



ORIGINAL ARTICLE

Establishing the Saudi pediatric and youth diabetes registry: initial data and challenges

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ABSTRACT

The Saudi National Diabetes Registry focuses mainly on adult patients. In 2020, the National Guard Health Authority (NGHA) launched the Saudi Pediatric and Youth Diabetes Registry (SPYDR), for children and adolescents with diabetes. This report is about the first data and the challenges we faced during SPYDR initiation. Patients were identified from the electronic medical records of the Saudi NGHA hospitals using the International Classification of Disease (ICD-10). A trained coordinator verified the diagnosis and entered patients' details into the registry and a random sample was validated by experienced endocrinologists. The data were analyzed according to patients' demography,

diabetes subtypes, duration, control, and complications. The challenges faced by the team were identified and addressed. At the time of manuscript submission, 2,344 individuals were enrolled. Their mean age at diagnosis was 9.08 (± 4.27) years and 1,136 (48.46%) were females. Of these, 91.3% have type 1 (T1D), and 6.4% have type 2 diabetes (T2D). The mean HbA1c was 10.45% (± 2.36) and duration of diabetes was 5.31 (± 3.05) years. The main challenges included the COVID-19 pandemic, data validation, and centers' participation. However, within 12 months of initiation enrolled subjects matched the expected number. Despite the challenges, the first step of SPYDR was achieved. The initial data confirmed that T1D is the most common form of childhood diabetes, and the frequency of

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T2D is comparable to regional and international data. SPYDR provides the infrastructure for data sharing and collaborative research with the enrollment of patients from other Saudi healthcare institutes.

KEYWORDS

Database; Diabetes; National guard; Pediatrics; Registry; SPYDR; Saudi Arabia.

INTRODUCTION

Diabetes research is a sophisticated endeavor because of the complex interactions between multiple body systems [1]. One of the critical aspects of diabetes research is understanding the essential indicators of the disease burden. In Saudi Arabia, important gaps still exist about the burden of diabetes on the local population, which is in part contributed to by relatively limited research that explored this task. To date, there is no reliable up-to-date estimate on the incidence of diabetes among children, the prevalence, or even health outcomes for the affected population.

The availability of a structured database would help us to understand the needs of our patients and will provide a platform to share experiences and benchmark our practice with data from other centers. The evidence has shown that scattered data could collectively inform our understanding of patients' needs and know better about challenges in management [2,3]. To a great extent, using data from the registry in benchmarking approximates our differences in clinical practice and improves awareness about research gaps and research opportunities. There were multiple scattered attempts to report on patterns of type 1 diabetes (T1D) in different parts of Saudi Arabia [4–14]. These included reports on: National surveillance for T1D, type 2 diabetes (T2D), and prediabetes among children and adolescents as well as the efficacy of healthcare services provided to T1D and T2D patients [5,6]. Other efforts assessed the incidence trends, epidemiological patterns, and clinical presentations of T1D at its onset [7–9]. However, additional systematic efforts should be conducted to understand the true burden of

diabetes on the health of the pediatric population in Saudi Arabia.

As Saudi Arabia moves toward more focus on prevention and improving population health, learning about the baselines of the disease burden is of paramount importance to achieve such a goal. Therefore, establishing a pediatric diabetes registry will significantly support our understanding of the trends and disease patterns and will be reflected in improving the population health of young patients with diabetes. Before the adaptation of electronic medical records (EMRs), creating a database that informs further development in clinical services and research had been a major challenge. Fortunately, identifying disease patterns has become much easier with the widespread adoption of information technology throughout health care [15]. At the National Guard Health Affairs (NGHA), we took the privilege of having a reliable common EMR system that is used by all of the NGHA institutes, to establish a Saudi pediatric and youth diabetes registry (SPYDR).

The primary aim of our SPYDR is to provide trustworthy and up-to-date information on epidemiological demographics, early and ongoing management as well as disease outcome over years of treatment in the pediatric diabetes population in Saudi Arabia. The initiative of this registry has started at the NGHA institutes with the ambition to expand and include other institutes across Saudi Arabia to serve as a national registry for the Saudi pediatric and youth population with diabetes.

