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Quality Of Life In Children With Type 1 Diabetes: Family And Health Care Professionals' Perspectives.

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ABSTRACT

Background: Type 1 diabetes mellitus (T1DM) is a chronic condition that affects children's physical, emotional, and social well-being. Understanding quality of life (QoL) from both family and health care professionals' perspectives is essential for holistic management.

Objective: To evaluate the QoL of children with T1DM aged 5–18 years, as perceived by parents and nurses, and to identify areas of agreement and divergence between these perspectives.

Methods: A cross-sectional descriptive study was conducted involving 24 children with T1DM. Parents completed a 15-item Likert-scale questionnaire covering five domains: physical well-being, emotional well-being, social functioning, family impact, and health care support. Additionally, 100 nurses working in pediatric diabetes care completed the same questionnaire based on their professional observations. Data were analyzed using descriptive statistics, domain averages, and comparative visualizations (bar charts, pie charts, line plots, box plots, and scatter plots).

Results:

- Parents reported higher emotional distress and social limitations compared to nurses.
- Nurses emphasized medical adherence and resilience, particularly in older children.
- Both groups acknowledged family stress and the importance of health care support.

Conclusion: Parents and nurses perceive QoL in children with T1DM differently, with families emphasizing emotional and social burdens and nurses focusing on medical management and resilience. Integrating both perspectives is critical for comprehensive care. Future studies should include children's self-reports and larger samples to strengthen findings..

Keywords: *Type 1 diabetes, children, quality of life, parents, nurses, Likert questionnaire, psychosocial impact*

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1. INTRODUCTION

Type 1 diabetes mellitus is one of the most common chronic illnesses in childhood, requiring lifelong insulin therapy, dietary regulation, and continuous monitoring. Beyond medical management, the disease affects psychosocial functioning, family dynamics, and overall quality of life.

Parents often witness the daily struggles of their children, while nurses provide professional insights into disease management and psychosocial support. Understanding both perspectives is crucial for designing interventions that improve QoL outcomes.

1. OBJECTIVES:

To assess the quality of life in children with T1DM from the perspectives of families and health care professionals

To identify areas of convergence and divergence in their perceptions.

2. METHODS

Study Design

- **Type:** Cross-sectional descriptive study
- **Participants:**
    - 24 children with T1DM (aged 5–18 years)
    - Parents of these children (primary respondents for family perspective)

Setting: : Four tertiary-level hospitals and one nursing college in India ((National Institute of Medical Sciences Jaipur 303121, Jaipur, Rajasthan, India; Government Institute of Medical Sciences, Gautam Buddha Nagar 201310, Uttar Pradesh, India; Fortis Hospital, Malviya Nagar, Jaipur 302017, Rajasthan, India; Rajasthan College of Nursing, Bagru, Jaipur, Rajasthan).

Duration: June – September 2025

Sample Size: 124 participants

Inclusion Criteria

- Participants enrolled as MBBS, dental, nursing students, or paramedical staff in the selected four hospitals.
- Individuals who were willing to participate and provided informed consent.
- Respondents who had basic knowledge or exposure to pediatric diabetes care through their curriculum or clinical postings.
- Families of children with Type 1 Diabetes who were available and willing to share perspectives.
- Age group: ≥18 years for healthcare students/staff; parents/guardians of children with Type 1 Diabetes.

Exclusion Criteria

- Healthcare professionals or students not affiliated with the selected hospitals.
- Participants who declined consent or were unwilling to complete the questionnaire.
- Families of children with other types of diabetes (Type 2, MODY, secondary diabetes).
- Children or family members with serious comorbid conditions that could confound quality of life assessment.
- Incomplete or invalid questionnaires (e.g., missing responses on the Likert scale).

Ethical considerations: Permission from respective Institutional ethics committees was not deemed necessary for this study.

Instrument: A validated 15 item, 5-point Likert-scale questionnaire (Strongly Agree to Strongly Disagree).

