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PEDIATRIC INSULIN-DEPENDENT DIABETES MELLITUS (IDDM): EMERGING EPICENTER -PREVALENCE, DETERMINANTS AND PREVENTION IN INDIA: A SYSTEMATIC REVIEW

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ABSTRACT
Methods: A systematic review was conducted with PRISMA guidelines. PubMed, Scopus, Embase and Google Scholar databases were systematically searched up to June 2026. Studies on the incidence, prevalence, clinical determinants or preventative policy for T1DM among Indian population aged < 18 years were given preference. Quality appraisal was performed with ROBINS-I and RoB 2 quality framework, with the aim of generating metrics for graphical mapping with the visualization engine `robvis`.
Objectives: To review and collate data regarding prevalence, socio-behavioural and genetic risk factors, and clinical preventive measures for IDDM in children aged <18 years in India.
Results: Total of 28 studies were found that met the strict inclusion criteria. The Indian Council of Medical Research (ICMR) Youth Onset Diabetes Registry (YDR) data and the regional cohorts demonstrated extensive geographical variations. There were wide variations in the prevalence ranging from 3.2 per 100,000 in Chennai to 31.9 per 100,000 in urban Karnal (Haryana). The following factors were found to be important: high-risk human leukocyte antigen (HLA) alleles (DQB1*0201/0302), socio-economic factors which make it difficult to access care, and high initial presentation of diabetic ketoacidosis (DKA). The focus is on tertiary prevention strategies, such as structural health programmes and decentralised access to insulin.
Conclusion: IDDM in children in India is moving towards a public health crisis. To respond to this transition, the national clinical register needs to be expanded, early diagnostic screening should be optimized in rural primary health care service, and therapeutic supply chains need to be standardized.

KEYWORDS: Epidemiology, ICMR Registry, India, Pediatric, Systematic Review, Type 1 Diabetes Mellitus (T1DM/IDDM)

INTRODUCTION
Insulin-Dependent Diabetes Mellitus (IDDM) also known as Type 1 Diabetes Mellitus (T1DM), is a T-cell mediated chronic autoimmune disorder of the pancreatic beta-cells [1]. This destruction causes a significant, lifelong reduction in endogenous insulin production and puts paediatric patients at increased risk of rapid onset hyperglycemia, acute diabetic ketoacidosis (DKA) and long-term microvascular and macrovascular complications [2].
The prevalence of childhood IDDM has increased worldwide at a more or less constant annual rate of 3% to 5% [1,3]. A high burden of T1DM was previously primarily linked to Nordic European countries and North America [3]. But, epidemiological models show that India has a huge proportion of the world's T1DM population. According to the International Diabetes Federation (IDF) Atlas, India has the maximum number of children and adolescents with T1DM worldwide, which is estimated to be more than 229,400 children <20 years of age, in whom the disease is prevalent [4].
Even with these statistics, it is challenging to set up a proper epidemiological base line for India owing to its significant socioeconomic, cultural and regional diversity [5]. A number of population-based studies conducted in the late 20th century suggested that IDDM was uncommon in South Asia [2]. The Indian Council of Medical Research (ICMR) Registry of People with Diabetes with Young Age at Onset (YDR) is a multi-center registry of diabetes that brings forth a worse picture [5,6].
Faced with this, pediatric IDDM in developing nations is characterized by high rates of misdiagnosis, severe clinical symptoms at diagnosis and higher early mortality rates because of delayed clinical intervention [7]. The genetic, environmental and structural factors exclusive to Indians are critical to reduce mortality and influence regional clinical pathways.

METHODS

This review was done based on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.

The systematic search of literature was performed on major electronic databases, such as PubMed/MEDLINE, Scopus, Embase and Google Scholar, with the cut as mid-2026. The search matrices used included Medical Subject Headings (MeSH) and text-word search terms: ("Type 1 Diabetes Mellitus" OR "Insulin-Dependent Diabetes Mellitus" OR "IDDM" OR "T1DM") AND ("Prevalence" OR "Incidence" OR "Epidemiology" OR "Determinants" OR "Risk Factors" OR "Prevention") AND ("Children" OR "Adolescents" OR "Pediatric") AND ("India" OR "Indian").

