

Type 1 diabetes: Awareness, management and challenges: Current scenario in India

K.M. Prasanna Kumar, Banshi Saboo¹, P.V. Rao², Archana Sarda³, Vijay Viswanathan⁴, Sanjay Kalra⁵, Bipin Sethi⁶, Nalini Shah⁷, S.S. Srikanta⁸, Sunil M Jain⁹, P. Raghupathy¹⁰, Rishi Shukla¹¹, Ashok Jhingan¹², Subhankar Chowdhury¹³, P.K. Jabbar¹⁴, Alok Kanungo¹⁵, Rajesh Joshi¹⁶, Surendra Kumar¹⁷, Nikhil Tandon¹⁸, Vaman Khadilkar¹⁹, Manoj Chadha²⁰

Consultant Endocrinologist, Centre for Diabetes and Endocrine Care, Bangalore Diabetes hospital, ¹Diabetologist and Endocrine and Metabolic Physician at Diabetes Care and Hormone Clinic, Ahmedabad, Gujarat, ²Senior Professor and Head, Department of Endocrinology and Metabolism, Nizam's Institute of Medical Sciences University, Hyderabad, ³Director and Consultant, Sarda Centre for Diabetes and Self-care, Aurangabad, Maharashtra, ⁴Head and Chief Diabetologist, M.V Hospital for Diabetes and Prof. M. Viswanathan Diabetes Research Centre, Royapuram, Chennai, Tamil Nadu, ⁵Consultant Endocrinologist, Bharti Hospital and B.R.I.D.E., Karnal, Haryana, ⁶Consultant Endocrinologist at Care Hospital, Hyderabad, Telangana, ⁷Professor and Head, Department of Endocrinology, King Edward Memorial (KEM) Hospital, Mumbai, ⁸Medical Director and Senior Consultant, Samatvam Endocrinology Diabetes Center, Samatvam: Science and Research for Human Welfare Trust, Jnana Sanjeevini Diabetes Hospital and Medical Center, Bangalore, Karnataka, ⁹Chief Endocrinologist at TOTALL Diabetes Hormone Institute, Indore, Madhya Pradesh, ¹⁰Professor of Paediatric Endocrinology, Indira Gandhi Institute of Child Health and Senior Consultant in Paediatric Endocrinology, Sagar Hospitals, Bangalore, Karnataka, ¹¹Consultant Endocrinologist, Regency Hospital, Kanpur, Uttar Pradesh, ¹²Chairman and Consultant Physician, Delhi Diabetes Research Center, Rajouri Garden, West Delhi, ¹³Professor and Head, Department of Endocrinology at IPGME and R and SSKM Hospital, Kolkata, ¹⁴Professor and Head, Department of Endocrinology, Medical College, TVM, ¹⁵Founder and Chairman of Kanungo Institute of Diabetes Specialities (KIDS), Bhubaneswar and Founder of and Chief Consultant, Cuttack Diabetes Research Foundation (CDRF), ¹⁶Professor, Department of Pediatrics, at B.J. Wadia Hospital for Children, Mumbai, ¹⁷Associate Professor, Department of Endocrinology, Patna Medical College and Hospital, Patna, Bihar, ¹⁸Professor, Department of Endocrinology and Metabolism All India Institute of Medical Sciences (AIIMS), Ansari Nagar, New Delhi, ¹⁹Consultant Paediatric Endocrinologist, Jehangir Hospital and Bombay hospital, Mumbai and Ira Endocrine Clinic, Pune, ²⁰Consultant Endocrinologist, PD Hinduja National Hospital and Hope and Care Centre, Vashi, Mumbai, Maharashtra, India

ABSTRACT

Type 1 diabetes mellitus (T1DM) has a wide presence in children and has a high mortality rates. The disease, if left unmanaged, poses various challenges to the patient and healthcare providers, including development of diabetic complications and thus decreasing the life expectancy of the affected child. The challenges of T1DM include awareness of the disease that is very poor among the general public and also in parents of T1DM children along with the health care professionals. The challenge of lack of awareness of T1DM can be met by increasing public awareness programs, conducting workshops for diabetes educators regarding T1DM in children, newsletters, CMEs, online courses, and by structured teaching modules for diabetes educators. Diagnosis of T1DM was a challenge a few decades ago but the situation has improved today with diagnostic tests and facilities, made available even in villages. Investigation facilities and infrastructure, however, are very poor at the primary care level, especially in rural areas. Insulin availability, acceptability, and affordability are also major problems, compounded by the various types of insulin that are available in the market with a varied price range. But effective use of insulin remains a matter of utmost importance.

Key words: Awareness, challenges, type 1 diabetes mellitus

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INTRODUCTION

Type 1 diabetes mellitus (T1DM) has a wide presence in children and has a high mortality rates. The disease, if left unmanaged, poses various challenges to the patient and health care providers, including development of diabetic complications and thus decreasing the life expectancy

Corresponding Author: Dr. K.M. Prasanna Kumar, Bangalore Diabetes Hospital, 16/M, Miller Tank Bed Area, Thimmaiah Road, Vasanth Nagar, Bangalore - 560 002, India. E-mail: dr.kmpk@gmail.com

of the affected child.^[1] A study in USA showed that when a 10-year-old boy or girl develops diabetes, he/she loses almost 18.7–19 years of life compared to their nondiabetic counterparts. A researcher has also stated “focused studies show that outcomes can be improved by better management, but there is no evidence of this actually happening on a worldwide basis.” Newer treatment approaches have facilitated improved outcomes in terms of both glycemic control and reduced risks for development of complications. The major challenges remain in the development of approaches to the prevention and management of T1DM and its complications.