- Domains assessed:
    - Physical well-being (energy, symptoms, treatment burden)
    - Emotional well-being (anxiety, mood, self-esteem)
    - Social functioning (peer relationships, school participation)
    - Family impact (stress, financial burden, caregiving challenges)
    - Health care support (accessibility, communication, trust in professionals) experiences.
- Instructions: Please rate each statement on a scale from 1 to 5. 1 = Strongly disagree; 2 = Disagree; 3 = Neutral; 4 = Agree; 5 = Strongly agree

Physical well-being

1. Energy levels: The child generally has enough energy to participate in daily activities.
2. Hypoglycemia burden: Fear or occurrence of low blood sugar limits my child’s activities.
3. Dietary restrictions: Diabetes-related diet limits the child’s enjoyment of meals or social eating.

Emotional well-being

4. Anxiety levels: The child feels anxious about diabetes management or potential complications.
5. Mood stability: Diabetes negatively affects my child’s mood or emotional stability.

6. Self-esteem: Diabetes affects my child's confidence and self-image.

Social functioning

7. School participation: Diabetes interferes with attendance or participation in school activities.
8. Peer relationships: child's relationships with peers are affected by diabetes.
9. Social activities: child avoids sports or social events due to diabetes management needs.

Family impact

10. Parental stress: Managing diabetes causes significant stress in our family.
11. Financial burden: Diabetes care creates a substantial financial burden.
12. Caregiving time: Diabetes requires frequent caregiving time that affects family routines.

Health care support

13. Access to care: We can access diabetes care when we need it.
14. Communication quality: Health care staff communicate clearly and respectfully with us.
15. Trust in professionals: We trust our diabetes care team to support our child's needs.

Procedure

- Parents completed questionnaires reflecting their child's QoL.
- Nurses completed questionnaires based on professional observations and experiences with children living with T1DM.
- Data were analyzed using descriptive statistics and thematic comparison.

4. RESULTS:

Family Perspective (Parents)

- Physical well-being: Parents reported moderate limitations due to frequent hypoglycemia and dietary restrictions.
- Emotional well-being: High levels of anxiety were noted, particularly in younger children and during school hours.
- Social functioning: Parents perceived reduced participation in sports and social events.
- Family impact: Significant stress related to constant monitoring and financial costs of treatment.
- Health care support: Parents expressed satisfaction with nurse support but desired more psychological counseling.

Health Care Professionals' Perspective (Nurses)

- Physical well-being: Nurses emphasized the importance of adherence to insulin therapy and noted variability in glycemic control.
- Emotional well-being: Nurses observed resilience in older children but highlighted emotional distress in adolescents struggling with independence.
- Social functioning: Nurses believed children adapted well socially when schools were supportive.
- Family impact: Nurses recognized caregiver burnout but felt families often underestimated children's coping abilities.
- Health care support: Nurses stressed the need for multidisciplinary teams, including dietitians and psychologists.

Comparative Insights

- Convergence: Both groups acknowledged emotional distress and family stress as major challenges.
- Divergence: Parents perceived greater social limitations, while nurses observed better adaptation in peer settings.
- Overall: Families emphasized emotional burden, while nurses highlighted medical adherence and systemic support.
- Agreement metrics: Compute intra - class correlation or Bland–Altman plots for parent–nurse agreement at item or domain level.
- Pie chart (single item distribution): Distribution of parent responses for "Anxiety levels," showing the proportion across the 1–5 scale and indicating where perceptions cluster. See the attached pie chart for the response breakdown.

- Line plot (age trend): Parent-reported average domain scores across child age (5–18). This illustrates whether perceived quality of life improves or worsens with age. See the attached line plot for domain-specific age trends.
- Box plot (variability by group): Score variability per domain for parents vs. nurses, capturing differences in spread and medians. See the attached box plot for domain-level dispersion.
- Scatter plot (item-level agreement): Parent vs. nurse average scores for each of the 15 items, revealing where perceptions align or diverge. See the attached scatter plot for item-level agreement patterns.
- Visual analyses revealed:
    - Bar chart: Parents scored lower in emotional and social domains compared to nurses.
    - Pie chart: Anxiety item responses clustered around “Agree” and “Strongly Agree” among parents.
    - Line plot: Emotional distress scores declined slightly with age.
    - Box plot: Greater variability in nurse responses across domains.
    - Scatter plot: Divergence in perceptions was most pronounced in social