MATERIALS AND METHODS

This descriptive study included all patients attending the Saudi NGHA hospitals who met the eligibility criteria of the SPYDR. NGHA institutes include five hospitals that serve all employees and dependents of the Ministry of National Guard in the central, western, and eastern regions of Saudi Arabia (Figure 1). King Abdullah Specialized Children Hospital (KASCH) has a capacity of 420 beds for pediatric patients, of which 60 are in the emergency department. In addition, diabetes service is also provided to adolescents and young adults

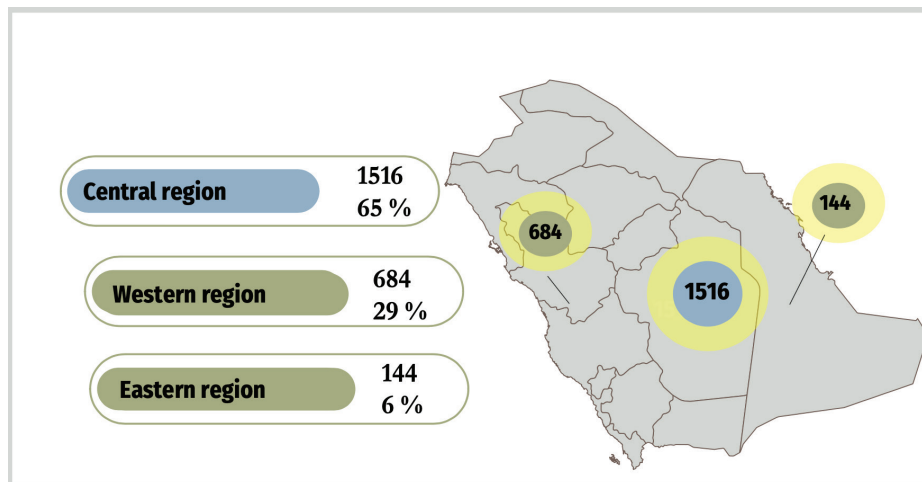


Figure 1. Distribution of children and youth with diabetes in SPYDR* (2022) at different institutes of National Guard Health Affairs in Saudi Arabia, $n = 2,344$.
*SPYDR – Saudi Pediatric & Youth Diabetes Registry.

in KASCH that will eventually be included and longitudinally followed in the registry. Other NGHAs tributaries include King Abdulaziz Medical City (KAMC) in Jeddah, the second largest tertiary NGHAs tributary (751 beds) that provides medical care and prevention programs, and Prince Mohamed bin Abdulaziz Hospital in Madinah, King Abdulaziz Hospital (KAH) in Al Ahsa and Imam Abdulrahman Al Faisal Hospital in Dammam, with a bed capacity of 100 beds, both representing the eastern region. KAH (bed capacity of 300 patients) offers primary and secondary medical care for NGHAs employee and their dependents in the eastern region.

The database included all pediatric patients treated for diabetes in the different institutes of the National Guard Health Affairs (NGHA) between 2016 and 2021. Data collection was initiated in 2020 including retrospective data from 2016 and continued onwards to include the data in 2021. The main site was KASCH in Riyadh, and then other centers followed in the registry. The first phase of the registry was started in 2016 and lasted 12 months including only patients from KACSH. The second phase started in 2017 and included patients recruited from KAMC in Jeddah, Prince Mohamed bin Abdulaziz Hospital in Madinah, KAH in Al Ahsa and Imam Abdulrahman Al Faisal Hospital in Dammam.

Study subjects

Cases were identified for the registry via the EMR using International Classification of Disease (ICD-10) for T1D, T2D, Maturity onset diabetes in young, or other undefined or secondary diabetes. A trained data registrar used a query system within the EMR to identify all patients meeting the age and the diagnostic criteria. Subsequently, a research coordinator verified the diagnosis for each patient from EMR. The training of the data registrar and the research coordinator was conducted by two pediatric endocrinologists to ensure a standardized ascertainment of case diagnosis, data collection, and data entry. The research coordinator abstracted all the essential information into the registry system, which was hosted by an online platform (RedCap). The final data entry and verifications were conducted by the research team in KASCH; however, we ascertained the accuracy of cases' diagnosis and other relevant data in different cities using the EMR system and the local teams when necessary. The registry has been quarterly updated with retrospective information including those from newly diagnosed patients.