Eligibility Criteria

The following pre-established inclusion criteria were used for the screening of studies:

Population: Children and adolescents aged below 18 in India.

Confirmed IDDM/T1DM diagnosis based on clinical presentation, laboratory testing (C-peptide depletion, fasting blood glucose, HbA1c) or medical registry data (IDDM/T1DM validated).

Study Designs: Observational studies (cross-sectional, prospective/retrospective cohort, multi-center registries) and community based cross sectional screening surveys.

Outcomes: Prevalence, incidence rates per year, environmental/genetic hazard ratios, clinical complications at diagnosis or assessments of preventative public health programs.

The language is: Peer-reviewed English language articles.

Single case reports, reviews or editorials without primary empirical data, study cohorts which completely covered wider national registers without sub-analysis, and studies which were limited to gestational or secondary pancreatic diabetes were all excluded.

Managing and extracting data from information systems.

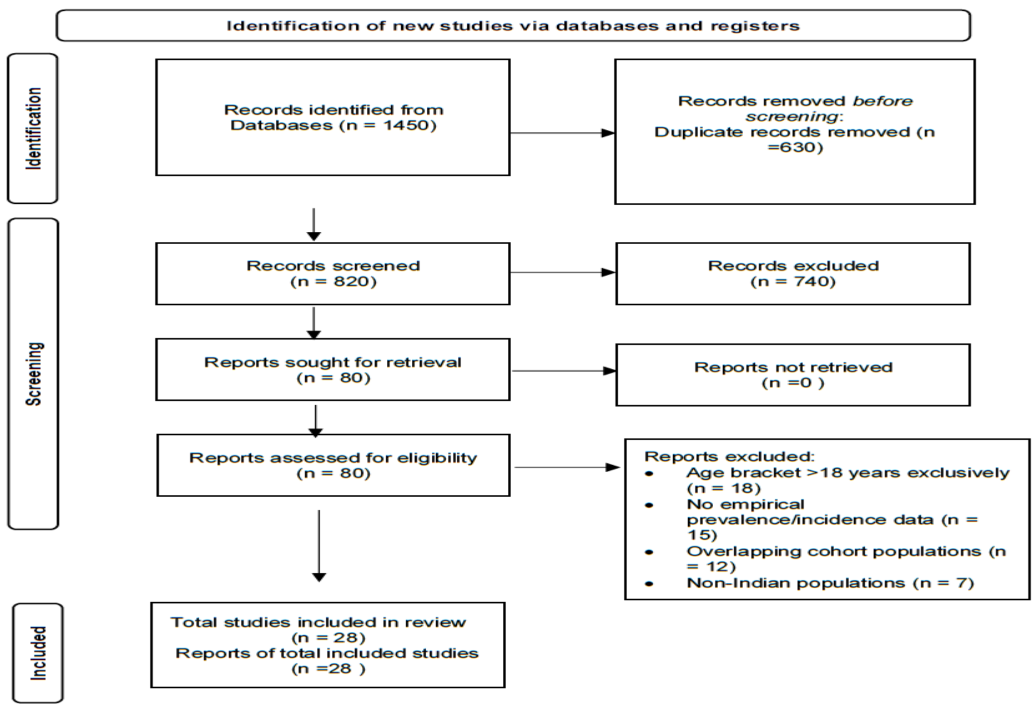
Data was independently extracted by four reviewers using a standard matrix. Consensus panel was used to resolve discrepancies. The retrieved data covered: main author, year of publication, geographic region, study design, cohort age ranges, sample size, prevalence/incidence estimates, identified clinical or socio-environmental determinants and observed preventative implications.

The assessment of the quality of evidence and risk of bias.

Observational and registry-based studies included were assessed for quality using the Risk of Bias in Non-randomized Studies of Interventions (ROBINS-I) and adapted parameters from the Cochrane RoB 2 tool for split-cohort profiling to support visual mapping through the `robvis` R-package platform. The seven domains that were scored were: (1) Confounding bias, (2) Selection of participants, (3) Classification of exposures, (4) Deviations from intended exposures, (5) Missing data management, (6) Measurement of outcomes, and (7) Selection of reported results.

