Descriptive Statistics for Parent-DDS Domains (N = 13(8 fathers and 5 mothers))

Domain	Mean	SD	Min	Max
Teen Management Distress	2.62	0.65	1.50	3.75
Parent–Teen Distress	2.73	0.68	1.50	3.70
Healthcare Team Distress	2.63	1.09	1.00	4.00
Overall Distress	2.60	0.67	1.40	3.65

Note: 1.0–1.9 = Low; 2.0–2.9 = Moderate; 3.0–3.9 = High; 4.0–6.0 = Very high distress.

Across domains, parents reported distress levels largely within the moderate range. Among the domains, parent–teen relationship distress appeared relatively elevated, suggesting greater strain related to interpersonal dynamics. Healthcare team distress demonstrated the widest variability, indicating differing parental experiences with medical care.

Approximately one-quarter of parents scored in the high distress range on overall distress, highlighting heterogeneity within the sample and indicating that a subgroup of parents experienced substantial emotional burden.

3.2 Associations Among Distress Domains

Correlations among Parent-DDS domains and overall distress are presented in Table 4.

Table 4. Correlations Between Parent-DDS Domains and Overall Distress (N =13)

Domain	Teen Mgmt.	Parent–Teen	Personal	Healthcare	Overall
Teen Mgmt.	1.00	0.38	0.64	0.50	0.69
Parent–Teen	0.38	1.00	0.79	0.52	0.78
Personal Distress	0.64	0.79	1.00	0.85	0.91
Healthcare Team	0.50	0.52	0.85	1.00	0.86

All domains showed positive associations with overall distress. Stronger relationships were observed for personal distress and healthcare team distress, suggesting that emotional strain and healthcare-related challenges tended to co-occur in this sample. These associations are descriptive and should be interpreted cautiously due to the smaller sample size.

3.3 Exploratory Regression Analysis

A multiple regression procedure was used in an exploratory manner to examine how the distress domains related to overall parental distress (Table 5).

Table 5. Exploratory Multiple Regression Predicting Overall Distress: Standardised Beta Coefficients. (N = 13)

Domain	β
Healthcare Team Distress	0.64
Parent–Teen Distress	0.53
Teen Management Distress	0.33
Personal Distress	-0.26

In this small sample, scores reflecting healthcare team distress and parent–teen distress showed comparatively stronger associations with total distress, suggesting closer descriptive correspondence than other domains. Personal distress did not appear to contribute uniquely when all domains were considered together, which may indicate

conceptual overlap among measures. Because the sample size is limited, these observations are presented only as preliminary descriptive trends and should not be interpreted as predictive or generalizable findings.

3.4 Comparison by Parent Role

Mean distress scores by parent role (father vs. mother) are summarized in Table 6.

Table 6. Distress by Parent Role (N = 13)

Domain	Fathers (n=8) mean	Mothers(n=5) mean	Cohen's d
Teen Mngt. Distress	2.75	2.57	0.45
Parent-Teen distress	3.54	2.49	0.60
Personal distress	3.56	2.57	0.90
Healthcare Team Distress.	4.00	2.67	0.80

Fathers reported higher distress across most domains; however, the difference in overall distress between fathers and mothers was small and was not statistically meaningful. Effect size estimates suggested modest to large differences for some specific domains, indicating potential variation in how distress is experienced, though conclusions remain tentative given the limited sample.

3.5 High-Distress Subgroup

When participants were ordered by overall distress, four parents scored within the high distress range (≥ 3.20). This finding underscores the variability in parental experiences and suggests that while average distress was moderate, a subset of parents experienced notably elevated burden, indicating the potential need for targeted psychosocial support.

DISCUSSION

This exploratory study examined diabetes-related distress among parents of adolescents with T1D in an Indian clinical setting. Overall, parental distress was largely moderate, with parent–teen relationship distress emerging as the most prominent domain, suggesting strain in family interactions surrounding disease management. Distress associated with healthcare engagement showed substantial variability, indicating differences in perceived communication and support.