We recruited all patients ≤ 18 years of age who presented with any form of diabetes mellitus to the pediatric/adolescent diabetes service or the Emergency Department in the participating

NGHA institutes. Information collected in the registry included patients' demographics, clinical information (e.g., baseline diagnostic information, admission data, outpatient follow-up visits), and laboratory investigations (Table 1). Different sections of the registry include patients' demographics, baseline information at the diagnosis, and comprehensive clinical data were included such as body mass index (BMI), blood pressure, retinal, foot, and autoantibodies screening, and the treatment received by the patient. In addition, the registry captured information on clinical care such as referral to specialized services, such as child and adolescent mental health, dietitians, diabetes educators, or smoking cessation. Up to seven hospital admissions with their length of stays were captured and family history of chronic conditions including hyperthyroidism and celiac disease were also collected. The fourth section included laboratory variables for a maximum of four readings. These variables included total cholesterol, high density lipoprotein (HDL) cholesterol, low density lipoprotein (LDL) cholesterol, triglyceride, thyroid function tests, HbA1c, urinary albumin, and other markers of possibly associated autoimmunity. In addition, the registry captures follow-up information including growth, treatment modalities, nutrition, and acute and long-term complications including diabetic ketoacidosis (DKA) admissions.

Before data collection, the research team planned for a reasonable continuity of the process in the subsequent years. Based on the available resources and the pilot study, it was estimated that 300 patients will be enrolled in the registry every month in the coming 2 years. This was set as the predicted number of a monthly register of the new patients and was monitored for in every quarter of the year. We keep track of the annual records of total number of patients in the registry.

Statistical analysis

All statistical analyses were performed using STATA 15 for Mac. Descriptive statistics such as frequencies, means, and standard deviations were used to describe the initial epidemiological data and clinical course of diabetes among our included patients.

RESULTS

At the time of submitting the manuscript, 2,344 patients were enrolled in the SPYDR. The process of data collection was slower than predicted between Q4-2020 and Q3-2021. However, after this initial period, the pace of data collection accelerated and was more in keeping with the expected rate (Figure 2). Descriptive analyses are depicted in Table 2. The average age of the patient population was 9.0 years and a little over a half were males (51.7%). The majority of the patients were captured in the central region (64.6%) followed by the western region (24.7%) of Saudi Arabia (Figure 1).

The majority of cases were diagnosed with T1D throughout the study period (91.3%). The disease duration was 5 years (SD = 3.0) on average. Approximately, a third of the pediatric patients had a family history of diabetes (Table 2). An 8.2% of pediatric patients had at least one additional comorbidity. During initial and follow-up data collection, 1.8% of the patients were transferred to adult clinics after the age of 16 and no deaths were reported. The average HA1C was 10.4% at diagnosis and missing values of collected variables ranged between 0% and 79.9%. The mean blood insulin level was also high, at 20.38 uIU/ml, and the mean blood gas pH was 7.3. The mean initial platelet count was $339.48 \times 10^9/l$, and the mean white blood cell count was $9.1 \times 10^9/l$ (Table 2).

The presence of anti-GAD, insulin, and islet antibodies was unknown for most patients at this registry phase: 68%, 92%, and 81%. At this stage, 5.72% of patients tested positive for GAD antibodies, 2.73% tested positive for insulin antibodies, and 0.68% tested positive for islet antibodies (Table 2). Finally, while around 7.8% of patients had missing information about DKA, 22% of patients suffered from DKA during follow up.

During data collection of SPYDR from different NGHA institutes, in terms of data safety and confidentiality, the ownership of the registry data and availability to be used by different contributors in the registry required written clarification and signing of contracts.

Table 1. Variables collected in the SPYDR.