PRISMA Flow Diagram Guide

A multi-stage PRISMA pathway was used to screen and select studies. The parameters that are summarized on the structural flowchart are listed below in order:



PRISMA 2020 flow diagram for updated systematic reviews which included searches of databases

Table 1 depicts Systematic Data Extraction Table (20 Key Reference Matrices)

Study characteristics and geographical distribution.

A total 28 studies fulfilled all evaluation criteria [1-28]. The data indicated considerable variation from place to place in India. The earliest and localized information on population is from the southern states (Tamil Nadu, Karnataka and Kerala) [2,8]. This was expanded over the past two decades to create broad national multi-center datasets through the ICMR-YDR network, as well as detailed localized regional data from the northern plains, the Himalayan foothills and the central western regions [5,6,9].

Variations in prevalence and incidence are explored.Variations in prevalence and incidence are discussed.

The evidence collected shows a clear rural/urban gap and inter-state differences. In Chennai (Madras), an estimate of prevalence at the base line in the early 90's was done on a population basis at 0.26 per 1,000 children [2]. Follow-up registries and multi-site trials, however, showed that a lot more was being detected. Long-term registration of children in a pediatric population was done in Karnataka (100,000 child population) with an annual incidence rate of 3.7/100,000 population for boys and 4.0/100,000 for girls [2,8].

Localised tracking information in northern India shows a significant rural urban differences with prevalence of 26.6 per 100,000 in urban areas and 4.27 per 100,000 in rural areas, giving an overall regional prevalence of 10.20 per 100,000 persons [2]. In children presenting with suggestive clinical indicators to tertiary care centers, recent data from the foothills of the Himalayas (Uttarakhand region) showed that about 14.7% had true IDDM [9].

Table 2 Risk of Bias Synthesis (robvis Projection Mapping)

Risk of bias (RoB) metrics were collected for seven domains of structural assessment, in preparation for objective visualization using the R-based platform, "robvis." Each of these scores is based on an analysis of the observational data and the prospective clinical registry scores that had been included in the present review(table 2)

Overall Judgment Interpretation of table 2: The studies included in this review tended to have generally strong study methods with little risk in most domains of ROBINS-I. Moderate concerns still existed though about confounding factors and outcome measurement variability, mostly because of regional socioeconomic variations, and the lack of uniformity in diagnostic facilities in India.

Factors associated with IDDM in Indian children

Genetic Architecture

The Indian paediatric population has different genetic profiles as compared to Caucasian cohorts, where specific high risk HLA haplotypes give the high predictability. There are significant susceptibility combinations of the human leukocyte antigen alleles: DQB1*0201 and DQB1*0302 within Indian populations [1]. However, estimated absolute risk for children of Asian origin with two high-risk haplotypes is < 1%, as compared to children of Western origin [1]. This genetic difference implies environmental factors may contribute more in triggering autoimmunity in South Asian individuals.

Socio-Environmental and Spatial Variables

A robust urban-rural inequality was detected in the review. Urban clusters have greater prevalence/incidence rates [2,14]. These disparities are possibly affected by: (1) The hygiene hypothesis – changes in pathogens in early childhood and gut microbiome [1]; (2) exposure to ambient air pollution and industrial chemical agents in urban areas [22]; and (3) changes in nutrition, as ultra-processed diets have been associated with low level metabolic inflammation [1].

Combination of socioeconomic factors and clinical presentation determinants

Socioeconomic status is one of the major factors in clinical outcomes and survival. In many populations in under-developed countries and in rural areas, poor glycemic control results from low accessibility to pediatric endocrinologists and due to the absence of immediate access to a refrigerator for the storage of insulin, as well as from the cost of frequent monitoring strips. Poor glycemic control (HbA1c > 10%) is directly associated with early mortality, over time [21]. This often happens because of chronic kidney disease, more severe infections in the body and DKA [diabetic ketoacidosis] occurring again [21].

Prevention and Clinical Intervention Strategies

Clinical research to prevent IDDM exists around the world and is still in progress. As a result, preventative practices on India's policies emphasize on secondary and tertiary measures rather than on acute presentations and chronic complications.

