



Original research

Improving the school experience of children with diabetes: Evaluation of the KiDS project



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A B S T R A C T

Background: The International Diabetes Federation (IDF) launched the Kids and Diabetes in School (KiDS) project in collaboration with the International Society for Paediatric and Adolescent Diabetes (ISPAD) and Sanofi Diabetes to inform and teach school staff, children and parents on the management of diabetes in school. Brazil and India were chosen as pilot countries.

Methods: The evaluation was conducted using a qualitative methodology using semi-structured face to face in-depth interviews. Five out of fifteen schools were selected, where teachers and parents of children with and without diabetes were interviewed. Interviews took place one and three months after the implementation of KiDS.

Findings: Diabetes knowledge among the school staff and parents of children without diabetes was very limited prior to the KiDS Project in both countries. After introducing the KiDS information pack both groups mentioned increased knowledge on the management of diabetes. This was reflected through healthier food choices at school and the encouragement of physical activities. Increased awareness and understanding in the school staff were observed by parents of children with diabetes.

Interpretation: The KiDS project received positive feedback on the educational materials. The pack was deemed informative, interesting and engaging, creating increased awareness and understanding among school staff, parents and children. The project has created a demand for diabetes intervention in schools. The pack has been translated into fourteen languages and was downloaded over 17,000 times by November 2018.

Introduction

The incidence of diabetes among children is increasing in many countries; current estimates suggest around 79,000 children under 15 years develop Type 1 diabetes (T1DM) annually worldwide [1–2]. In addition the incidence of Type 2 diabetes (T2DM) is increasing among children and adolescents at an alarming rate [3].

School forms a significant part of every child's life. Developing diabetes in childhood can negatively influence the school experience. Poor glycaemic control, persistent high glucose and frequent hypoglycaemia, can directly affect cognitive function, even more so in those who develop diabetes before starting primary school [4–7].

Unfortunately, schools in many countries do not have support from clinical staff with expertise in diabetes, or information and age-appropriate education resources about diabetes available. Strategies are required to help children, teenagers and their families cope with diabetes in school, and also to inform and assist the teaching and administrative staff responsible for pupils with diabetes.

In order to tackle these issues, the International Diabetes Federation (IDF) co-developed the Kids and Diabetes in Schools (KiDS) project in collaboration with the International Society for Paediatric and Adolescent Diabetes (ISPAD) and Sanofi [8]. Brazil and India were chosen as pilot countries due to their significant burden of T1DM and T2DM [9–12], and the need for guidelines for the care of children with

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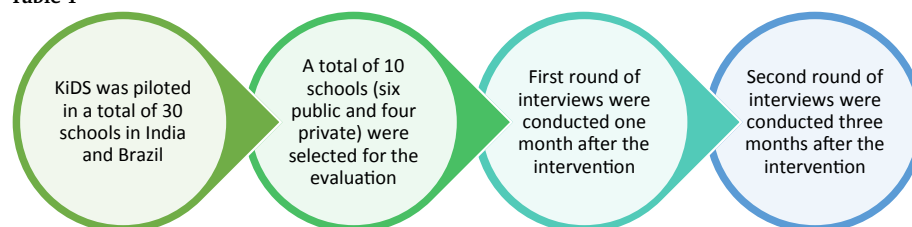
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Table 1



diabetes at school. The aims of the project were:

- To foster a safe and supportive school environment for children with type 1 diabetes to enable them to manage their diabetes, and to prevent discrimination.
- To raise awareness about prevention of type 2 diabetes and the benefits of healthy food choices and physical activity among school-age children.

The KiDS project was a two-phase initiative. During the first phase (July 2013 – December 2014), an information pack was developed to support the project in both countries. The KiDS pack is composed of four different modules addressed to teachers, parents of children with diabetes, parents of children without diabetes and to children (<https://kids.idf.org/>). The pack provides these key groups with information on diabetes prevention, diabetes management and tips for leading a healthy lifestyle. Quick reference sections also feature in the pack giving essential details on how to deal with hyper- and hypoglycaemia. For teachers and parents, there is a diabetes management plan within the pack which gives both parties the opportunity to clearly state the needs of a child with diabetes during a typical school day. It was developed in English and culturally adapted and translated into Hindi and Portuguese for use in India and Brazil respectively. The project was implemented in India by the Public Health Foundation of India (PHFI), All India Institute of Medical Sciences (AIIMS) and Health Related Information Dissemination Amongst Youth (HRIDAY). In Brazil project implementation was led by the ADJ Diabetes Brasil (ADJ).

