Integrated Care for Type 1 Diabetes: The West Bengal Model

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Abstract

Introduction: A structured dedicated health programme for Type 1 diabetes mellitus (T1DM) has been initiated in the state of West Bengal, India. **Aim:** The aim is to provide comprehensive healthcare to all children, adolescents and young adults living with T1DM, along with the provision of free supply of insulin, glucose measuring devices, blood glucose test strips, and other logistics. The strategic framework for programme implementation is to utilise the infrastructure and manpower of the already existing non-communicable disease (NCD) clinic under National Health Mission. **Methodology:** Establishing dedicated T1DM clinics in each district hospital by utilising existing healthcare delivery systems, intensive training and hand-holding of named human resources; providing comprehensive healthcare service and structured diabetes education to all T1DM patients; and building an electronic registry of patients are important components of the programme. T1DM clinics run once a week on the same day throughout the state. All T1DM patients are treated with the correct dose of insulin, both human regular insulin and glargine insulin. Patients are routinely monitored monthly to ensure good glycaemic control and prevent complications of the disease. Routine anthropometric examination and required laboratory investigations are conducted in terms of glycated haemoglobin (HbA1c) values, growth and development, complication rates, psychological well-being, quality of life, and direct and indirect expenditure incurred by families. Through this programme, any bottlenecks or gaps in service delivery will be identified and corrective measures will be adopted to ensure better health outcomes for those living with T1DM.

Keywords: Integrated care, model of care, type 1 diabetes

INTRODUCTION

Type 1 diabetes mellitus (T1DM) is characterised by loss of pancreatic beta cell function, resulting in absolute insulin deficiency. Children and adolescents suffering from T1DM require daily multiple insulin injections to survive. In addition to this, self-monitoring of blood glucose on a daily basis is the cornerstone of T1DM management. If not treated with insulin, associated complications are manifold, ranging from acute life-threatening complications such as severe hypoglycaemia and ketoacidosis to chronic complications such as neuropathy, nephropathy, retinopathy and cardiovascular disease.^[1,2] In India, T1DM patients face many challenges including a lack of free supply of insulin, glucose measuring devices, blood glucose test strips, and

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other consumables, lack of structured diabetes education, lack of psychosocial support and inadequately trained healthcare workers. According to the International Diabetes Federation (IDF) Diabetes Atlas 2021, approximately 2,29,442 children and adolescents between 0 and 19 years of age are living with T1DM in India, which is the highest in

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the world.^[3] However, this number could be underestimated because, in the absence of standard care, most children do not live long enough to be counted.

Currently, there is no structured dedicated health programme for the management of T1DM in India or any other developing country. The chronic care model for the management of T1DM is the need of the hour. The model must be implementable, deliverable, scalable, replicable and pharmaco-economically viable.^[4] With this background, we have embarked upon developing, implementing and evaluating a health programme for the management of T1DM in the state of West Bengal, India. Initially, five districts have been selected as a pilot, with Kolkata as the nodal centre. The programme aims to provide comprehensive healthcare services (detection, management of disease and complications, appropriate referral and even rehabilitation) for T1DM patients, utilising the existing healthcare delivery system and building up a registry of T1DM patients for careful monitoring and following up of care services. Once the model gets established successfully in these pilot districts, the programme will be scaled up to cover the remaining health districts of West Bengal and is likely to become a model of care elsewhere.

Programme objectives are to run dedicated T1DM clinic once a week in each district hospital utilising existing set-up of the current non-communicable disease (NCD) clinic; provide comprehensive healthcare service for all T1DM patients, including provision of free supply of insulin, glucose measuring devices, blood glucose test strips, lancing devices and lancets, routine anthropometric examination including monitoring of growth and development, required laboratory investigations, emergency care services, monthly follow-up care services and timely referral to tertiary healthcare facility whenever necessary; provide structured diabetes education for self-management of disease, monitoring of blood glucose level and tackling its complications; adequately train human resources within the public health setup viz doctors, paramedics, nursing staff and counsellors to provide effective management and structured diabetes education to the patients; and build a registry of all T1DM patients to systematically collect, store, summarise information about each patient. The plan of implementation is by utilising the infrastructure and manpower of the currently existing NCD clinics under the National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke (NPCDCS) in the National Health Mission framework.^[5]

Framework for establishing dedicated T1DM clinics in district hospitals of West Bengal [Figures 1]

Step 1: Sensitisation programme

A sensitisation programme for stakeholders was conducted at the state level for all the identified districts. Salient points including the establishment of dedicated T1DM clinics in district hospitals of each identified district, initial supervisory visits by the core team, identification of dedicated human resources, their training

and hand-holding, maintenance of electronic patient registry and stock maintenance were discussed. Dedicated T1DM clinics would run once a week in the existing NCD clinics of district hospitals, utilising the existing physical resources as well as human resources in the set-up of the NCD clinic.

