

Executive Summary: ICMR- YDR Registry (Phase-1) Report

With the aim of addressing the relative scarcity of information on youth onset diabetes in India, the Indian Council of Medical Research (ICMR) decided to establish the Registry of People with Diabetes with Young Age at Onset (YDR). The primary objective of the registry is to understand the disease pattern or types of youth onset diabetes including their geographical variations within the country and to estimate the burden of diabetes complications. The YDR registry was established with the aim of enrolling all the cases of diabetes reported after 1st January 2000, who satisfy an inclusion criteria (age less than or equal to 25 years with fasting plasma glucose >126 mg/dl and/or 2hr post-load plasma glucose >200mg/dl, referred/non-referred, treated/untreated residing within the assigned geographical area of the reporting centres).

The registry was launched in the year 2006 with eight collaborating centres across India. These centres are recruiting patients from their own hospitals as well as from the interacting reporting centres. Data from the period 2000-2006 were collected retrospectively from medical records available at the reporting centres. A baseline and an annual follow up proforma were used to obtain information on socio demographic details, clinical profile, anthropometric and laboratory measurements of the patients.

Towards the end of the first phase (31st July 2011) the registry has enrolled 5546 patients with youth onset diabetes. Symptom-based clinical criteria were used to classify the diagnosed cases. There were more than ten variants of youth onset diabetes reported, in which Type 1 Diabetes Mellitus (T1DM) was the most prevalent (63.9%) followed by youth onset Type 2 Diabetes Mellitus (T2DM) (25.3%). Other forms of diabetes such as Gestational Diabetes (3.9%), Maturity Onset Diabetes of the Young (MODY) (3.1%), Chronic Pancreatitis (1.3%), Secondary Diabetes (1.0%), Latent Autoimmune Diabetes in Adults (LADA) (1.0%), Drug Induced Diabetes (0.3%) and Malnutrition Modulated Diabetes (0.1%) were also reported from the participating centres. The relative proportion of patients with T1DM and T2DM varied between centres. In Chennai and Dibrugarh, 40 % of the total patients were diagnosed as T2DM. In all the other collaborating centres, T1DM contributed a significant majority (71.5 % to 94.4%), while the proportion of patients with youth onset T2DM was

below 25%. In children below 10 years, T1DM was the most common form of diabetes in all centres.

The mean age at diagnosis for T1DM was 12.9 ± 6.5 years, while that for T2DM in youth was 21.6 ± 3.7 years. The age at diagnosis did not show much variation across the centres. Out of total enrolees, 49.5% were males and 50.5% were females. In both T1DM and T2DM categories, number of males with disease was more compared to females. 23.3% of the YDR patients belonged to the low socio economic strata.

More than 60% of the registered patients developed diabetes before 20 years of age. Nearly half the patients with T1DM registered within 6 months of the onset of symptoms of disease. Most cases of T2DM (47.3%) were registered after 3 years from their date of diagnosis.

Paternal and maternal history of diabetes was observed in 22.6% and 18.7% of YDR subjects respectively, while both parents of 9.6% subjects had history of diabetes. Among YDR patients, 3.9 % reported that their siblings also suffered from diabetes. Family history of diabetes in maternal or paternal grand parents was present in 27.9% of YDR patients.

The most common mode of presentation among patients with T1DM was a combination of osmotic symptoms and weight loss (28.8%). Ketosis, one of the common modes of presentations of T1DM, was reported by 25.2% of the patients. One-third of youth onset T2DM patients were identified incidentally during routine medical examination. Other common presentations for these patients were osmotic symptoms alone (27.1%) and history of isolated weight loss (22.6 %).

At each age, mean BMI values of children and adolescents with T2DM was more than that of T1DM. Acanthosis nigricans, a marker of insulin resistance, was present in 18.8% of subjects with young T2DM, but only in 4.1% patients with T1DM. Urine ketones were more prevalent among patients with T1DM (32.7%) compared to T2DM (6.0%) and other categories (8.5%) of youth onset diabetes.

15.4 % of patients (11.1 % of T1DM patients; 26.4 % of T2DM patients) had at least one chronic complication of diabetes at registration. In all the diabetes categories, retinopathy was reported as the most common diabetes complication (3.6% in T1DM and 10.4 % in T2

DM). This was followed by nephropathy in T1DM and neuropathy in T2DM. The prevalence of complications increased with duration of disease. Retinopathy and neuropathy appeared to manifest within a short duration since diagnosis among T2DM patients compared to T1DM. Among those who have lived with diabetes for more than 20 years, the prevalence of coronary disease was more among T2DM patients (9.8%) compared to those with T1DM (4.8%).

14.1 % of the YDR patients had at least one co-morbid condition such as hypothyroidism, dyslipidaemia, hypertension, tuberculosis, sepsis etc., with the most common co-morbid being hypothyroidism (3.1%). 20.8 % of the early onset T2DM patients were reported to have co-morbidities such as dyslipidemia (11.3%), hypertension (7.4%) and hypothyroidism (2.1%).

Data from YDR showed that 96.2% of patients solely depend on practitioners of modern medicine for their diabetes management. The remaining had also sought care from alternate systems of medicine such as Ayurveda (0.9%), Homeopathy (0.4%), Unani (0.2%) and Sidha (0.1%).

97.1 % of the T1DM patients and 32.6 % of the T2DM patients in the registry were on insulin therapy alone. In addition, 39.5 % of the T2DM and 1.7% of the T1DM patients were on oral anti hyperglycaemic agents alone. 56.1% of the registered patients had at least one episode of hospitalization due to acute medical conditions related to diabetes. The most common reason behind hospitalization among the YDR patients was diabetic ketoacidosis /uncontrolled hyperglycemia (31.8 % of all YDR patients followed by hypoglycaemia (11.0% of the YDR patients).

The YDR registry has shed light on growing burden of youth onset diabetes in India with significant geographic variation in disease type and clinical profile. However, being a hospital based registry, the estimates may not reflect the actual population burden of youth onset diabetes in the country. The registry data on analysis showed high prevalence of complications among patients with youth onset diabetes even at registration. Despite many limitations, this registry provides a unique opportunity to study the natural history of youth onset diabetes in a low and middle income setting like India. Further the data generated by this registry would serve as a strong platform for formulating treatment guidelines and

designing interventions for improving the clinical outcomes as well as quality of life of youth onset diabetes patients in India.