

A Unique Government–NGO–Industry Partnership Care Model to Reduce Morbidity and Mortality Among Underprivileged Children With Type 1 Diabetes Mellitus in LMIC: A Pilot Study From Tamil Nadu, India

Krishnan Swaminathan, Suruliappan Sopnajothis¹, Krishnamurthy Nidharshana², Govindasamy Prakash³

Idhayangal Charitable Trust, Coimbatore, ¹Department of Medicine, Theni Government Medical College Hospital, Theni, ²Department of Pediatrics, Coimbatore Medical College Hospital, Coimbatore, ³Department of Diabetes, Salem Mohan Kumaramangalam Medical College Hospital, Salem, Tamil Nadu, India

Abstract

Aim: To pilot a 1-year comprehensive type 1 diabetes mellitus program, assessing outcomes on glycemic control and diabetic ketoacidosis (DKA) admissions pre- and post-intervention in underprivileged children with type 1 diabetes mellitus from three selected Government Medical College Hospitals across Tamil Nadu state, through a Government–nongovernmental organization (NGO)–Industry partnership. **Materials and Methods:** A total of 214 children were identified through the hospital database. Highly focused diabetes mellitus and insulin education along with analog insulins in penfill cartridges in the basal-bolus regime, high quality 800 memory glucometers with 100 glucose strips per month, ultrafine needles, 24/7 telephone support, and monthly review were supported to all the children. Data on baseline characteristics, pre- and post-intervention glycosylated hemoglobin A1c (HbA1c), and DKA admissions were tabulated on Microsoft Excel, and the results were analyzed. **Results:** A 2.4% reduction in HbA1c and more than 90% reductions in DKA admissions were seen post-intervention compared with baseline. This can potentially translate to huge reductions in mortality and cost savings for all stakeholders. **Conclusions:** A combined Government–NGO–Industry partnership is the need of the hour to reduce morbidity and mortality associated with type 1 diabetes mellitus among underprivileged children in India. Our model has the potential to serve as a blueprint for type 1 diabetes mellitus care in low- and middle-income countries.

Keywords: LMIC, outcomes, type 1 diabetes mellitus

INTRODUCTION

Type 1 diabetes mellitus is exponentially increasing worldwide with an estimated 8.4 million individuals as of 2021.^[1] The largest relative increase by 2040, predicted to be 60%–107% of 2021 numbers, is expected to be in lower and lower-middle-income countries. The prevalence of type 1 diabetes mellitus <20 years of age in India (2021) is estimated to be 56.9/100,000 population with 50% of individuals receiving only “minimal care” as defined by a simple insulin regime, no or minimal self-monitoring of glucose, glycosylated hemoglobin A1c (HbA1c) or diabetes

mellitus education.^[2] Not surprisingly, this translates to a huge medical, economic, and social burden, especially for rural underprivileged families.^[3] Significant challenges faced by families, especially from low socio-economic strata include surviving diabetic ketoacidosis (DKA) admission either at presentation or multiple admissions

Address for correspondence: Dr. Krishnan Swaminathan,

Idhayangal Charitable Trust, Site 10 to 11, Natchatra Classic Phase 2, Greenfield Housing, Era Mohan Nagar, Coimbatore 641048, Tamil Nadu, India.