Demographics	
Age	Gender
Area of residence	Nationality
Hospital site	Duration of the disease
Type of diabetes	Patient status
Baseline information	
Was the patient diagnosed in one of the National Guard Health Affairs (NGHA) hospital?	BMI at diagnosis
Location of diagnosis	Glycated hemoglobin (HbA1C) at diagnosis
Comorbidities	Antibodies status
Blood insulin level	Glucose level – Point of care (POC)
Did the patient have DKA?	Patient admitted
Length of hospital stay	Family history of diabetes
Family member(s) with diabetes	Age at diagnosis
Clinical information (On admission)	
Age at admission	Length of stay
Reason for admission	Computerized tomography (CT) scan result
HbA1C at admission	Glucose level (POC)
Initial white blood cells count (WBC)	Initial hemoglobin (Hgb)
Glucose level random (Glu R)	BMI at admission
Clinical information (Outpatient Visit)	
Non-insulin anti diabetic	Age
Care giver	BMI classification
Systolic blood pressure	Foot examination result
Diabetes treatment at time of HbA1C measurement	Dietitian/Nutrition clinic
Diabetic educator clinic	How many times the patient was admitted to the ward?
How many times the patient was admitted to the intensive care unit?	Emergency visit
Insulin pump therapy	Retinal screening result
Type of basal insulin	Virtual visit
Laboratory information	
Total cholesterol level	LDL cholesterol level
HDL cholesterol level	Urinary albumin level
HbA1C value	Celiac disease screening
Thyroid stimulating hormone (TSH)	Free thyroxine (T4) level
Outcome	
DKA	
Death	
Reason of death	
Transfer to adult services	

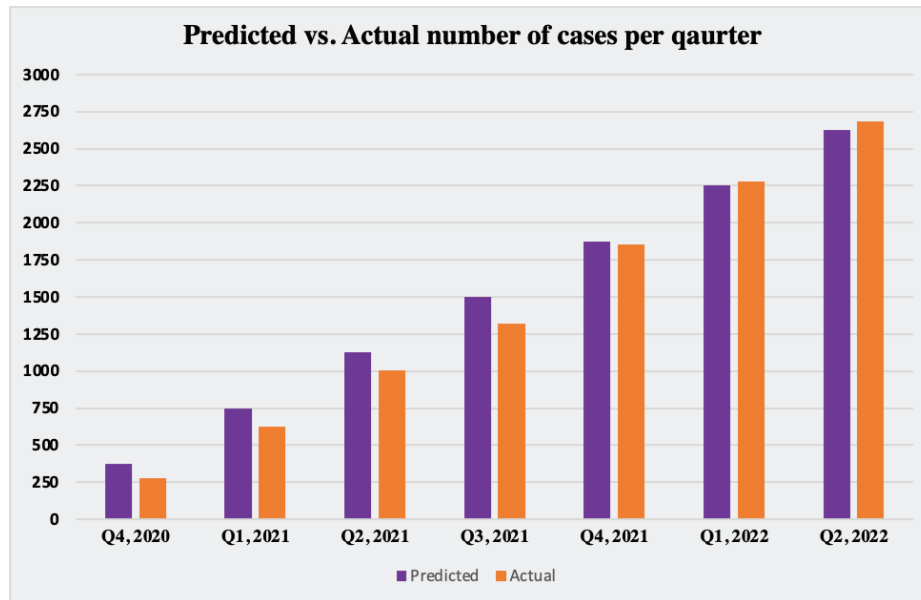


Figure 2. Registry progress in data collection since the establishment of SPYDR*. *SPYDR – Saudi Pediatric & Youth Diabetes Registry.

DISCUSSION

In the initial documentation of SPYDR, the demographics, clinical, and laboratory data of the patients were included. We highlighted the barriers and challenges that were encountered by the investigators during data collection and data entry. SPYDR confirmed that T1D accounts for more than 90% of childhood diabetes and that the frequency of pediatric T2D is comparable to some regional and some international figures. Although SPYDR is not the only Saudi national diabetes registry, it is the first one to specifically focus on diabetes mellitus in the pediatric age group in Saudi Arabia.

The Saudi National Diabetes Registry was initiated in 2001, and while it included children, its main target group was adult patients with impaired glucose tolerance, type 1 or type 2 diabetes, and gestational diabetes mellitus [16,17]. SPYDR primarily targets children and adolescents with diabetes mellitus. Additionally, data collected in SPYDR include the presence or absence of diabetes autoantibodies as well as the presence of monogenic diabetes as an underlying etiology, both of which are of distinct value when evaluating the cause of diabetes in children and youth. Moreover, with the increasing use and

availability of technology for the management of diabetes, one of the focuses of our SPYDR was to capture the utilization of insulin pumps in the target population. Some previous reports focused on challenges in treatment including risk factors, predictors, severity, and outcomes of hyperglycemia or DKA and hypoglycemia as well as long-term complications and all-cause mortality risks [15,18,19]. Moreover, some investigated the effect of other associated factors such as vitamin D status in children with T1D and the perinatal morbidity of infants of diabetic mothers have also been previously investigated [9,20]. SPYDR will inform clinicians and investigators in this field about the extent, patterns, and outcomes of the rapidly expanding problem of diabetes in children and youth in Saudi Arabia. It will also enhance the clinical practice and facilitate future quality improvement projects that would ultimately improve patients' care and outcomes.