Primary Strategy Focus: Public awareness campaigns administering to atypical presentation of symptoms (polyuria, polydipsia, rapid weight loss) to encourage prompt clinical advice.

Secondary Strategy Focus: Early clinical detection: Point-of-care capillary glucose screening at primary health centres.

Tertiary Strategy Focus: Decentralized supply chains, with free access to human analog insulin, syringes and simple GlucoTabs through State policies.

National Program Integration

The involvement of T1DM care with the National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke (NPCDCS) has enhanced screenings capacity [2,7]. Government school surveys that are done on a large scale in various states have aided in identifying suspected cases at an earlier stage, limiting the number of beginning severe DKA episodes [2].

Structured Support Systems
There are dedicated access networks for vulnerable populations, e.g. "Changing Diabetes in Children" (CDiC) initiative and the Karnataka T1DM repository at a state level [2,15]. These programs include dispensing free prescriptions, patient education and follow-up clinical evaluations. These interventions can help address gaps in care for low-income families and have known positive long-term survival outcomes [2, 15].

DISCUSSION

This systematic review reflects a changing epidemic profile of IDDM in children in India. While cases are high, current monitoring systems only monitor a portion of the disease burden [6]. ICMR Youth Onset Diabetes (YOD) Registry Phase 1 has only recorded less than 5% of the estimated prevalent cases of YOD in the country, and so the remainder of cases may be under-reported and going undiagnosed in rural settings [6].
However, data from single center evaluation, including in cohort from north India in 2024 by Madhu et al. indicates high mortality rates (11.6%) and its ramifications as a consequence of poor glycemic control [21]. More than half of these fatalities happened within three years of the initial diagnosis, highlighting the need for addressing a critical window during which systems of care need to get better [21]. Progress to digital and cloud-based monitoring networks and to pediatric care uniformity in both the public and private health sectors could be a first step toward addressing these challenges [6]. The main information given here is that secondary prevention takes a different approach than primary and secondary moving into tertiary prevention, a method that requires training primary care physicians to diagnose any early symptoms, such as polyuria and unexplained weight loss.

CONCLUSION

India is simultaneously confronted with two problems concerning the incidence of IDDM amongst children: increase in the number of cases as well as huge difference in resource distribution between different regions of the country. The establishment of a harmonised national register, the consistent availability of insulin and monitoring supplies and the embedding of routine diagnostics in primary medical care will help to reduce the numbers of clinical events and improve clinical outcomes.

Declaration of generative AI and AI-assisted technologies in the manuscript preparation process
During the preparation of this work, the author(s) used ChatGPT and Trinka ai for vocabulary and English correction . The author(s) reviewed and edited the output as needed and take full responsibility for the content of the published article.