Fathers reported somewhat higher distress across several domains, and a subgroup of parents demonstrated elevated distress, highlighting heterogeneity in caregiver experiences. Tailored interventions that acknowledge gender-specific stressors may enhance uptake and effectiveness of psychosocial services. Targeted engagement strategies that include parents in educational sessions and counselling interventions can help in reducing stress, particularly in India, where caregiving roles are often assumed primarily by mothers.

The prominence of relational distress aligns with previous studies identifying adolescence as a period of increased family tension in chronic disease management, including diabetes, where autonomy development and negotiation of responsibility of the teenager may increase the caregiver strain [5, 7]. Evidence suggests that communication challenges between parents and adolescents are closely associated with emotional burden, supporting family systems perspectives that consider chronic illness as a shared stressor requiring adjustments [2, 6]. Variability in healthcare-related distress observed in this study is consistent with the studies demonstrating that clarity of communication and continuity of care influence caregiver confidence and stress levels [1, 4].

Child Life Specialists can address relational strain by providing brief, structured interventions that focus on shared problem-solving around treatment tasks, negotiation of responsibilities, and the gradual transfer of disease management roles to adolescents in a developmentally appropriate manner [9, 10]. In addition, psychologists and Child Life Specialists may assist families in navigating clinical interactions by clarifying treatment plans, preparing parents and adolescents for consultations, and facilitating bidirectional communication with medical teams to reduce misunderstanding and anxiety [1,4]. This improves parental confidence and enhances adherence to care plans.

Programme leaders should integrate psychosocial roles within multidisciplinary diabetes teams through clearly defined referral pathways, consultation time, and collaborative case discussions involving medical and psychosocial staff [1,2]. Training programmes for paediatric diabetes professionals should incorporate basic competencies in family communication and distress recognition to strengthen early support.

Differences in emotional burden across various studies reflect the influence of surrounding conditions, such as cultural expectations, caregiving norms, and access to psychosocial resources. In India, these factors are further modified by sociocultural values emphasising parental duty, academic performance, and long-term security, which intensify anxiety about disease outcomes. Limited availability of integrated psychosocial services within routine diabetes care may also increase reliance on families to manage emotional and practical challenges independently. Routine screening of parental distress during outpatient visits may enable early identification of families requiring additional psychosocial support [1, 8].

Brief screening tools could be administered alongside clinical assessments to normalise discussion of emotional burden and reduce stigma associated with psychological help. For parents with persistently elevated distress, stepped-care approaches may be appropriate, beginning with psychoeducation on coping strategies and progressing to

structured family-based counselling when relational conflict or emotional overload is evident [6, 8].

The present study contributes preliminary evidence from a clinical setting and reinforces the importance of psychosocial dimensions in paediatric diabetes care. Interpretation of the findings is constrained by the small sample size and cross-sectional design, which limit generalisability and preclude examination of distress over time.

The absence of child-reported outcomes and the limited assessment of broader surrounding factors, such as socioeconomic status and healthcare access, are the other limitations.

Future studies should examine whether the role-specific interventions reduce parental distress, improve family functioning, and contribute to better treatment adherence and metabolic outcomes over time. Longitudinal studies with larger and more diverse samples, incorporating parent, child, and clinician perspectives, are required to clarify changes in parental distress and to determine how relational and healthcare-related stressors influence adolescent health outcomes over time [1,11].

Policy initiatives where trained Child Life Specialists and other psychosocial professionals can be accessed within paediatric diabetes services improve continuity of care and address gaps between medical and emotional support needs [9, 11]. Investment in integrated care models could strengthen long-term outcomes for children and adolescents with T1D and their families.

CONCLUSION

This study indicates that parents of adolescents with T1D experience predominantly moderate diabetes-related distress, with relational and healthcare-related challenges emerging as prominent contributors. Gender differences were small, while fathers showed elevated distress, underscoring heterogeneity in parental experience. These findings support the relevance of routine parental distress screening and the integration of psychosocial support within paediatric diabetes care in Indian clinical settings.

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