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ORIGINAL ARTICLE

"KiDS and Diabetes in Schools" project: Experience with an international educational intervention among parents and school professionals

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Background: Although it is known that school care is a major challenge in diabetes treatment, there is still no published international initiative.

Objectives: The aims of this study were to introduce an international educational intervention tool, the International Diabetes Federation (IDF) KiDS and Diabetes in Schools project (KiDS project), and to describe its impact on diabetes knowledge and behavior of caregivers and school professionals.

Methods: The KiDS project was developed with the support of IDF and the International Society for Pediatric and Adolescent Diabetes and provides online free material in 10 languages, directed to caregivers and school personnel. A pilot evaluation of the KiDS intervention was performed in Brazil. An educational intervention was conducted in 5 primary schools, with 42 parents and school staff, followed by 2 individual interviews after 1 and 3 months. The results were evaluated in a qualitative study with a descriptive design based on content analysis.

Results: School staff acquired new knowledge on diabetes and its treatment. They felt more confident when helping students with diabetes and said the educational intervention promoted a positive impact on the teacher-student relationship, on the caring for health, and on school infrastructure. Family members of children with diabetes stated that the educational intervention gave them an opportunity to strengthen and update information on treatment and improve their knowledge.

Conclusions: The KiDS project is the first international tool directed to foster a safe and supportive environment and a better understanding of diabetes in schools. In this pilot evaluation, it achieved the goal of informing and changing the behavior of parents and school staff, thus improving the care provided to children with diabetes in schools.

KEYWORDS
children, pediatric, prevention, schools, type 1 diabetes

1 | INTRODUCTION

Treatment of type 1 diabetes (T1D) patients is complex and encompasses specific knowledge and invasive procedures. Once the diagnosis of diabetes is made, there must be changes in routine and development of self-care behavior throughout the patients' life.[1] In the last decades, the recommendation of intensive insulin therapy became a consensus,[2] and today, one of the major challenges is the care of children with diabetes in schools. The Dawn Youth Study performed a fact-finding survey in 24 countries and demonstrated that diabetes laws and regulations, availability of nurses, and diabetes training in schools were inadequate or limited in a great majority of them.[3] Other studies confirm that the majority of children are not receiving proper care in schools due to many factors, such as lack of nurses and appropriate school staff support.[4]

One other issue that also creates difficulties in training school staff is the limited access to teaching material. Many services develop their own protocol, but they are always difficult to replicate due to cultural and language specificities, besides cost and access.

KiDS and Diabetes in Schools [KiDS] is a global program created and supported by the International Diabetes Federation (IDF) and the International Society for Pediatric and Adolescent Diabetes (ISPAD) to improve the quality of the support of diabetes in schools.[5]

1.1 | KiDS and Diabetes in Schools program

The objective of the KiDS program is to promote a safe school environment and support children with T1D. It helps them manage their diabetes, avoid discrimination, raise awareness about diabetes and the benefits of healthy eating and exercise habits among all school-age children, and encourage teachers and other professionals to discuss healthy habits as part of efforts to control overweight and obesity in children.

To achieve the project's objectives, an information pack about diabetes in schools was created in 10 languages (Arabic, Chinese, English, English-India, French, Hindi, Greek, Portuguese, Russian, and Spanish), targeting professionals, parents, and students in schools, with information on how to deal with students with diabetes. The website of the KiDS program is accessible at www.kids.idf.org, and it can also be accessed via the ISPAD website (ispad.org). There is also information on how to conduct educational interventions through practical workshops. It explains how to use supplies in the treatment of diabetes and describes interactive lectures on diabetes (concept, physiopathology, signs and symptoms, follow up, and treatment), nutrition in schools and in special situations (eg, camping trips), physical activities for students with diabetes, common complications of diabetes during school hours (hypoglycemia and hyperglycemia), techniques for the development of new skills, self-knowledge on diabetes, and common situations in diabetes. The package was designed by IDF/ISPAD for 4 different audiences: students, family members of students with diabetes, family members of students without diabetes, and school staff. Brazil and India were the first countries to conduct the evaluations in practice.

This paper aims to describe the impact of the KiDS program educational intervention on diabetes knowledge and behavior of caregivers and school professionals.

