Type 1 diabetes in children: Fighting for a place under the sun

K. M. Prasanna Kumar, Kishwar Azad, Bedwora Zabeen, Sanjay Kalra
Department of Endocrinology, Bangalore Diabetes Hospital, Bangalore, 1Birdem Hospital, Dhaka, Bangladesh, 2Department of Endocrinology, Bharti Hospital and B.R.I.D.E, Karnal, Haryana, India

The Magnitude

Type 1 diabetes (T1DM) is not an insignificant disease. One of the most common pediatric endocrine illness, it affects nearly 500,000 children below the age of 15 years. Of these, over half live in developing nations, with India being home to an estimated 97,700 children with T1DM. This is more than the relative burden of type 2 diabetes India has to shoulder: every fifth T1DM child in the world is an Indian, while (only) every seventh type 2 diabetes mellitus (T2DM) adult across the globe claims Indian nationality. In Bangladesh the estimated prevalence of diabetes for the year 2010 in age group 20-79 years was 6.1% and for the year 2011 it has been raised to 9.58%.

The incidence of T1DM is rising by 3% per annum, especially in younger children and in so-called “low-prevalence” countries. This increase in incidence along with enhanced access to insulin and better survival rates will lead to a higher prevalence in the near future. Already 70,000 fresh children are diagnosed to have T1DM every year.

In Bangladesh the estimated prevalence of diabetes for the year 2010 in age group 20-79 years was 6.1% and for the year 2011 it has been raised to 9.58%

In spite of these “outrageous and abhorrent” statistics, T1DM does not receive the attention that it should. Eyeballs are grabbed by T2DM, which affects 366 million adults (8% of the global adult population) and is projected to afflict 522 million by 2030. It is these numbers that propel the tide of noncommunicable disease (NCD) and are used to motivate governments, politicians, society leaders and nongovernmental organization to act against diabetes.

T1DM is 26.6/100,000 in urban and 4.27/100,000 in rural areas of the district, leading to an average prevalence of 10.20/100,000 population. Karnal city has a relatively high prevalence of T1DM (31.9/100,000).

In Bangladesh the estimated incidence rate of Type 1 diabetes in age 0-14 years is 4.2 per 100,000 per year.

Poor Cousin of Type 2 Diabetes Mellitus

In spite of these “outrageous and abhorrent” statistics, T1DM does not receive the attention that it should.

Eyeballs are grabbed by T2DM, which affects 366 million adults (8% of the global adult population) and is projected to afflict 522 million by 2030. It is these numbers that propel the tide of noncommunicable disease (NCD) and are used to motivate governments, politicians, society leaders and nongovernmental organization to act against diabetes.

Because of the enormous difference in prevalence, T1DM has resigned to being treated, epidemiologically at least, as a poor cousin of T2DM. But, should this poor cousin treatment extend to the clinical sphere as well?

Because of the sheer magnitude of T2DM in adults, most continuing medical education (CME) programmes tend to concentrate on management issues related to this variety of diabetes mellitus. A typical CME deals with newer oral hypoglycemic agents or modern insulin, or management of chronic macrovascular complications. Other aspects of diabetology are often ignored. Rarely, if ever, is any attention paid to the nuances of T1DM therapy.
Unfortunately for Type 1 Diabetes Mellitus

This is unfortunate. Medical practitioners and paramedical staff who have been trained in T2DM treatment alone, without any exposure to T1DM, often assume that both entities are similar. T1DM children therefore end up receiving care that may be appropriate for T2DM but is not optimal for them.

The Distinction

People with T1DM have a clinical presentation that is totally different from their T2DM counterparts. Because of absolute insulin deficiency, the optimal insulin regime is a basal-bolus one or, if available, an insulin pump. Autoimmune disease such as hypothyroidism and celiac disease need to be screened for. A T1DM child requires frequent monitoring for glycemia and ketonuria as well as for musculoskeletal and rheumatologic complications. Emphasis on diet, calorie counting, regular physical activity, injection technique and sick day management is essential. The unique psychological needs and challenges of growing children need to be addressed. What may be optional management for a T2DM patient becomes essential in T1DM. All these and other such factors underline the need for a structured diabetes education programme, for both patients and providers, which focuses on T1DM management. This is not a luxury. It is a necessity.

As of today, the standard of care received by the vast majority of T1DM children is not adequate. Lack of access to insulin is a major issue in some developing countries. Apart from this, societal taboos that prevent children, especially girls, from taking treatment (“She will get addicted to insulin!” “Who will marry her?”) take their toll. Blind application of adult T2DM insulin regimes to children results in suboptimal control and avoidable complications. Even if all this is corrected, children with T1DM have double the mortality rate of their nondiabetic peers, in high-income countries as well. [7]

Who is to blame?

