STRATEGIES TO EDUCATE YOUNG PEOPLE WITH TYPE 1 DIABETES *MELLITUS* ON INSULIN THERAPY: SYSTEMATIC REVIEW

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ABSTRACT

Objective: to identify evidence available in the literature on educational strategies used in the teaching of insulin therapy to children and adolescents with Type 1 diabetes *mellitus*.

Method: systematic review undertaken in five databases, using the descriptors Insulin/therapeutic use, Patient education as topic, Diabetes mellitus type 1, Child, Infant, Adolescent and keywords, without any time limit. Primary studies on insulin therapy teaching were included, while research on insulin pumps was excluded.

Results: 243 studies were identified, 13 of which were included. The results present educational strategies focused on children, adolescents and young people of up to 24 years of age, applied individually or in groups; by telephone contact or text messages by mobile phone; dramatization and educational camps; by a single professional or a multidisciplinary team. The strategies described in the analyzed studies addressed the adjustment of insulin dosages in everyday situations and education for insulin management, associated with the nutritional strategy of carbohydrate counting, diabetes education with a specific module on insulin therapy and intensive insulin use. The studies analyzed the effect of the educational intervention on several clinical and behavioral outcomes, such as glycated hemoglobin and self-efficacy.

Conclusion: this review could not identify a single educational strategy able to improve metabolic and psychosocial outcomes. In most cases, nurses are the professionals responsible for the development of educational strategies focused on insulin therapy in children and adolescents with diabetes, regardless of the context in which they will be deployed. This confirms their role as educators.

DESCRIPTORS: Type 1 Diabetes *Mellitus*. Health Education. Insulin. Review. Child. Adolescent. Pediatric Nursing.

ESTRATÉGIAS PARA EDUCAR JOVENS COM DIABETES *MELLITUS* TIPO 1 SOBRE INSULINOTERAPIA: REVISÃO SISTEMÁTICA

RESUMO

Objetivo: identificar evidências disponíveis na literatura sobre estratégias educativas utilizadas no ensino da insulinoterapia às crianças e adolescentes com diabetes *mellitus* tipo 1.

Método: revisão sistemática, realizada em cinco bases de dados, com os descritores *Insulin/therapeutic use, Patient education as topic, Diabetes mellitus type 1, Child, Infant, Adolescent* e palavras-chave, sem delimitação de período. Incluídos estudos primários acerca do ensino da insulinoterapia e excluídas pesquisas sobre bomba de insulina.

Resultados: identificados 243 estudos, dos quais foram incluídos 13. Os resultados apresentam estratégias educativas direcionadas às crianças, adolescentes e jovens de até 24 anos de idade, aplicadas de forma individual ou em grupos; por contato telefônico ou mensagens de texto por celular; dramatização e acampamentos educativos; por um único profissional ou equipe multidisciplinar. As estratégias descritas nos estudos analisados abordaram ajuste da insulina em situações cotidianas e educação para manejo da insulina, associados com a estratégia nutricional de contagem de carboidratos, educação em diabetes com módulo específico sobre insulinoterapia e uso da insulina de forma intensiva. Os estudos analisaram o efeito da intervenção educativa sobre diversos desfechos clínicos e comportamentais, como a hemoglobina glicada e autoeficácia.

Conclusão: não foi possível determinar uma única estratégia sobre a insulinoterapia capaz de melhorar o controle metabólico e psicossocial. O desenvolvimento de estratégias educativas voltadas à insulinoterapia de crianças e adolescentes com diabetes, independentemente do contexto em que serão implementadas, tem, em sua maioria, o enfermeiro como profissional responsável, o que reafirma seu papel educador.

DESCRITORES: Diabetes *Mellitus* Tipo 1. Educação em saúde. Insulina. Revisão. Criança. Adolescente. Enfermagem pediátrica.