The challenges of T1DM include awareness of the disease which is very poor amongst the general public and also in parents of T1DM children, and this needs to be improved to effectively counter the problem of T1DM. The general population is unaware of the existence of diabetes in children of 2–5 years of age and believe that it affects only the middle-aged group. Awareness among the public health care professionals is also very poor, and the syllabus curriculum of medicine students does not emphasize much on T1DM. The challenge of lack of awareness of T1DM can be met by increasing public awareness programs, conducting workshops for diabetes educators regarding T1DM in children (giving details of symptoms, diagnosis, diet, monitoring and management), newsletters, CMEs, online courses, and by structured teaching modules for diabetes educators. The Changing Diabetes in Children (CDiC) program is working on all these methods to increase T1DM awareness for the past few years. Diabetes care professionals, including nurses, dieticians and doctors, may not possess the specific skills required to optimally manage T1DM, and they may not have the time or energy to put these skills into practice. The need for a structured diabetes education program, for patients and parents/healthcare providers, which focuses on T1DM management, persists. The Indian Diabetes Educators Programme in 2010–2012 in association with project Health Opportunities for People Everywhere and International Diabetes Federation (IDF) have trained nearly 5000 diabetes educators in India. This program, however, specifically lacked education on T1DM but has planned for future T1DM specific training to such health educators.

The psycho-social aspect of diabetes in children is another challenge in T1DM management. The patients/children sometimes fail to understand the severity of blood sugar levels and only focus on the incentives provided by the social workers/health care workers of the CDiC program. This would need regular interaction between parents,

nurses, doctors, teachers, and the school authorities, which must be assured for close monitoring. The child must be encouraged to participate in the school and family activities. Proper education of self-care must be given to the child so that the child can cope with his/her existing disease, maintain self-confidence, ensure self-management and adapt with life at large.^[2]

The disease has many challenges, and these are not global but specific to developing countries. Diagnosis of T1DM was a challenge a few decades back, but the situation has improved today with diagnostic tests and facilities, made available even in villages. Investigation facilities and infrastructure, however, are very poor at the primary care level, especially in rural areas. Insulin availability, acceptability, and affordability are also major problems, compounded by the various types of insulin that are available in the market with a varied price range: From a few rupees to a few thousand rupees. However, effective use of insulin remains a matter of utmost importance, rather than the different types of insulin. Furthermore, the problem persists with insulin storage; up to 80% patients lack a good storage facility at home.

Another major problem is the lack of a T1DM registry in India and the data provided is an assumed number. A registry should be developed and include every child detected with T1DM. This would help the health care providers and the government for planning and delivery of diabetes management techniques and medicines. A statement from the American Diabetes Association says that every child newly diagnosed with T1DM should be evaluated by a diabetes team (consisting of a pediatric endocrinologist, a nurse educator, a dietician, and a mental health professional) qualified to provide up-to-date pediatric specific education and support.^[3] In India, however, this type of team may be difficult to set up for the general public health, but the CDiC team is working toward it.

The CDiC team is improving the infrastructure for managing T1DM better and is reaching out pan-India through 21 CDiC centers and 20 satellite centers. CDiC has plans to extend this to over 100 centers across the country. The center network should be such that it has a terminal and supervising centers at the village, district and state levels. The present condition forces a child to travel 150–300 km in 4–12 h time for reaching a CDiC center, which is at a much higher cost than the medications given to the child.

There are approximately 70,000–75,000 children with T1DM in the country and CDiC is only able to cater to

about 4000 of these children. CDiC, however, has been able to successfully produce a model for delivery of standard of care for these children.

Steps toward the further enhancement of the program would involve establishment of infrastructure, providing insulin (even small amounts of insulin would be able to prevent ketosis and subsequent death in children), tackling the barriers and challenges as discussed above (lack of awareness, monitoring, etc.) and making expensive insulin available to all T1DM patients, with government removing the tax levied on insulin. This could be possible if both the state and central governments are actively involved in this program. A public-private partnership initiative is needed involving the ministry of health in the central government, civil society, World Diabetes Foundation/IDF/Juvenile Diabetes Foundation, State Governments, City Corporations and the Local Nongovernmental Organization (NGOs). NGOs and public-private partnerships, without support from the government, would not be able to do much about the cause. CDiC looks forward for support from the government and would be able to give the data collected so far, share the roadmap of achievements till now, and the roadmap for the next 3 years. This would lead to increased participation from children.

Changing Diabetes in Children is working with some agencies to supply diabetes strips at about 2 rupees/strip, which usually costs around 25 rupees. The CDiC aims to give 60 strips to each child along with the contact details of a social worker/diabetes educator who can be contacted telephonically in case of any variations in daily blood sugar levels, following which he/she can suggest remedies or increase insulin dose. The diagnostic tests available are fairly expensive in the country and the CDiC program has made the same available to a very large number of children who could not afford the same; subsequently achieving in controlling and bringing down HbA1c levels. The key impact on deliverables by CDiC is reduction of the number of children developing diabetic ketoacidosis, decrease in mortality, reduction in the number and duration of admissions in hospitals, reduction

in the number of school days lost, growth of child to their adequate growth potential, and a significant increase in body weight of children with T1DM.

At the patient level the disease poses challenges in terms of difficulties in education, marriage, and job opportunities. CDiC is also looking into the motivation of children for continuing their school education which is essential and would help them sustain themselves in the future. In this regard, CDiC is planning for introduction of scholarship to children enrolled in this program, for admission into schools. The program is also providing school books and other necessary materials to children for helping them continue their education.

SUMMARY

The wide disparities in socioeconomic levels, educational background, and availability of diabetes care pose major hurdles in the management of this disease in India. Parents and the family tend to view T1DM as a stigma. People need to take the lead to ensure comprehensive clinical and psychological care for all children with T1DM by preconceptional planning program. The final aim of all such programs should be that no child should die of diabetes.

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