Who is to blame for this situation? Children with T1DM represent perhaps the least vocal and most unheard segment of people with diabetes. Dependent as they are upon family and other care givers, they find it difficult to voice their needs and wishes. In a busy pediatric or endocrine clinic, they are sometimes viewed as an intrusion, as they require more time for counselling and management as compared with a run-of-the-mill diarrhea or a common-garden T2DM patient. Diabetes care professionals, including nurses, dieticians and doctors, may not possess the specific skills required to optimally manage T1DM. Or, more often than not, they may not have the time or energy to put these skills into practice.

In some cultures, parents and family tend to view T1DM as a stigma. This prevents the T1DM community from becoming a strong force in patient advocacy and from sensitizing society to their unique needs. Governments, too, grappling with multiple public health issues, may not understand the distinct nature of T1DM. They tend to focus on the umbrella term of noncommunicable disease, which revolves predominantly around the chronic macrovascular complications of diabetes.

While the blame for our dismal work can be distributed among various stakeholders, who should be the first to bell the cat?

Our Responsibility, Our Response

The responsibility lies with us, the endocrinologists. A concerted effort needs to be made to sensitize our colleagues to the special needs of T1DM children, both medical and psychological. In this regard, the DAWN Youth programme has been a trailblazer, highlighting the specific attitudes, wishes and needs of this vulnerable group.[8] The Indian Journal of Endocrinology and Metabolism (IJEM) has been carrying articles related to T1DM, and hopes to do so with increasing frequency in the future. One such original article and review appear in this issue as well.[9,10]

While highlighting the psychological needs, we must also remember to provide tools for improvement. Concepts such as patient empowerment, shared decision making, behavioral change counselling, motivational interviewing and coping skills training should be translated into real-life practice. The IJEM hopes to contribute to this campaign through relevant articles and editorials as well.[11]

The International Diabetes Federation’s Life for a Child campaign supports T1DM services in resource-challenged societies. The federation has also collaborated with the International Society for Pediatric and Adolescent Diabetes to produce guidelines for T1DM.

Apart from education, and guidelines, however, we need access to medical care. The Changing Diabetes in Children programme, launched in eight Asian and African countries, has already covered 4000 economically disadvantaged children, including 2000 Indians, who will receive free...
insulin, syringes, glucometers and glucose-measuring sticks along with free consultation and investigations for a period of 3 years.

**Conclusion**

As responsible endocrinologists, we need to take the lead to ensure comprehensive clinical and psychological care for all children with T1DM. Let us ensure that T1DM gets its rightful place under the endocrine sun, not as a poor cousin of T2DM but as a separate and distinct entity. If we do not, who else will?

**References**

1. International Diabetes Federation Diabetes Atlas. 5th ed. Brussels: IDF; 2011.
2. International Diabetes Federation Diabetes Atlas, 4th ed. IDF Brussels 2010.
3. Ramachandran A, Snehalatha C, Krishnaswamy CV. The incidence of IDDM in children in urban population in southern India. Madras South India. Diabetes Res Clin Pract 1996;34:79-82.
4. Prasanna Kumar KM, Krishna P, Reddy SC, Gurappa M, Aravind SR, Murugoodappa C. Incidence of Type 1 diabetes mellitus and associated complications among children and young adults: Results from Karnataka Diabetes Registry 1995-2008. J Indian Med Assoc 2008;106:708-11.
5. Kalra S, Kalra B, Sharma A. Prevalence of type 1 diabetes mellitus in Karnal district, Haryana state, India. Diabetol Metab Syndr 2010:2:14.
6. Mbanya JC. Calling out around the world. Diabetes Voice 2011;56:4.
7. International Diabetes Federation. Diabetes Atlas. 3rd ed. Brussels: IDF; 2007.
8. DAWN Youth. Available from: http://dawnstudy.com/dawnprogramme/dawnyouth.asp. [Last Accessed on 2012 Feb 11].
9. Koshy AS, Kumari JS, Ayyar V, Kumar P Evaluation of serum Vitamin B12 levels in type 1 diabetic attending a tertiary care hospital: A preliminary cross-sectional study. Indian J Endocrinol Metab 2012;16 (Suppl 1):S79-82.
10. Poudel RR. Latent autoimmune diabetes of adults from oral hypoglycemic agents to early insulin. Indian J Endocrinol Metab 2012;16 (Suppl 1):S41-46.
11. Kalra S, Unnikrishnan AG, Skovlund SE. Patient empowerment in endocrinology. Indian J Endocrinol Metab 2012;16:1-3.