ESTRATEGIAS PARA EDUCAR A LOS JÓVENES CON DIABETES MELITUS TIPO 1 SOBRE LA INSULINOTERAPIA: UNA REVISIÓN SISTEMÁTICA

RESUMEN

Objetivo: identificar la evidencia disponible en la literatura sobre las estrategias educativas utilizadas para enseñar la terapia con insulina a niños y adolescentes con diabetes mellitus tipo 1.

Método: revisión sistemática, realizada en cinco bases de datos, con los descriptores Insulina / uso terapéutico, Educación del paciente como tema, Diabetes mellitus tipo 1, Niño, Lactante, Adolescente y palabras clave, sin delimitación de períodos. Se incluyeron estudios primarios sobre la enseñanza de la terapia con insulina y se excluyó la investigación sobre la bomba de insulina.

Resultados: se identificaron 243 estudios, de los cuales se incluyeron 13. Los resultados presentan estrategias educativas dirigidas a niños, adolescentes y jóvenes hasta los 24 años, aplicadas individualmente o en grupos; por contacto telefónico o mensajes de texto por teléfono celular; juegos de rol y campamentos educativos; por un solo equipo profesional o multidisciplinar. Las estrategias descritas en los estudios analizados abordaron el ajuste de la insulina en situaciones cotidianas y la educación para el manejo de la insulina, asociadas a la estrategia nutricional de conteo de carbohidratos, educación en diabetes con módulo específico sobre terapia insulínica y uso intensivo de insulina. Los estudios analizaron el efecto de la intervención educativa sobre varios resultados clínicos y conductuales, como la hemoglobina glucosilada y la autoeficacia.

Conclusión: no fue posible determinar una única estrategia sobre la terapia con insulina capaz de mejorar el control metabólico y psicosocial. El desarrollo de estrategias educativas orientadas a la terapia con insulina para niños y adolescentes con diabetes, independientemente del contexto en el que se implementen, tiene, en su mayor parte, al enfermero como profesional responsable, lo que reafirma su rol educativo.

DESCRIPTORES: Diabetes Mellitus Tipo 1. Educación para la salud. Insulina. Revisión. Niño. Adolescente. Enfermería pediátrica.

INTRODUCTION

According to the International Diabetes Federation, more than 88 thousand Brazilian children and adolescents have Type 1 diabetes mellitus (T1D) and Brazil is the third country with the highest number of cases.[1] From the start of the T1D diagnosis, children, adolescents, and their families need to develop skills and acquire knowledge to perform self-care tasks. The process that leads to the acquisition of new behaviors, including the incorporation of tools that contribute to the achievement of the treatment goals, is called diabetes education.[2]

The American Association of Diabetes Educators recommends seven self-care behaviors that should be developed in the educational process[3]. One of them involves adherence to the medication regimen, which is a challenge for those working with the pediatric age group. Intensive T1D treatment, with three or more daily doses of insulin, aims to reduce the incidence of acute and chronic complications, in addition to offering flexibility to adjust doses according to the physical activity performed and to the diet.[4–5]

In order to encourage young people and family members to comply with intensive multi-dose insulin therapy, diabetes education should range from the types of insulin available on the market, including their respective action profiles, concentration, peak and duration of therapeutic effect, to aspects of safe practices of the injection technique. Thus, guidelines on storage, application sites and absorption rate, syringe or pen handling, needle selection, insertion angle, indication of skin fold, combination of two types of insulin in the same syringe and disposal of waste materials are essential for proper adherence to the medication regimen.[2]

Despite the obvious benefits of intensive treatment, most Brazilians with T1D do not adhere to the intensive insulin regimen. It is known that 40% of newly diagnosed pediatric patients mention fear or pain during the application.[6,7] Based on these findings, the intensive insulin treatment is considered a highly complex topic, requiring planning and an appropriate approach to the age group, especially when analyzing children and adolescents, so that they can gain practical skills essential for autonomy in insulin therapy.

In order to contribute to the construction of knowledge about the best practices for teaching this behavior in pediatric diabetes education, this study aimed to identify evidence available in the literature on educational strategies used in the teaching of insulin therapy to children and adolescents with T1D.