Step 2: Hand-holding

The core team, in charge of implementing, sustaining and evaluating the programme met for further brainstorming. Important components of the programme including training sessions at the state level, training resources and content, initial needs assessment, on-site training, hand-holding and community mobilisation were discussed. Each district hospital was tagged with a tertiary care centre for training and hand-holding and emergency care services. Unlike other forms of diabetes, there are various educational and training needs for T1DM care. Identified human resources of district hospitals underwent intensive training and hand-holding with endocrinologists of tertiary care centres.

Step 3: Identification and utilisation of currently existing resources

Human resources namely doctors, nursing staff, counsellors and data entry operators at the district level were identified for each T1DM clinic. These named personnel would be rigorously trained in T1DM care and would be responsible for running the clinics. Physical infrastructure already existing in the NCD clinic, such as a weighing machine, stadiometer, sphygmomanometer, stethoscope and ophthalmoscope would be utilised.

Step 4: Preparation of training modules

Specific training modules for doctors, nurses and paramedic staff were prepared and finalised. Hard copies of resources and materials were prepared for distribution to all human resources.

Step 5: Preparation of formats for data keeping

Formats for patient identity cards, patient diaries, logbooks for self-monitoring of blood glucose, and letters to schools in local languages were developed and finalised after scrutiny. The patient diary includes the initial visit format, monthly visit format and annual visit format. Patient education booklets were written in an easily understandable pictorial format and translated into local languages. The monthly summary report format and signage for the clinic were also prepared.

Step 6: Development of an electronic registry

Web-based application for T1DM programme was developed for maintaining an electronic database of patients. It has two components-visited patient details in the form of initial visit formats, monthly visit formats and annual visit formats, and stock maintenance of clinics.

Step 7: Training programme for identified human resources at the state level

The day-long training programme was organised at the state level for initial orientation and training of identified



Figure 1: Components of the T1DM programme in West Bengal

human resources. The programme agenda and schedule were prepared and shared with all stakeholders. The training programme had the following components-programme overview, didactic lecture sessions, hands-on demonstration of insulin administration and self-monitoring of blood glucose, demonstration of an electronic registry for data keeping and stock maintenance and pre- and post-training assessment. Lectures were delivered in four sessions, which are Session 1: introduction, diagnosis and classification of Type 1 diabetes, Session 2: management of Type 1 diabetes, Session 3: monitoring, nutrition and exercise in Type 1 diabetes and Session 4: complications, special situations and psychosocial aspects of Type 1 diabetes. The lecture sessions were facilitated by endocrinologists of tertiary healthcare centres.

Step 8: Needs assessment

Needs assessment in the form of initial supervisory visits to the NCD clinics was carried out by the core team to ensure the availability of all essential physical infrastructure, equipment, drugs and consumables. A checklist for health facility supervision was prepared for the same. Availability of essential physical infrastructure was assessed in terms of a separate clinic area, separate waiting area, utilities such as drinking water and electricity, toilet and handwashing facilities, adequate tables and chairs, a cabinet for storing registers and formats, laboratory facility, and internet facility. Laboratory facility was assessed in terms of availability of tests such as fasting blood glucose, post-prandial blood glucose, glycated haemoglobin (HbA1c) using high-performance liquid chromatography (HPLC) method, blood urea, creatinine, thyroid-stimulating hormone, fasting lipid profile, liver function test, kidney function test, complete blood count and urinary albumin-creatinine ratio. It was expected that NCD clinics would already have laboratory facilities in place for running these routine tests but it was cross-checked during site visits.

Availability of equipment such as weighing machine, stadiometer, sphygmomanometer (with both adult and child cuff)



Figure 2: Package of services being provided to patients at T1DM clinics

and stethoscope, ophthalmoscope, monofilaments, sharps boxes for safe disposal of sharps equipment, fridge for storage of insulin, computer and printer, and stationery items was noted. Drugs and consumables include human regular insulin, glargine insulin, 40 IU insulin syringes, 100 IU insulin syringes, glucose measuring devices, blood glucose test strips, lancing devices, lancets and oral glucose tablets for the management of hypoglycaemia. Using an observation checklist, gaps were identified and stakeholders of each clinic were notified.