Training sessions were conducted from July to December 2014; teachers were trained in using the pack to incorporate key messages into lesson plans for their classes. Printed materials were provided for distribution to the children and their parents. Almost 1,400 school staff (1,149 in India and 247 in Brazil) and almost 38,000 students (27,937 in India; from $n = 15$ schools (7 public and 8 private) and 9,944 in Brazil; $n = 15$ schools (8 public and 7 private) were trained using the materials in the pack. Sixty-nine students were reported to have type 1 or type 2 diabetes in India, and 26 with type 1 diabetes in Brazil.

This article describes the evaluation of the impact of the KiDS project, which is important for the sustainability of the project.

Methods

The aim of the evaluation was to assess the experience and the satisfaction with the KiDS project intervention by interviewing school staff, parents of students with and without diabetes. The specific objectives of the evaluation were to assess the:

- Knowledge and (behavioural) skills gained about diabetes and maintenance of a healthy lifestyle
- Quality of care and support for children with diabetes in the schools (including technical and social environmental factors)
- Level of satisfaction with the information pack (with its content, layout, clarity of information, etc.)
- Satisfaction with the training for school staff (content, presentation, clarity of information, etc.)

Study design and recruitment

The evaluation was conducted using qualitative methodology i.e. semi-structured face to face in-depth interviews. Five (3 public and 2 private) of the fifteen schools where KiDS was implemented in each country were selected for the evaluation. Schools were included if the KiDS training and follow up activities were conducted within one month prior to the evaluation, and if the school authorities gave consent to participate in the evaluation. The project was undertaken from January to August 2015.

Sampling

Out of the 30 schools where KiDS was implemented, 5 schools in each country (3 Public and 2 Private, to ensure representation of both types of school) were selected for the evaluation phase (see Table 1 above). The criteria for the selection of schools included: - Date of teachers' KiDS training: schools were included if the teachers KiDS training and follow up activities were conducted 1 month before the evaluation. - Consent from school authorities to participate in the evaluation phase of the project. A purposive sample included the following types of participants from selected schools in each country that were recruited for the evaluation:

- 20 teachers (10 each from private and government schools);
- One parent of every child with diabetes attending the schools and
- Fifteen parents of children without diabetes.

Participants were recruited according to the following inclusion criteria: age 18 years or over; affiliation to one of the schools involved in the KiDS project; in the case of school staff, participation in the KiDS training and other related activities; the parents and caregivers of students with or without diabetes must have had free access to the KiDS pack.

Study procedure

The opinions, knowledge and perception of the participants were examined in one-on-one face-to-face semi-structured interviews. Each participant was interviewed twice: at one and three months after the delivery of the intervention in the school in order to assess the knowledge retention and to verify any changes in school settings. The interviews were recorded using a digital voice recorder to facilitate data collection and framing of themes. Each interviewer was trained on how to conduct the interviews via video conference training conducted by IDF staff in Brussels.

Three different interview schedules were developed, one for each of the above listed types of participant. These were adapted to suit the specific cultures of each country, while ensuring that the content remained similar. The interview guideline consisted of questions around four main themes: knowledge about diabetes and healthy lifestyle (key learnings); skills and behaviour in the care and management of children with diabetes in schools specifically for teachers and parents of children with diabetes; satisfaction with the information pack and training; and the impact of the project on the school environment (including both

technical and social environment, e.g.: discrimination). The interviews were designed to last no longer than 30 min.

In Brazil, the evaluation phase began after the approval of the Research Ethics Committee of the Methodist University of São Paulo. In India, the ethics clearance for Project KiDS evaluation study (including both the tools; English and Hindi) was obtained from PHFI's Institutional Ethics Committee (IEC).

Data analysis

The data obtained from interviews was transcribed and translated by the PHFI and HRIDAY data collection team in India and by ADJ in Brazil as required. Two researchers (a nutritionist and a psychologist, both also diabetes educators) were involved in data analysis in Brazil. In India five researchers were involved in the data analysis (an anthropologist and a dentist, both with research interests in child and adolescent health, two nutritionists involved in public health research and a public health scientist with research interest in health promotion). All the recordings were transcribed according to a pre-designed transcription protocol. As a first step, five transcripts were coded by two researchers independently and applied codes were compared to develop a list of *a priori* codes. These codes were then defined and grouped into categories, resulting in analytical frameworks which were then discussed and finalised by the team. These analytical frameworks were used to code the remaining transcripts and for indexing. Data were coded thematically by two qualitative researchers, using themes that emerged during analysis. Atlas.ti (6.2.11) software was used for the analysis in India and Nvivo 10 was used in Brazil.