Other parts of the world have been progressing well in terms of understanding the disease in the pediatric population. For instance, the "SWEET" registry endorsed by the International Society of Pediatric and Adolescents with Diabetes includes a platform for sharing experiences and benchmarking clinical practice with other similar centers, worldwide [21]. At a regional

Table 2. Descriptive statistics of the overall SPYDR* population at baseline.

Nationality	n (%)
Saudi	2,281 (97.31)
Non-Saudi	63 (2.69)
At the time of diagnosis, n (%)	
Patient diagnosed in a National Guard Health Affairs (NGHA) hospital	
No	496 (21.16)
Yes	1,741 (74.27)
Missing	107 (4.56)
Family history of diabetes	
No	1,015 (43.30)
Yes	670 (28.58)
Missing	659 (28.11)
Type of diabetes	
Type 1	2,142 (91.38)
Type 2	151 (6.44)
Other (e.g., monogenic, neonatal, secondary etc.)	44 (1.88)
Missing	7 (0.30)
Mean glycated hemoglobin (HBA1C) at diagnosis (SD)	10.45 (2.36)
Mean blood insulin level (SD) uIU/m	20.38 (28.27)
Mean blood gas (Initial HCO3) (SD)	17.94 (11.22)
Mean blood gas (Initial PH) (SD)	7.3 (0.13)
Mean initial platelet count $\times 10^9/l$ (SD)	339.48 (105.14)
Mean White blood cells count (WBC) $\times 10^9/l$ (SD)	9.1 (5.8)
Comorbidities	
No	2,150 (91.72)
Yes	194 (8.28)
Anti-GAD autoantibody	
Positive	134 (5.72)
Negative	608 (25.94)
Unknown	1,602 (68.34)
Insulin antibodies (IA) status	
Positive	64 (2.73)
Negative	109 (4.65)
Unknown	2,171 (92.62)
Islet cell antibodies (ICA) status	
Positive	16 (0.68)
Negative	428 (18.26)
Unknown	1,900 (81.06)
Outcome	

(Continued)

Nationality	n (%)
Mean duration of the disease – years (SD)	5.31 (3.05)
Transfer to adults, n (%)	
No	2,280 (97.27)
Yes	43 (1.83)
Missing	21 (0.90)
DKA	
No	1,833 (70.12)
Yes	575 (22.0)
Missing	206 (7.88)

*SPYDR – Saudi Pediatric & Youth Diabetes Registry.

level, the experience of some diabetes centers in Egypt of getting involved in SWEET registry is encouraging and stimulating, although, they just received preliminary reports following their recent participation in the ongoing exercise. As expected, T1D represented the most common underlying etiology of diabetes at 91.3%, with T2D and other causes of diabetes representing 6.4% and 1.9% of cases, respectively. This is in keeping with a recent report from the SWEET registry, where 95.5% of patients had T1D, 1.3% had T2D and 3.2% had other forms of diabetes such as cystic-fibrosis related diabetes or maturity-onset diabetes [21]. The proportion of children with T2D in our registry was lower than that recently reported in Qatar (8%) but higher than some other lower rates such as that reported in Italy (1%) [21–23]. The slightly higher proportion of T2D captured in our registry can be explained by the high rates of obesity/overweight in our community. The majority of subjects included so far were from the central region, as it is one of the most populated regions in Saudi Arabia. Larger population-based studies are needed to explore the prevalence of T2D in the Kingdom of Saudi Arabia.

The investigators faced some barriers during the process of initiating SPYDR. Despite working under one administrative umbrella of NGHHA, contracts need to be signed to ensure the rights of data privacy for each of the participating institutes, any potential financial benefits, and research activities that originate from this data registry for co-investigators and their collaborators. Co-investigators should be reassured that they have

shared ownership of the registry data and they could use it for potential future local audits or research projects. This increases the motivation to participate and to keep updating the registry among collaborators. Evidence in the literature showed that patient-focused registries can improve healthcare and science which in itself is a strong motivator of the personnel working on database registry [24]. Moreover, it convinces and reassures other potential collaborators to join the registry in the future [24]. In addition, there is also an ethical commitment toward patients ensuring a safe collection of their data in a secured EMR system [25–27]. The data of the registry can be used in treatment analyses that ultimately lead to improvement in healthcare quality and safety [24,28,29]. All in all, disseminating base knowledge about the importance of establishing a registry of clinical data helps in keeping motivation and sustainable contribution in the registry [24].