Step 9: Supply chain maintenance

The NCD cell of each district hospital is responsible for maintaining a steady supply chain of insulin and all other logistics. Stocks are updated and evaluated regularly in each T1DM clinic.

Step 10: On-site training cum orientation workshop

Intensive on-site training cum orientation workshops were conducted separately at each district hospital to adequately train named human resources already within the existing healthcare delivery system who are responsible for running the T1DM programme. Sessions were interactive in nature, where evidence-based content along with clinical cases of T1DM was discussed. Topics included epidemiology in India (and missing cases), diagnosis, pathogenesis, vascular complications, metabolic complications, history taking, physical examination, diet (including carbohydrate counting), exercise, types of insulin and insulin regimen, insulin storage, insulin injection technique, principles of insulin dose adjustment, self-monitoring of blood glucose, laboratory investigations (including pitfalls with glycated haemoglobin), hypoglycaemia recognition and management, sick day rules, foot care and referrals that might be necessary. Data keeping both in hard copy and electronic registry, and stock maintenance were reiterated. Pre- and post-training knowledge assessment was performed.

During these visits, clinics were again assessed using a health facility supervision checklist to find out any gaps remaining.

Step 11: Community mobilisation

Grass root level workers such as auxiliary nurse midwives (ANM) and accredited social health activists (ASHA) are important stakeholders in awareness generation at individual and family levels. Beyond empowering the public with knowledge regarding signs and symptoms of the disease, they spread awareness of complications, and the gross impact of delay in diagnosis and treatment and facilitate timely referral of patients to dedicated T1DM clinics. In addition, Institutional Ethics Committee (IEC) materials in the form of leaflets and posters have been displayed at primary health centres and sub-centres to spread information at the community level. Ethics committee approval is obtained on 26/02/2022.

It has been proposed that the community-based assessment checklist (CBAC) form used by ASHAs for early detection of NCDs should be modified to include an additional question (Does anybody/any child in your family suffer from type 1 diabetes?). This will further facilitate community mobilisation.

Step 12: Clinic initiation

After ensuring the availability of physical resources and trained human resources, T1DM clinics have been initiated in each district hospital. Endocrinologists of tertiary care centres are providing initial hand-holding to the named personnel. T1DM patients and their caregivers also have access to telephonic contact with a trained programme coordinator for emergency management.

Step 13: Educational camps

Organising educational camps for T1DM patients at an interval of 3–6 months is an important component of the programme. Patients and their caregivers are trained regarding insulin administration, dose adjustment, injection site rotation, self-monitoring of blood glucose levels, tackling complications, sick day management, healthy meal planning, regular physical activity and psychosocial issues.

Framework for running established T1DM clinics in each district hospital shown in Figure 2

Step 1: Patient enrolment during the initial visit

All suspected/diagnosed cases of T1DM, irrespective of their age, are eligible to receive comprehensive healthcare services at the established T1DM clinics in their respective districts. On their initial visit to the clinic, patients are enrolled in the programme. They are given an identity card specifying their unique identification number and demographic details. Patients are advised to carry this identity card on every monthly visit to the clinic.

Step 2: Routine anthropometric examination including monitoring of growth and development

Anthropometric examinations including body weight, height, body mass index (BMI) centile, and blood pressure are measured routinely at each visit. Already existing infrastructure at district NCD clinics such as weighing machines, stadiometers, sphygmomanometers (with both adult and child cuffs), stethoscopes and ophthalmoscopes are used for anthropometric examination of T1DM patients. Insulin injection sites are checked every month to avoid lipohypertrophy and lipoatrophy.

Step 3: Management of disease and its complications

All patients with suspected/diagnosed T1DM are treated by already existing and trained named doctors posted at the T1DM clinic of each district hospital. A correct dose of insulin, both human regular insulin and glargine insulin, is prescribed to help achieve optimal glycaemic control for each patient without causing hypoglycaemia and resulting in normal growth and development. Premixed insulin in T1DM care is suboptimal and should be avoided. Comprehensive management of T1DM consists of lifelong insulin therapy with multiple injections per day, self-monitoring of blood glucose, nutritional management, regular physical activity, rules for sick days and psychosocial support.

