LETTER TO EDITOR

Young Diabetes Registry at SKIMS An overview

Long- term prospective patient's registries are important epidemiological tool to build knowledge for many chronic disease conditions. For many years both hospital and population based Registries have contributed tremendously to epidemiology of chronic diseases such as cancers[1-3]. In the developed countries, registries play pivotal role in the health system to assess the quality of care delivered to chronic conditions such as diabetes[4-6]. Due to exponential increase in the global burden of diabetes, even well-established health systems are unable to deliver efficient patient monitoring and patient care. From the patients prospective the registries narrates health status over time to assess improvement and identifies areas of concerns. It also enables them to compare their clinical parameters and health outcome with other patients seeking care from the same health system.

The utility of such registries targeting children and adolescents with diabetes has been recognized over the past couple of decades. Current literature on youth onset diabetes, particularly type 1 Diabetes (T1DM) has been contributed mainly by registry collaborations such as World Health Organizations DIAMOND project, EURODIAB study, and national registries such as the SEARCH for diabetes in youth study in the United States [7-9]. However such data is not available from developing countries. In India, there is a substantial gap in the existing literature relating to the burden and natural history of youth onset diabetes. There were no national registers to record data of people with youth-onset diabetes since most published studies are from isolated clinics [10, 11.]

As the prevalence of diabetes among the young people in India is growing high, The Indian Council of Medical Research (ICMR) decided to establish the Registry of people with diabetes with Young Age at Onset (YDR) in 2006. The major objectives of YDR are to generate information on disease pattern or types of youth-onset diabetes including their geographical variations within India and estimate the burden of diabetes complications. The secondary objectives were:

1. To facilitate research in the areas of basic clinical, epidemiological, genetic, and molecular levels pertaining to young-onset diabetes.
2. To help promote awareness about the magnitude of problem among professionals and public health partners
3. To help in diabetes monitoring programs.
4. To assist in the Development of disease management guidelines
5. To develop human resources in diabetes epidemiology.

Official commencement of prospective data collection in YDR was on September 1, 2006. However, the registry included retrospective data from 2000 to 2006. Hence, the phase 1 period of the registry spans from January 1, 2000, to July 31, 2011. Subsequently, recruitment for the phase 2 of the registry has commenced and is currently on going.

YDR is implemented through regional collaborating centres (RCCs) which coordinate data collection with reporting centres. The registry started with 5 RCCs and 3 more were added in the year 2009. These centres are tertiary care public or private institutions with proven track record of conducting multicenter clinical trials and translational research projects in the field of diabetes. RCCs were selected on the basis of the anticipated quantum of enrolled patients with young onset diabetes.

Baseline pro forma is used to collect data at the time of registration and an annual follow up is taken with follow-up pro forma.

Phase 2 of YDR was started in 2012 and SKIMS became the 11th Regional Collaborating Centre on 15th of March 2015 with GMC Srinagar and other Health care institutes of Kashmir division as its reporting centres. The staff includes a MBBS doctor (SRF Medical) for collecting the clinical data and a Data entry operator (DEO). The staffs visit the peripheral Health centres of the valley for briefing the doctors about this project and referring any young diabetic patient to SKIMS for registry. As a part of the YDR project, training workshops are conducted for field doctors about data entry and importance of YDR. The young diabetics are

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also invited to attend these workshops for the purpose of diabetes education and interaction with doctors treating diabetes which helps to formulate ideas how to tackle the burden of young diabetes in the Kashmir valley. Also, the Department of Endocrinology holds Young Diabetic clinic on every Saturday where young diabetics are seen on priority basis in addition to routine Paediatric Endocrinology OPD. Despite its limitations, YDR registry provides a unique opportunity to study the natural history of youth-onset diabetes in Kashmir. Furthermore, 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 Kashmir.

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