E-mail: snehasswaminathan@gmail.com

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during the disease in peripheral centers with poor access to high-quality protocol-based treatments, nonexistent dedicated type 1 diabetes mellitus clinics in many centers, cost of insulins, especially analogs, patchy to nonexistent supply of pen insulins from government hospitals, variable potency of vial insulins, lack of fridges to store insulins, poor access to self-monitoring of blood glucose (SMBG), poor insight into advanced diabetes mellitus technologies like continuous glucose monitors and insulin pumps, poor awareness among both healthcare professionals and families on small nuances of insulin management, high risk of severe hypoglycemia, suboptimal screening for complications, to name a few. Most families from rural underprivileged areas are below poverty line (BPL) families with an average combined parenteral income of less than Rs. 2 lacs per annum. Such families are stuck either way. State hospitals, while trying to do their best within limited resources, are hampered by long waiting lines, vial insulins with painful syringes, no dedicated type 1 diabetes mellitus clinics in most centers, suboptimal diabetes mellitus education, nonexistent diabetes mellitus educators support, and high incidence of recurrent DKA admissions. Recourse to private practitioners has its own set of problems for families, mainly relating to unaffordable recurrent consulting fees, analog insulin, and glucose strips prescription beyond reach for the common man with monthly expenses around Rs. 5000 and high cost of diabetic emergency admissions. At some point, underprivileged families give up on their children leading to a painful increase in morbidity and mortality. Therefore, tackling this burden needs a fresh, out-of-the-box thought process to ensure that no single poor child with type 1 diabetes mellitus suffers for want of the best treatment to lead happy, healthy productive lives. This is possible only through a Public–nongovernmental organization (NGO)–Industry partnership, considering the huge burden of type 1 diabetes mellitus in India. Our previous published work^[4–6] and current pilot work presented here are a result of a partnership of multiple stakeholders including Idhayangal Charitable Trust, NGO focused on type 1 diabetes mellitus among underprivileged children across India, Life for a Child (LFAC), an organization based at Australia with the same ethos of not letting one poor child suffer with type 1 diabetes mellitus across the globe, selected Government Hospitals across Tamil Nadu State and National Health Mission, Tamil Nadu State. We hope the results of this pilot project serve as a blueprint for rolling out such partnerships across low- and middle-income countries worldwide.

Aim

To pilot a Public–NGO–Industry partnership program focusing on improving care for underprivileged children with type 1 diabetes mellitus across three selected Government Hospitals in Tamil Nadu State.

MATERIALS AND METHODS

Selected Government Medical College Hospitals Diabetes Departments, Idhayangal Charitable Trust (www.idhayangal.org), a registered Charitable Trust focused on type 1 diabetes mellitus along with National Health Mission (Tamil Nadu) and LFAC (Australia) were the main stakeholders in this pilot project. The study period was from April 2022 to March 2023. Children were selected by the respective Head of Departments through their database from three major Government Medical College Hospitals across Tamil Nadu. Idhayangal Charitable Trust was the executor of the project with baseline and three monthly visits to the respective Medical College Hospitals. All children received insulin glulisine from the Idhayangal Charitable Trust. LFAC, Australia was involved in supporting this project with an unrestricted supply of Accucheck glucometers (India) along with 100 strips per child per month and basal insulin supply in the form of Insulin glargine. Idhayangal Team comprising of consultant endocrinologist, diabetes specialist nurses, physician assistants, diabetes educators, and volunteers initiated comprehensive diabetes education in every center with a huge focus on insulin potency, storage, insulin injection techniques, site rotation, SMBG, hypoglycemia education, and sick day rules. Baseline HbA1c was done in all children using an Afinion HbA1c analyzer (Abbott, India) followed by a three-monthly A1c assessment. After comprehensive education, every child was provided with basal-bolus insulins (Insulin glulisine and Insulin glargine), glucometer (Accu-Chek Activ, Roche India), 100 strips per month, glucose diary, 45 needles per month (4 mm Ypsomed needles, Ypsomed India), InsuliCool fridge (Godrej) to store insulins at manufacturers recommendations, if the family did not possess a fridge and 24/7 dedicated telephone support with a network of diabetes educators working for Idhayangal Charitable Trust. Informed consent was obtained from all families. Data, including demographics, age, gender, baseline, and three-monthly A1c's, and frequency of diabetes ketoacidosis admissions, were collected in Microsoft Excel, and the results were analyzed. Paired *t* test was used to assess for significance between baseline HbA1c and 12 months follow-up value. A *P* value of <0.05 was considered significant.

Ethical Approval

The study did not need ethical approval as it was standard of care and no treatment or medications were given.

RESULTS

A total of 214 children were supported in this pilot study from three Government Hospitals. The mean age of children was 11.9 years with a mean duration of type 1 diabetes mellitus of 6.1 years. The age range was between 3 and 20 years. Females outnumbered males (129: 85).