2 | METHOD

The educational interventions were performed in 15 schools (7 private and 8 public from São Paulo city and Fortaleza) from 2014 to 2015. A total of 9944 students, 26 of whom had T1D; 236 school professionals; and 32 family members of students with T1D participated. In the educational interventions, all students and school staff professionals received the Educational Package with information about diabetes in schools. The educational interventions were performed in groups, with the presence of a diabetes educator (dietitian, psychologist, and physical educator). Two sessions were performed, one directed to parents of students with diabetes and school staff and the other to all the students with and without diabetes, divided by age group. Case discussions were also held in groups, with parents of students with diabetes and school professionals as an audience.

From the initial 15 schools, 5 primary schools were randomly selected to conduct the evaluation of the intervention program, 3 public and 2 private. Data collection occurred in individual interviews, inside the schools, in confidence, and 42 people were interviewed twice, 1 and 3 months after the intervention. Groups evaluated were: parents of students with diabetes, parents of students who do not have diabetes, and school staff. They were evaluated regarding the perception of improvement in knowledge on many aspects: diabetes and maintenance of health, responsibilities, impact, children's behavior in school, life style, caring for children with diabetes, and satisfaction with the KiDS Project after the educational intervention. All participants were chosen based on convenience.[6] They were all older than 18 years, and 86% of the participants were female. There were 2 absences in the second interview, 1 teacher and 1 mother of a child with diabetes. All patients signed a Confidentiality Agreement. The responsible researcher psychologist (G.M.B.) conducted all interviews.

The single criterion for participation was that school staff members and parents of students had participated in the KiDS educational intervention. The participation criterion for parents of students who do not have diabetes was to have access to the Educational Package on diabetes in schools, regardless of their participation in the educational intervention.

This is a qualitative study with descriptive design.[7–9] In Brazil, this intervention was organized by ADJ Diabetes Brasil (a non-profit association of parents of children with diabetes) and coordinated by IDF.

2.1 | Tools

Tools used in the research included 3 guides for semistructured interviews with specific content to the audiences: school professionals and family members of students with and without diabetes. Topics included: knowledge on diabetes (main learning, treatment, and healthy lifestyle), behavior and skills in caring for diabetes/treatment, keeping and changing lifestyles, satisfaction, perception, suggestions for the KiDS educational package and the educational intervention, and perception of school environment regarding diabetes.

The information on how to conduct educational interventions through practical workshops is also available on the IDF-KiDS website. It explains the basics of diabetes treatment; is a guide through interactive lectures on diabetes (concept, physiopathology, signs and symptoms, follow up, and treatment); and also develops topics like nutrition in schools, special situations, physical activities and common complications of diabetes during school hours (hypoglycemia and hyperglycemia). In the intervention with parents and school staff, glucagon indication and use was discussed, as well as pens, syringes, and glucometers. The objective of this part of the intervention was to present these materials to parents and school staff, but they were not trained to inject glucagon due to legislation constraints.

This research began after approval and authorization from the Ethics Committee in Research with Human Beings from the Methodist University of São Paulo—UMESP, CAAE: 37291014.4.0000.5508, Number of Approval: 918.324, December 15, 2014.

2.2 | Data analysis

Data collected in the interviews were submitted for content analysis, using a clinical-qualitative method, which consisted of the use of systematic and objective description procedures of the message content.[10,11] Once the interviews were transcribed, data were analyzed following three steps: reading, decoding, and categorization.

3 | RESULTS

Results were presented per categories and through fragments extracted from the participants' verbatim. The participants' quotes were included in an annexed file, divided by categories.

The mean age of the school staff professionals was 40.8 ± 9.9 years. Under the education variable, 12% completed high school, 3% did not complete their undergraduate education, 67% graduated from university, and 18% completed postgraduation. In the group of families of students with diabetes, the mean age was 34.5 ± 8.2 years; 17% of the family members did not complete high school, 17% did not complete their undergraduate education, and 66% graduated from university. In the group of families of students who did not have diabetes, mean age was 33.5 ± 4.9 years, and they had completed university.

3.1 | Categories

3.1.1 | Knowledge on diabetes treatment

Results showed that school staff professionals were exposed to diabetes management only when one of the students was diagnosed with the disease. The child's family members provided information and guidance on diabetes care, either after the return of a student who was recently diagnosed or when a student with diabetes enrolled in the school. Professionals had doubts and fears about dealing with students with diabetes. During the second evaluation, there seemed to be a new perception of diabetes, treatment, and prevention. Knowledge and information on diabetes in schools seemed to have an impact on school staff regarding interest in helping with diabetes care in school.