Effective diabetes research relies on pattern recognition. Building clinical database registries that support research as well as promotion of health care systems can be faced by a number of challenges such as understanding data sources, volatility of data, the variabilities in study protocols, the complexity and completeness of data provenance and data vulnerability [30–32]. Establishing SPYDR has faced several challenges that need to be highlighted to inform other efforts to expand nationally. First, funding is limited, and it may affect the sustainability of the registry to additional sites outside the NGHHA. The need for funding is mainly to recruit data collectors. If

the registry is to expand to other sites, additional funding will be needed. Fortunately, the Kingdom is undergoing a healthcare transformation, and understanding the disease burden is crucial. Therefore, governmental support to expand the disease registry is aligned with ongoing efforts. The establishment of the Saudi National Institute of Health is a testament to those efforts [33]. Second, technical challenges in capturing patients were also present because the online query system sometimes identified non-diabetic patients due to an error in inputting the ICD-10. Therefore, we ensured data integrity by reviewing the patients' medical charts and verifying the diagnoses. On some occasions, other technical difficulties included the inability to access the registry's electronic platform. This was due to periods of updating security configurations in the Information Technology department that caused some delays in data collection. This matter was resolved by coordination with relevant departments to update and enhance the system without disrupting data capture. Despite challenges, SPYDR relied on a centralized datawarehouse, which helped collect information efficiently in one site covering all five hospitals. There is no doubt that a potential enhancement of this registry will be supported by interfacing it with Bestcare and other electronic healthcare systems of other contributing centres in the future.

SPYDR had some limitations. First, the introduction of the EMR faced some difficulties in some NGHAs institutions; hence, the starting point of data collection was variable in different recruiting centers. This also contributed to some discrepancy in the number of patients between different NGHAs hospitals making the majority of our captured patients from KASCH. Second, there were some variations in the amount of available data that was introduced to feed EMR with prior patients' information. Missing data or indetermination in the coding of the initial diagnosis such as diagnosis of T2D/Unidentified diabetes were also limitations in entering complete data in SPYDR. Some of these will possibly improve later in the prospective approach when SPYDR is already in place. Last but not least, the COVID-19 pandemic has affected capturing patients in the registry impacting the data

quality. We ensured data integrity by reviewing the patients' medical charts and verifying the diagnoses. On some occasions, some technical difficulties were faced including the inability to access the registry's electronic platform due to periods of updating security configurations in the IT department that caused some delays in data collection. This matter was resolved by coordination with relevant departments to update and enhance the system without disrupting data capture.

SPYDR data was collected, so far, retrospectively. Future efforts should aim to identify cases prospectively to allow calculating important indicators such as incidence rate. In addition, future expansion of the registry should include further measures that may facilitate a comprehensive overview of the burden of diabetes. Moreover, further efforts should incorporate additional information to be collected from the patients and their families, especially those related to social determinants of health such as those related to socioeconomic status (e.g., income and education of parents) and neighborhoods' health-related features (e.g., healthy style behaviors of walkability, availability of recreational areas, and accessibility of healthy diet) [34]. These can have a significant impact on outcomes of diabetes management [34]. Last but not least, school performance and/or absence is an interesting area that is worth exploring in future investigations.

CONCLUSION

This study presents the initial data and challenges of establishing SPYDR that paved the way for a national registry to serve as a foundational element for a better understanding of the needs of our children with diabetes and their care providers. It can also inform decisions' making to improve the health outcomes of these patients.

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CONFLICT OF INTEREST

The authors declare that they have no conflicts of interest regarding this article's publication.

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ETHICAL APPROVAL

This study was approved by the Institutional Review Board (IRB) of KAIMRC in 2020. Informed consent was obtained from parents. This is an ongoing prospective registry with some retrospective record-based data; permission to access patients' records was obtained from hospital authorities, ensuring the confidentiality of all participants' information at all levels.

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