The baseline HbA1c was 11.1% (98 mmol/mol, standard deviation = 2.5) before the pilot study. The range of HbA1c at baseline was 5.7%–19.7%. This level reflected the glycemic control on predominantly twice-daily vial insulins supported by the State hospital system. Post-intervention with basal-bolus four times insulin, the HbA1c values were 8.9 (2.0), 8.8 (1.9), 8.9 (1.9), and 8.7 (1.6), respectively, at 3, 6, 9, and 12 months duration, for the whole study group [Figure 1]. Only 3 children had an HbA1c of $\leq 7\%$ at baseline compared with 14 children at the end of the study. All children had to do three times a day SMBG on an 800-memory glucometer, which was cross-checked during every three-monthly visit. About 90% compliance was observed for three times SMBG, the rest were compliant at least once or twice a day. The difference between baseline HbA1c and 12-month post-intervention HbA1c was 2.4% ($P < 0.01$). The total number of DKA admissions reduced from 82 pre-intervention (preceding year) to 11 admissions 1 year post-intervention ($P < 0.01$) [Figure 2]. The number of severe hypoglycemia reduced from 43 admissions to 2 admissions over the study period. Insulin dose requirements were <5 years: 0.68 units/kg body weight, 6–10 years: 0.74 units/kg body weight, 11–15 years: 0.90 units/kg body weight, and >15 years: 0.89 units/kg body weight.

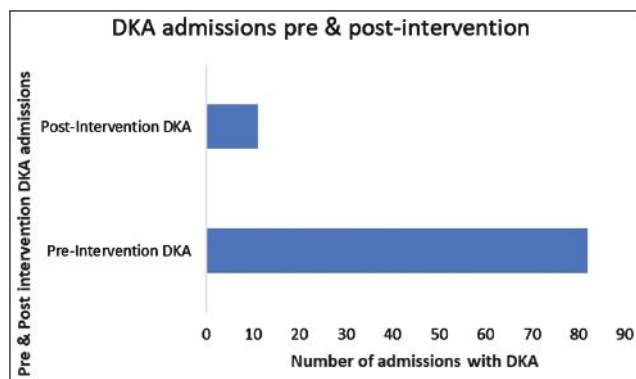


Figure 1: HbA1c over 12 months

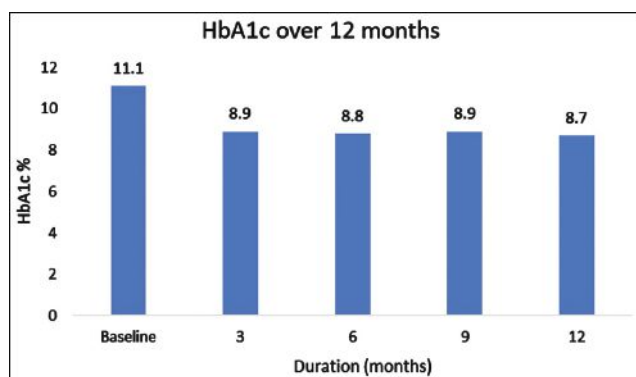


Figure 2: DKA admissions pre- and post-intervention over a 12-month period

DISCUSSION

Our pilot study has shown that a focused Public–NGO–Industry partnership can lead to significant reductions in HbA1c and DKA admissions among deserving underprivileged children with type 1 diabetes mellitus registered in government hospitals. If sustained, such reductions should lead to meaningful outcomes in microvascular and macrovascular complications, quality of life, cost savings, and resource allocations.

There is a resigned exasperation, both among medical professionals and BPL families concerning type 1 diabetes mellitus in India. Well-meaning doctors in State hospitals have their limitations due to huge competing constraints to deliver high-quality care within limited resources. Private practitioners feel a huge strain of supporting poor families considering the financial burden and the time needed within their busy schedule to support such children and their families. This leads to a huge increase in morbidity and mortality of deserving underprivileged children with type 1 diabetes mellitus for no fault of their own. Anecdotally, we believe that most children with type 1 diabetes mellitus from BPL families in India do not survive past their 20s with mortality related to either end-stage kidney disease or severe DKA admission. We, therefore, need “out of the box” solutions for improving outcomes in these strata in low and low-middle-income countries. This is the rationale for our pilot study to assess whether a combined effort would lead to meaningful clinical outcomes among underprivileged children enrolled in State Hospitals.