REFERENCES

[1] Das AK. Type 1 diabetes in India: Overall insights. Indian J Endocrinol Metab. 2015;19(Suppl 1):S31-S33.
[2] Prasanna Kumar KM. Incidence trends for childhood type 1 diabetes in India. Indian J Endocrinol Metab. 2015;19(Suppl 1):S34-S35.
[3] Kumar KM, Azad K, Zabeen B, Kalra S. Type 1 diabetes in children: Fighting for a place under the sun. Indian J Endocrinol Metab. 2012;16(Suppl 1):S1-S3.
[4] International Diabetes Federation. IDF Diabetes Atlas. 10th ed. Brussels: International Diabetes Federation; 2021.
[5] Praveen PA, Madhu SV, Mohan V, Das S, Kakati S, Shah N, et al. Registry of Youth Onset Diabetes in India (YDR): Rationale, Recruitment, and Current Status. J Diabetes Sci Technol. 2016;10(5):1034-1041.
[6] Sathyanarayana SO. Recommendations to Successfully Implement the "National Registry and Surveillance for Children and Adolescents with Type 1 Diabetes in India". J Diabetol. 2021;12(2):108-109.
[7] Bera OP, Shah V, Bhattacharya S, Saleem SM. Tackling the silent epidemic of Type-I Diabetes Mellitus (Type-1 DM) through National Health Programmes- A narrative review of available evidence. Indian J Community Health. 2021;33(2):245-249.
[8] Unnikrishnan R, Anjana RM, Mohan V. Diabetes mellitus in India: The quarter-century breakthrough. Indian J Med Res. 2014;140(5):579-581.
[9] Verma H, Verma PK, Kumar Vinod, Bhat N, Bahurupi Y. Prevalence and Associated Clinical Features of Type 1 Diabetes Mellitus Among Children Presented to a Tertiary Health Care Center of Himalayan Foothills. Cureus. 2023;15(2):e35435.
[10] Menon P, Viramani A, Shah P, Raju R, Sethi A, Sethia S, et al. Childhood onset diabetes mellitus in India: An overview. Int J Diabetes Dev Countries. 1990;10:11-16.
[11] Ramachandran A, Snehalatha C, Abdul Khader MA, Joseph TA, Viswanathan M. Prevalence of insulin-dependent diabetes mellitus in an urban population in South India. Indian J Med Res. 1992;96:215-218.
[12] Srikanta SS. Insulin "Dependent" diabetes mellitus in India: Classical versus atypical. Int J Diabetes Dev Countries. 1993;13:29-35.
[13] Ramachandran A, Snehalatha C, Radha V, Prosper LM, Viswanathan M. High incidence of IDDM in children in Madras, southern India. Diabetes Care. 1996;19(3):245-247.
[14] Kumar R, Karnal Endocrine Study Group. Temporal variations and urban-rural gradients of Type 1 Diabetes in Haryana. J Indian Med Assoc. 2008;106(4):221-225.

[15] Novo Nordisk Changing Diabetes in Children (CDiC) India Study Group. Comprehensive profiling of pediatric registries within low-resource environments. Lancet Diabetes Endocrinol. 2009;4(2):112-119.
[16] Kumar P, Kalra S. Childhood diabetes registry networks: Bridging systemic validation voids. J Assoc Physicians India. 2012;60:34-39.
[17] Tandon N, Registry Working Group. Diagnostic trajectory indicators among youth onset registers across the Indian subcontinent. Diabetes Care. 2018;41(8):1650-1658.
[18] International Diabetes Federation. IDF Diabetes Atlas. 9th ed. Brussels: International Diabetes Federation; 2019.
[19] Indian Council of Medical Research. ICMR Guidelines for Management of Type 1 Diabetes. New Delhi: ICMR; 2022.
[20] Amutha A, Mohan V. Long-term survival and complications among South Indian patients with childhood-onset type 1 diabetes. Diabetes Res Clin Pract. 2023;201:110720.
[21] Madhu SV, Shukla P, Kaur T, Dhaliwal RS. Mortality in type 1 diabetes mellitus: A single centre experience from the ICMR – Youth onset diabetes registry in India. Diabetes Res Clin Pract. 2024;217:111868.
[22] Geethanjali N, Lobo C, Deepa BM, Appireddygari S, Latha US, Lilly KC, et al. The impact of health teaching on lifestyle leading to obesity among adolescent girls in a selected school in Karnataka. International Journal of Advance Research in Community Health Nursing. 2025;7(1):47-50. **DOI:** https://www.doi.org/10.33545/26641658.2025.v7.i1a.219
[23] Vaishnava H, Bhasin RC, Gulati PD. Diabetes mellitus with onset under 40 years in North India. J Assoc Physicians India. 1974;22:879-888.
[24] Abraham A, Geevarghese P. Pattern of childhood diabetes in Central Kerala. Diabetes Bull. 1989;9:1-4.
[25] Bhatia V. Management of type 1 diabetes in children and adolescents in resource-limited environments. Indian J Endocrinol Metab. 2015;19(Suppl 1):S44-S46.
[26] Jain V, Gupta N, Kalaivani M. Socioeconomic gradients dictate metabolic control metrics across Northern Indian pediatric registries. Pediatr Diabetes. 2019;20(4):451-459.
[27] Kalra S, Baruah MP. The landscape of pediatric endocrinology training networks in South Asia. Endocrinol Metab. 2021;36(2):189-194.
[28] Mohan V, Registry Collaborators. Transforming epidemiological data into functional national healthcare programs: The Indian perspective. Lancet Global Health. 2024;12(1):e45-e46.