For the family members of students with diabetes, results showed that 67% of parents felt that schools are not prepared; 67% perceived the treatment of T1D as conflicting for school professionals. Parents said that students with diabetes were often withdrawn from classroom activities in case they had a malaise, even if this was not diabetes related, which resulted in a lack of motivation to go to school.

Parents felt unsupported and frustrated when talking about treatment, symptom recognition, hypoglycemia and hyperglycemia, and diabetes in school. They were all worried about who would be responsible for the child in the school environment in case something happened.

Half of the parents said there was resistance in learning more about diabetes in previous schools, which resulted in children being transferred to other schools, but 50% of them claimed that they were satisfied with the service and reception children received at the new school.

During the first days of school adaptation, all parents said they had to be available for the schools, either in person or on call, to solve any questions around the treatment of diabetes. A total of 50% of the family members of students with diabetes quit their jobs after their children were diagnosed because they felt more confident in participating in the children's routine at the school. The information provided during the intervention and the given support made 66% of the parents feel more confident with the school environment.

Family members of children who do not have diabetes have mentioned that they knew people with diabetes; however, they were unable to distinguish the type of diabetes and would make up myths regarding this condition.

3.1.2 | Responsibilities and behavior in school about diabetes and healthcare

Reports showed that school staff did not want to be responsible for deciding insulin doses, injecting insulin and doing finger pricks. There is a knowledge gap in knowing what to do in an emergency, which results in teachers being overwhelmed dealing with students with diabetes and, finally, increasing the number of students dismissed from everyday activities.

School professionals said that they had changed after the educational intervention, and 82% stated its importance. Changes in strategies related to healthcare regarding the treatment and prevention of diabetes after the intervention were also mentioned. Only 1 in 5 (20%) of the schools that participated in the evaluation had a first aid station and a professional responsible for taking care of students with diabetes. After the intervention, 52% of the school professionals were more available to help and give support to children with diabetes during school hours, and 35% of the school professionals seemed to be happy with the possibility of helping in the treatment of diabetes. They also said that they were able to talk to students about diabetes and healthy dieting.

According to the members of the families of the children with diabetes, the most common fears were: hypoglycemia or insulin being administrated incorrectly or in excess while their children were in school; rejection from peers for having diabetes; and that school staff professionals would not help to cope to the routine it entails.

Parents of children without diabetes said that they broadened their knowledge on the treatment of diabetes, and 66% became aware that their children needed to improve their healthy habits.

3.1.3 | Perception of the KiDS educational intervention

The experience in participating in the educational intervention was described as "enlightening" and "enriching," and messages were clear and accessible. The education package was understood as a complement to the educational activity.

Information is important to make people aware of diabetes in school, and 56% of teachers said that the topic was never considered in a school context; the project drew their attention to T1D, disease prevention and diagnosis.

The material was used to provide correct information to school staff, who could spread the knowledge and be able to contribute to discussions on diabetes in the school.

Parents of children with diabetes were happy to have an educational project in their children's school. The information that they received changed the relationship between their children and the professionals and their classmates. Parents are aware that their children will miss out their childhood if they do not have a school life and if they do not participate in all activities.

Parents of children who did not have diabetes had contact with the educational package, and also with the intervention based on their children's testimonials. Their opinions about the educational package were very positive.

3.1.4 | School environment and general measures expected from the schools

School staff (94%) agreed that the support provided to children with diabetes may be considered to be: the ability to take appropriate action in a case of hypoglycemia; the ability to show affection and confidence to the child; making regular contact with families; and being more effective and affectionate. They think that their students are not being discriminated against and that there is no prejudice. However, they acknowledge that the other children can be curious about diabetes procedures, which can lead to embarrassment, and that being informed may be of help. A total of 38% of the school professionals would share their doubts and solve them with family members in a very pertinent way, resulting in a perception that their children do have support at school.

All family members of students with diabetes stated their satisfaction of the support their children are receiving at school; however, they did think that it is essential to have more access to information.

3.1.5 | Impacts on school environment

After the implementation of the educational intervention, reports described some healthy habits that were adopted by the schools and a calmer environment when children with diabetes were having their meals. This set of actions resulted in a higher student attendance to class and school staff feeling less insecure.