Results

In Brazil, 42 people were interviewed at one and three months (34 school staff, 6 parents of students with diabetes and 2 mothers of students without diabetes.) In India, 38 people were interviewed at one month (20 school staff, 3 parents of students with diabetes and 15 parents of students without diabetes) and 27 were interviewed at three months (18 school staff; 3 parents of students with diabetes and 6 parents of students without diabetes). The Table 2 below summarize the interviews distribution. The Table 3 below summarise the key findings assembled by types of participants in Brazil and India.

Knowledge about diabetes and maintenance of a healthy lifestyle

School staff in India reported that their knowledge about diabetes was extremely basic before the KiDS training. Similarly, in Brazil, school staff reported that any knowledge they had on managing diabetes followed the diagnosis of a student with diabetes, or when a

student with diabetes enrolled at the school, with this knowledge being provided solely by the child's parents. Otherwise, diabetes had not been previously discussed within the school context. School staff in Brazil ($n = 28$) emphasized that knowledge of healthy-eating during childhood is important for all children, whether they have or do not have diabetes, some ($n = 12$) felt that it is important for people with diabetes to be empowered to take control of their condition with the help of qualified health professionals. The staff in India ($n = 12$) stressed the importance of not treating children with diabetes any differently from other children.

Regarding knowledge following the introduction of the KiDS Project educational materials, parents of children with diabetes in both countries accurately recalled the difference between the types of diabetes, making healthy food choices, how to deal with hypo- and hyper-glycaemia, myths around diabetes, diabetes treatment, symptoms at diagnosis and disease prevention. In India, in the first round of interviews, parents of children with diabetes mentioned that they gained no new knowledge from the KiDS pack. In both countries they emphasised the importance of staying informed about diabetes to avoid anxiety and that creating awareness about diabetes helps to avoid stigmatization towards children with diabetes.

Parents of children without diabetes in Brazil ($n = 2$) had little or no prior knowledge about the symptoms, diagnosis and causes of diabetes, and reported that they gained new knowledge from the KiDS information pack, including the importance of diet and physical activity in the management and prevention of diabetes. Similar results were found with parents in India ($n = 14$), with most parents mentioning that they had gained new knowledge from the KiDS intervention. In both countries, the common myths regarding the causes of diabetes were clarified. Parents felt the need for lifestyle changes to reduce the risk of type 2 diabetes and denounced the stigmatisation of children with diabetes.

Changes regarding individual behaviour, skills and behaviours in school

Across both Brazil and India, school staff ($n = 32$) felt confident to manage children with diabetes after the KiDS training. Moreover they ($n = 47$) changed their own behaviour in order to take better care of their health and reduce their risk of developing type 2 diabetes. Additionally, a positive change in student–teacher relationships was recognized ($n = 14$). School staff noticed that students without diabetes had become more supportive and empathetic towards students with diabetes.

Parents of a child with diabetes ($n = 4$) in Brazil stated that they observed increased awareness of the needs of their child in the school staff. Parents of children with diabetes in India noted that there was a

Table 2

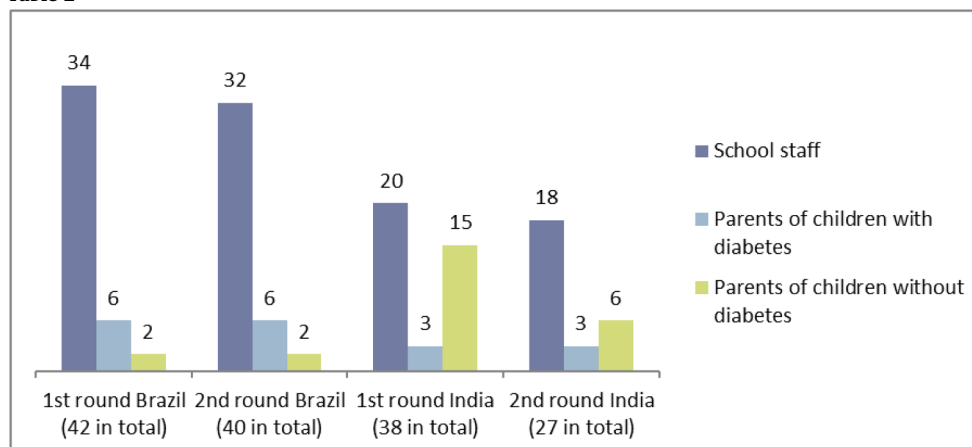


Table 3
Key findings by type of participants in Brazil and India.