Step 4: Required laboratory investigations

Laboratory investigations are advised as required following recommended guidelines.^[6] Routine investigations include fasting blood glucose, post-prandial blood glucose, HbA1c test using HPLC method, blood urea, creatinine, thyroid-stimulating hormone, fasting lipid profile, liver function test, kidney function test, complete blood count and urinary albumin creatinine ratio.

Step 5: Dispensing of insulin and other consumables

Insulin vials and other consumables are dispensed to each patient by already existing and trained named nursing staff of the T1DM clinic. There is free provision of human regular insulin and glargine insulin for the management of patients with T1DM. Along with this, 40 IU insulin syringes for administering human regular insulin and 100 IU insulin syringes for administering glargine insulin are provided to patients in adequate quantity. Self-monitoring of blood glucose being the cornerstone of T1DM management, patients are also given Self-monitoring of blood glucose (SMBG) logbooks for recording daily readings, glucose measuring devices, blood glucose test strips, lancing devices, and lancets. Ideally, blood glucose should be measured 4–5 times per day but due to practical reasons and logistic constraints, this model has provision for up to three blood glucose test strips per day.

Step 6: Patient education and counselling

Imparting structured diabetes education is an important component of the programme because proper self-care ensures glycaemic control and thereby reduces further complications. Patients and their caregivers are counselled at Outpatient Department (OPD) basis by already existing and trained named nursing staff or NCD counsellor for self-management of disease, monitoring of blood glucose level, tackling complications, sick day management, healthy meal planning, regular physical activity and psychosocial issues. Patients and their caregivers are trained for proper storage and administration of insulin, including insulin dose adjustment, and injection site rotation. In addition to this, patient education booklets in the local language are provided to them.

Step 7: Monthly monitoring of patients

All T1DM patients are routinely followed up once every month to ensure better glycaemic control and better prevention of complications. Their SMBG logs for the previous month are checked and appropriate dose adjustments and dietary modifications are performed. There is a screening of microvascular and macrovascular complications through anthropometric examination and laboratory investigations as per the recommended guidelines.^[6] Utilisation of insulin and blood glucose test strips is also cross-checked every month to prevent wastage.

Step 8: Day-care facility and emergency care services

Patients are provided day-care facilities and emergency care services for the management of sickness episodes such as severe hypoglycaemia, hyperglycaemia or diabetic ketoacidosis at the level of the district hospital where the T1DM clinic is located.

Step 9: Timely referral to nearest/tagged tertiary health care centre if necessary

T1DM patients are referred and fast-tracked to higher health facilities when there are life-threatening acute metabolic complications of diabetes, poor metabolic control that necessitates close monitoring of patients, severe chronic complications of diabetes that require intensive treatment and uncontrolled diabetes during pregnancy.

Step 10: Data keeping and stock maintenance

Hard copy data of each patient is maintained using a T1DM patient diary, which includes formats for initial visits, consecutive monthly visits and annual visits. Patient data are also entered into an electronic registry during each visit by a designated data entry operator and electronic prescriptions are generated. Stock maintenance is done on every clinic day and summary reports are generated monthly.

Framework for evaluating the T1DM programme Step 1: Patient point of view

Evaluation is being performed to find out the effect of the T1DM management programme in West Bengal primarily on the clinical parameters of patients, their psychological burden, and direct and indirect expenditure of their families through assessment at baseline, and assessment after 1 year and 2 years. HbA1c, growth and development, complication rates, psychological well-being, quality of life and direct and indirect expenditure incurred by families are some of the indicators for evaluation. The primary endpoint is HbA1c, our objective is to find out the effect of the programme primarily by showing improvement or non-inferiority of

HbA1c outcomes to demonstrate favourable effect on blood glucose control.

Step 2: Programme point of view

Key service delivery parameters in terms of availability, accessibility and quality of the T1DM management programme have been formulated. Any gaps or bottlenecks of the T1DM programme will be identified and appropriate corrective measures implemented.

CONCLUSION

Through this dedicated programme, we are hoping to improve care for children and adolescents living with T1DM in West Bengal. Evaluation of this programme will help in the identification of any gaps or bottlenecks and the implementation of appropriate corrective measures for the same. This will help to ensure better health outcomes for these children in the long run.

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Conflicts of interest

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