There was an expressive increased interest around the topic of 'diabetes in schools', and in the second stage of the interviews, 41% of the people seemed more reassured and mentioned a positive change and impact on their ability to help children with diabetes' needs. Data showed that the school staff understood that they should work together with parents and children to be able to support children with diabetes and their treatment, and 35% of the school staff reported that communication is fundamental.

For family members of children with diabetes, the KiDS project gave the families the chance to interact with school staff and the opportunity to share information on health, diabetes, and the project. There seemed to be a perception that everyone was engaged in the project, which increased confidence and had people discussing the topic openly.

Frequent phones calls diminished considerably after the intervention, and parents described substantial difference in the support schools were giving their children, which helped with the children's confidence. Regarding the discrimination of children with diabetes, they emphasized the importance of information to prevent prejudice from arising.

3.1.6 | Suggestions

The school staff suggested working together with parents, who are able to describe how their children with diabetes felt and what the most common symptoms in different situations were, such as hypoglycemia. They suggested promoting the project's educational material, which included the distribution of the printed material. They also emphasized the need for healthcare professionals in schools, standardized emergency procedures and student referrals, and partnerships with public healthcare units. Some teachers suggested the need for a change and the spread of information on diabetes through governmental actions, legislation, and the training of school staff.

School professionals suggested that the material should be in video format and suggested the creation of fun activities, such as crosswords or math games—depending on the children's age and the different audiences that the material is for.

Family members of children with and without diabetes said that a first aid station is fundamental in schools.

4 | DISCUSSION

Diabetes in schools is one of the most complex aspects of diabetes treatment. It involves a number of players, like patients and their families, school personnel (class teachers, physical education teachers, directors, cooks, and others), students without diabetes and their families, policy makers, and the society in general. To create a safe environment for a child with diabetes in school is not an easy task. The community involved in pediatric diabetes has already identified this problem, and many studies are being published regarding this issue.[12,13] Even in developed countries, where the legislation favors the teaching of diabetes, there are reports of more than 40% of children with no staff member who knows how to take care of diabetes.[14] In this study, the importance of strengthening the relationship between students with diabetes, their family, and the school was evident. The same group published an update on the evolution of support for children with diabetes in schools with 568 parents. They showed improvements from 2008 to 2015 in metabolic control, percentage of children with an action plan to treat hypoglycemia, and parents' satisfaction with school support but still claim that more efforts are needed to implement the national legislation to achieve equal support in all Swedish schools.[15]

Some studies also revealed a small, but significant, negative effect of T1D on schooling, emphasizing that the special needs of children with diabetes must be known and attended to by schools.[16]

Given the rising number of children being diagnosed with diabetes and the need for intensive treatment, schools have to be more prepared to take on these children. The use of reliable sources for the development of educational material is crucial. The idea of having reliable material is also important due to costs and time spent to develop this kind of resource. The IDF—KiDS and Diabetes Project, a free Internet-based program, proposes 4 packs in 10 languages with useful and ludic information to be used worldwide.

This intervention using KiDS and Diabetes in Schools material achieved the objective of informing and changing the behavior of parents and school staff, thus improving the care provided to children with diabetes in schools. The project will still have to be tested in other countries to validate both the material and the interventions employed. It is important to stress that, in Brazil, like in many other countries, only skilled professionals (pharmacists and nurses) are allowed to carry out procedures for the treatment of diabetes in schools, always following a doctor's prescription. The teacher's participation is voluntary and not compulsory. The American Diabetes Association statement on this issue supports the coordination of care among the family, school, and diabetes healthcare provider. This has to be performed with education and training of school staff, so children and youth with diabetes can participate in school safely.[17]

The strengths of this study are the support from important diabetes societies (ISPAD and IDF) and associations (ADJ) for the development of the material, along with being the first study to use this new method, the global perspective of its use, and the methodology and scopes of the evaluation. Weaknesses would include the number of interviews, the lack of a control group, and the absence of glycemic outcomes, despite the fact that this was not the objective.

The KiDS Project is the first international tool directed to foster a safe and supportive environment and a better understanding of diabetes in schools. In this evaluation, it achieved the goal of informing and bringing changes to the behavior of parents and school staff, thus improving the care provided to children with diabetes in schools.

Final quote:

> There is no diabetes in the world, if you stop and think about it. It feels it does not exist, likewise it did not exist to me, and I have a good background, I did post-graduate studies, and was never introduced to any of that. The world pretends it does not exist, and I think that calls for a change. Diabetes is so important and it is never looked at.—Participant 18-2

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