Main themes Target group	School staff	Parent of child with diabetes	Parents of a child without diabetes
Knowledge about diabetes and maintenance of a healthy lifestyle	School staff emphasised that knowledge about healthy eating during childhood is important for both children with and without diabetes. (n=28) School staff believe it is important for people with diabetes to be empowered to take control of their condition with the help of qualified professionals. (n=12) School staff stressed the importance of not treating children differently from other children. (n=12)	Parents of children with diabetes in both countries recalled the difference between the types of diabetes, the importance of healthy food choices, how to deal with hypo- and hyper-glycaemia, diabetes prevention, diabetes symptoms and diabetes treatment. Emphasis on the importance of staying informed about diabetes to create awareness and avoid stigmatisation towards children with diabetes.	Parents of a child without diabetes gained new knowledge from the KiDS information pack. (n=16) Parents felt the need of lifestyle changes to reduce the risk of type 2 diabetes
Changes regarding individual behaviour, skills and behaviours in school	School staff are more confident in assisting a child with diabetes during school hours. (n=32) School staff changed their own behaviour in order to improve their health and reduce the risk of developing type 2 diabetes (n=47).	Parents of a child with diabetes stated that they observed increased knowledge and awareness in the school staff of the needs of their child and in diabetes management. (n=4)	
Satisfaction of KiDS Project	High level of satisfaction because of the clarity and accessibility of the information. (n=20) For the first time the project drew attention to diabetes in childhood and prevention of diabetes in the school setting. (n=27)	Very appealing and interactive content. It uses very clear language and the material was appropriate for those seeking information on diabetes. Changed the relationship between their children and school staff and their classmates. (n=3)	Very appealing and interactive content. It uses very clear language and the material was appropriate for those seeking information on diabetes. Myths and misconceptions were clarified after reading the pack, and that facilitated interaction with people with diabetes. (n=2)
Impact on the school environment	The project had an impact on students in the classroom environment and student-teacher relationship. There was a significant increase in interest in the subject of diabetes in schools and. Schools have healthier food options in the canteen. Medical rooms were set up. Children are encouraged to participate in physical activities.	After the intervention, everyone seems to be involved in the care of a child with diabetes, creating more confidence and encourage open dialogue on diabetes. (n=4) Schools are more supportive in the care and management of a child with diabetes.	Children without diabetes are more understanding and empathetic towards children with diabetes.

need to change the perception about children with diabetes, and reinforce the message among people that such children should be treated the same as other children, and should be encouraged to participate in various physical activities.

In both countries, parents of students with diabetes, when asked about the skills of school staff for the treatment and prevention of diabetes, felt an increased knowledge and awareness of their children's welfare, in addition to the management of diabetes. The staff now encourages children to be more physically active by sending them out to play and reducing their screen time.

Satisfaction with KiDS project

School staff in Brazil expressed satisfaction with the KiDS Project ($n = 20$), deeming it to be informative, rewarding and objective, with clear and accessible language. Some teachers ($n = 27$) said such themes had never been discussed at school, and that the project draws attention to diabetes in childhood, prevention of myths around diabetes and its prompt diagnosis. Indian school staff showed similar satisfaction, while also praising the interactivity of the sessions.

In Brazil, it was reported that one student did not talk about his diagnosis with his peers before the KiDS Project. However after the intervention he loved the Thomas character of the KiDS project and his story. For a long time, he would ask his parents to read it at bed time every night. The everyday life of this boy with diabetes has improved with him feeling less insecure and more confident to speak up and know that school staff will listen to him. The members of his family realized that teachers became more supportive after the KiDS Project at the school, and also more attentive to their child, and appreciated that discrimination and prejudice were being addressed. One mother said she would not forget that day, because everyone was talking and becoming more aware of diabetes, increasing her confidence in the teacher's understanding and capabilities.

In India, parents of children ($n = 3$) with and without ($n = 13$) diabetes were satisfied with the content and appearance of the KiDS pack. The pack helped to reinforce and refresh the instructions provided to their children regarding management of diabetes. They believed that the KiDS material was appropriate for those seeking information on diabetes, while clarifying myths, in an interesting and interactive manner. Parents of children with diabetes ($n = 3$) in Brazil believed that the project changed the relationship between their children and school staff, and their classmates. Parents of children without diabetes ($n = 2$) thought that it challenged myths and perceptions, enabling better relationships with people with diabetes.