There are important messages from this study. First, within the resource limitations, the baseline HbA1c in state hospitals is around 11% for a mean duration of diabetes of 6.1 years. This is non-sustainable in the long term with a huge risk of recurrent DKA admissions, blindness, and renal failure. Second, the major limiting factors that need immediate input from the Health Ministry are the need for a dedicated type 1 diabetes mellitus registry and dedicated type 1 diabetes mellitus clinics in all Medical College Teaching Hospitals, availability of continuous supply of high-quality pen insulins and ultrafine needles, presence of diabetes educators to educate and guide children, access to self-monitoring of blood glucose, improved diabetes awareness and education to families. It is reassuring to see huge progress with the establishment of the Young Diabetes Registry through the Indian Council of Medical Research^[7] and the recently inaugurated Tamil Nadu Type 1 Diabetes Mellitus Registry by the Health Ministry and NHM, Tamil Nadu.

All the above issues were addressed before the start of this pilot work. The main strength of the work was the unrestricted support from both the NGOs, Idhayangal Charitable Trust, and LFAC in terms of analog insulins in pen devices, ultrafine 4 mm needles, excellent cold chain

storage including supply of fridges to homes of children if needed, high-quality glucometers, unrestricted glucose strips, huge focus on diabetes education by a dedicated team, and 24/7 support through a network of diabetes educators.

While cost-effectiveness analysis is beyond the scope of this pilot study, general inferences can be safely extrapolated. There is good evidence for a multi-fold increase in diabetes-related costs for those children with a history of DKA compared to those without.^[8-11] Studies from the US show that DKA episodes represent more than \$ 1 of every \$4 spent on direct medical care for those with type 1 diabetes mellitus and \$1 of every \$2 spent in those with multiple episodes of DKA. The median hospitalization cost for one admission of DKA in this study was close to \$30,000, far outweighing even the costliest insulin in the market. Our pilot study has shown impressive reductions in DKA episodes from 82 admissions the year preceding our work to 11 admissions 1-year post-intervention. The cost saved from preventing DKA admissions alone can potentially fund analog insulins (basal-bolus) for all Government Hospitals across our nation. In addition, there is evidence to suggest that even reducing the HbA1c to <9% will translate into significant reductions in complications of type 1 diabetes mellitus, especially proliferative retinopathy, and persistent macroalbuminuria for up to 20 years.^[12] A recent study from India has suggested that the economic burden of blindness in Indian children is estimated at INR 128 billion considering the economic productivity loss of 35 working years.^[13] Estimates will be much higher for renal failure and dialysis. We propose that reductions in HbA1c from 11.1% to 8.7% if sustained in the long term can potentially fund the entire type 1 diabetes mellitus program in India based on the above analysis.

Our study highlights the need for a focused Public–NGO–Private partnership that can completely transform the care of children with type 1 diabetes mellitus attending state hospitals in India. A 2.5% reduction in HbA1c and impressive reductions in recurrent DKA admissions over 12 months is not possible within the current limitations and constraints in state hospitals. However, a combined model of care is a win-win for all stakeholders. For underprivileged children and their families, access to high-quality analog insulins, glucometers, unrestricted glucose strips, 24/7 telephone support, huge reductions in admissions, and the smile on their child's face, all free of cost, gives great peace of mind as well as a priceless confidence that their children can also lead happy healthy lives. Outcome data from this study also helps stakeholders from state hospitals to lobby for more resources, as even one DKA admission saved or one end-stage kidney failure or avoidable blindness prevented is a huge cost saving for the government and life-transforming for the child and their families.

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Conflict of interest

There are no conflicts of interest.

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