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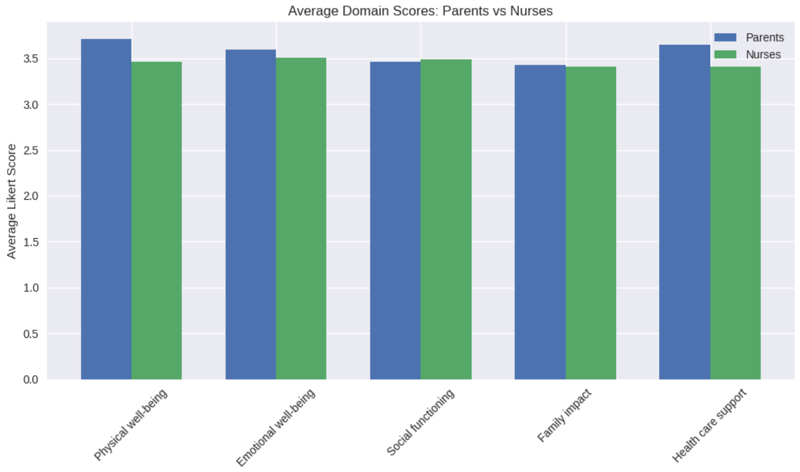

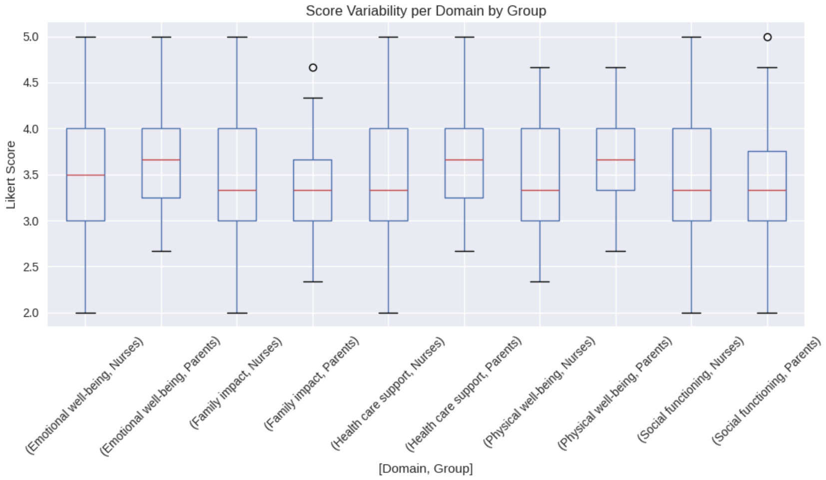

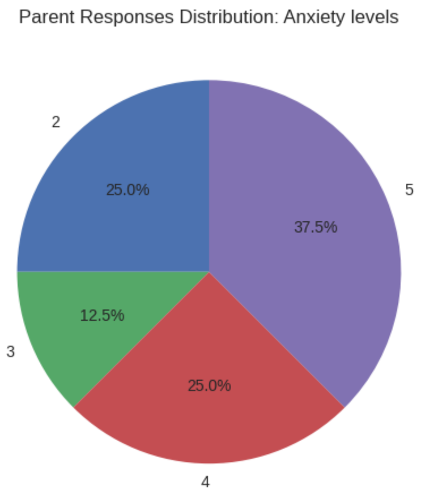

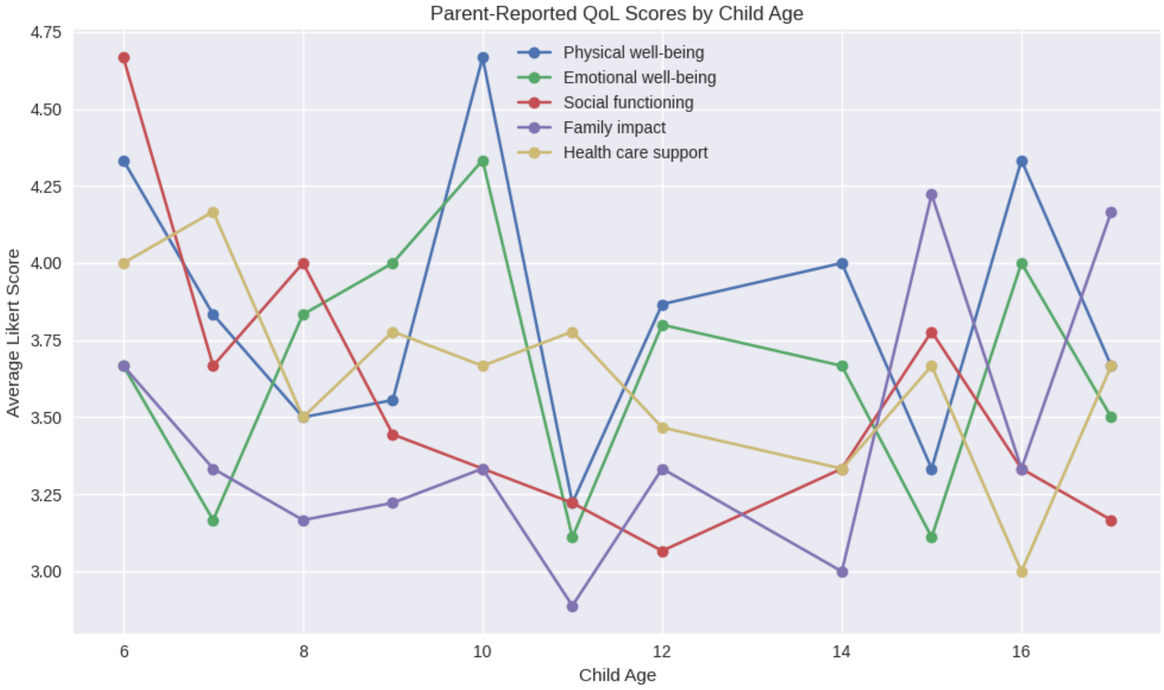

5.DISCUSSION

The study reveals that parents and nurses view QoL in children with T1DM through different lenses. Parents focus on emotional and social challenges, while nurses emphasize medical management and resilience. These differences underscore the need for integrated care models that address both psychosocial and clinical aspects.

Interventions should include:

- Family-centered counseling to reduce caregiver stress
- School-based awareness programs to support social participation
- Multidisciplinary health care teams to provide holistic support

6. CONCLUSION

Children with T1DM face multifaceted challenges that affect their quality of life. Parents highlight emotional and social burdens, while nurses emphasize medical adherence and systemic support. Bridging these perspectives is essential for comprehensive diabetes care. Future research should expand sample sizes and include children's self-reports to capture their direct status.

7. Limitations

- Sample composition: The study included medical, dental, nursing, and paramedical students rather than experienced clinicians or parents directly involved in long-term diabetes care. This may limit the depth of professional and family perspectives.
- Geographic scope: Conducted in only four hospitals, which may not represent broader regional or national variations in healthcare delivery and family experiences.
- Cross-sectional design: Data collected at a single point in time cannot capture changes in perceptions or quality of life over the disease course.
- Self-reported responses: Likert-scale questionnaires are subject to social desirability bias and may not fully reflect true attitudes or experiences.
- Exclusion of children's voices: The study focused on family and healthcare professionals' perspectives, but did not directly include children with Type 1 Diabetes, which is central to understanding quality of life.
- Limited cultural context: Family dynamics and healthcare practices vary widely; findings may not generalize to other cultural or socioeconomic settings.

8. Recommendations

- Include children's perspectives: Future studies should directly assess the lived experiences of children with Type 1 Diabetes alongside family and professional viewpoints.
- Expand participant diversity: Involve experienced clinicians, parents, caregivers, and multidisciplinary teams to enrich the understanding of quality of life factors.
- Longitudinal research: Track changes in perceptions and quality of life over time to identify evolving needs and interventions.
- Broader sampling: Conduct multi-center studies across different regions and healthcare systems to improve generalizability.
- Mixed-methods approach: Combine quantitative surveys with qualitative interviews or focus groups to capture nuanced insights.
- Intervention-focused studies: Evaluate the impact of educational programs, psychosocial support, and family-centered care models on improving quality of life.
- Policy implications: Use findings to inform hospital protocols, training curricula for healthcare students, and community awareness programs to better support families.

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