Impact on school environment

In Brazil, the successful outcomes of the project included healthier food choices being provided at school. These included the option of brown rice at meals and the exclusion of soft drinks and fried food in one of the school canteens. During the second phase of the evaluation, the results showed that the project had an impact on students in the classroom environment and student–teacher relationship. There was, significant increased awareness of the issue of diabetes in Brazil. Similarly, in India, more attention was given to the quality of meals available in the canteen of private schools; in addition to this, medical rooms were set up and children were encouraged to participate in physical activities with a special focus on children with diabetes, including yoga.

Positive feedback was given by parents of children with diabetes in Brazil ($n = 4$), highlighting that, after the intervention everyone seemed involved in the care of their child's diabetes, creating more confidence and encouraging open dialogue about the subject. Parents of children with diabetes in India reported that their child's school was supportive in the care and management of their child. According to them, as a result of KiDS intervention, teachers had become more

attentive to their child's needs. In both countries, parents of children without diabetes reported that their children were more understanding and empathetic towards children with diabetes.

Discussion

KiDS is one of the few school-based programs with a specific focus on diabetes and was widely appreciated by both teachers and parents of children with diabetes. The evaluation of the KiDS project demonstrates how an educational intervention, backed up by high quality and culturally specific materials can have a positive impact on the school experience of children living with diabetes, the confidence of staff in dealing with diabetes, as well as school policies towards promoting health eating and physical activity. The project has created a demand for the intervention to be sustained and scaled up in the pilot countries and elsewhere. The KiDS pack has subsequently been translated into nine languages and made available for download free of charge on the IDF website. By July 2017, the pack had been downloaded over 14,000 times.

KiDS meets a worldwide need for a comprehensive approach which fosters holistic management of children with diabetes at school, that requires engagement between the school and parents, to build trust and counter social stigma and discrimination associated with having diabetes. There is evidence that educational interventions in children and adolescents who have diabetes have a strong effect on psychosocial outcome [13]. Schools are in a unique position to play a pivotal role in promoting healthy lifestyles and helping to prevent obesity [14]. In short, the evidence in favour of educational interventions regarding diabetes is significant.

To our knowledge, this study was the first of its kind in India and Brazil. The findings highlight important information that can provide direction for school policies and scale-up interventions and programs and guide further research to promote prevention and management of diabetes in schools.

Limitations

Our study had methodological and operational challenges. Data collection overlapped with annual examinations and summer break in schools, resulting in data for the second round of interviews being collected at variable points in time, ranging between 1 and 3 + months. Data saturation was limited for parents of children with diabetes due to small sample size. Representation of “parents of children with diabetes” from public schools in India could not be included in the interviews due to certain administrative challenges. A purposive sampling strategy was used for selection of participants. In advance of this, attempts were made to minimize inherent biases; during the analysis stage, credibility was ensured by independent analysis of data by more than one qualitative researcher.

Recommendations

Following the implementation of the KiDS project, both pilot countries made recommendations. School staff in Brazil made several suggestions, they emphasized the need for a health professional employed in school, further involvement of parents of children without diabetes as well as further training. Widespread dissemination of KiDS material was deemed particularly useful. In India some school staff ($n = 6$) suggested inviting a person with diabetes to talk about their personal experiences (for use as a case study), and to conduct trainings more often to reinforce the message and also to include related videos.

In both Brazil and India, parents of children with diabetes suggested the availability of blood glucose monitoring machines (glucose meter) in schools and a separate medical room for children to check their blood glucose levels and have privacy for injecting insulin. This was also supported by parents of children without diabetes.

Parents of children without diabetes in Brazil suggested that the school staff should provide healthier food choices at school, implement a training programme for all new employees on diabetes and health care, and promote more physical activities.

The evaluation of the project is only the starting point. Lessons learned from this evaluation will be taken into account while expanding the project further in other countries. The project also allows the opportunity to study the behaviour of children. The KiDS project will aim to continue to foster a safe and supportive school environment for children with type 1 diabetes and to raise awareness about prevention of type 2 benefits.

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Conflict of interest

We declare what we have no conflict of interest.

Ethics committee approval

Prior to the conduct of the evaluation, the KiDS advisory committee developed the research protocol by October 2014; this was translated and adapted for India and Brazil by the country teams. In Brazil the research study was assessed and approved by the Ethics Committee on Human Research of the Methodist University of São Paulo (<http://aplicacao.saude.gov.br/plataformabrasil/login.jsf>) on December 17, 2014. In India the ethics clearance for the evaluation study (including the tools in both English and Hindi) was obtained from PHFI's Institutional Ethics Committee (IEC) on February 23, 2015.

Approval of the evaluation and study procedure was sought from the respective institutional ethics committees (IEC) in the two

countries.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.jcte.2018.12.001>.

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