METHOD

Systematic literature review, described in accordance with the PRISMA Statement, with the following guiding question: "which strategies are used to teach insulin therapy to children and adolescents with T1D?", elaborated according to the PICO strategy.[8–9]

The inclusion criteria were primary studies, without delimitation of language and year of publication, published in full, focused on strategies for teaching insulin therapy to children and adolescents with T1D. Studies that only discussed insulin therapy using continuous subcutaneous insulin infusion systems were excluded, as the particularities of teaching this technology differ from conventional insulin therapy. Experience reports, case studies, editorials, response letters, reviews and research that did not present the data of the educational strategy for the pediatric population separately from the other results were also excluded. Studies whose full texts could not be obtained even after sending requests to the journal in which they were published and to the authors were classified as unobtainable.

The searches in PubMed, EMBASE, CINAHL, LILACS/BDENF, and ERIC were carried out in December 2017 and, as already mentioned, without setting time limits. The descriptors were selected

in the *Medical Subject Headings* (MeSH) and in the Health Sciences Descriptors (DeCS). The search strategy in PubMed, exemplified in Chart 1, shows the use of the boolean operators AND and OR.

Chart 1 – Search strategy in PubMed. Ribeirão Preto, SP, Brazil, 2018.

Database	Search strategy
PubMed	("Insulin/therapeutic use"[Mesh]) AND "Patient Education as Topic"[Mesh]) AND "Diabetes Mellitus, Type 1"[Mesh]) AND (child* AND (Humans[Mesh] AND (infant[MeSH] OR child[MeSH] OR adolescent[MeSH]) NOT ("pump * AND (Humans[Mesh] AND (infant[MeSH] OR child[MeSH] OR adolescent[MeSH]) Filters: Humans, Child: birth-18 month, Infant: birth-23 months.

Two reviewers independently evaluated the titles and abstracts of all citations identified in the databases and eliminated duplicates. The eligible studies were consulted in full when the study was relevant or when the title and abstract were insufficient for inclusion. To obtain a consensus, a third reviewer's opinion was requested in case of disagreement. In addition, the researchers performed a manual search for primary studies. After identifying the citations in the databases, they searched the reference lists for other potential titles that suggested studies on educational strategies for insulin therapy.

For extraction and synthesis, the reviewers developed a chart in Microsoft Excel®, composed of the following items: authors, country, year of publication, study design, sample detail, type of educational and professional intervention involved, content of the intervention and duration, clinical and behavioral results and limitations. Two reviewers completed the chart separately with the data from the selected articles, and a third researcher judged divergent results to reach a consensus.

To judge the risk of bias, the tool developed by the Cochrane Collaboration was used, as the identified studies were randomized clinical trials and quasi-experiments.[10]

RESULTS

The results identified 243 citations: 18 from CINAHL, 15 from EMBASE, one from ERIC, 34 from LILACS / BDENF, 169 from PubMed, and six studies retrieved through a manual search. After removing duplicates and reading abstracts and titles, 17 studies were read in full, 13 of which reported educational strategies for the pediatric population and discussed aspects of insulin therapy, as shown in the flow chart in Figure 1.

Of the 13 articles included in the synthesis, seven were randomized clinical trials[11–17] (RCT) and six quasi-experiments,[18–23] as the same study generated two publications.[12–13] The studies were published between 1991 and 2016 and developed in the following countries: Germany,[21] Canada,[15,20] Scotland,[14,16] United States,[12–13] Finland,[11] Northern Ireland,[17] Pakistan,[22] United Kingdom,[18] Tanzania[23] and Turkey.[19] The contexts in which the educational strategies took place were educational camps,[19] pediatric diabetes clinics,[12,13,22] medical centers,[18] diabetes centers,[20] hospitals[11,17,21,23] and at a distance, by telephone[14,15] and texting by mobile phone.[16]
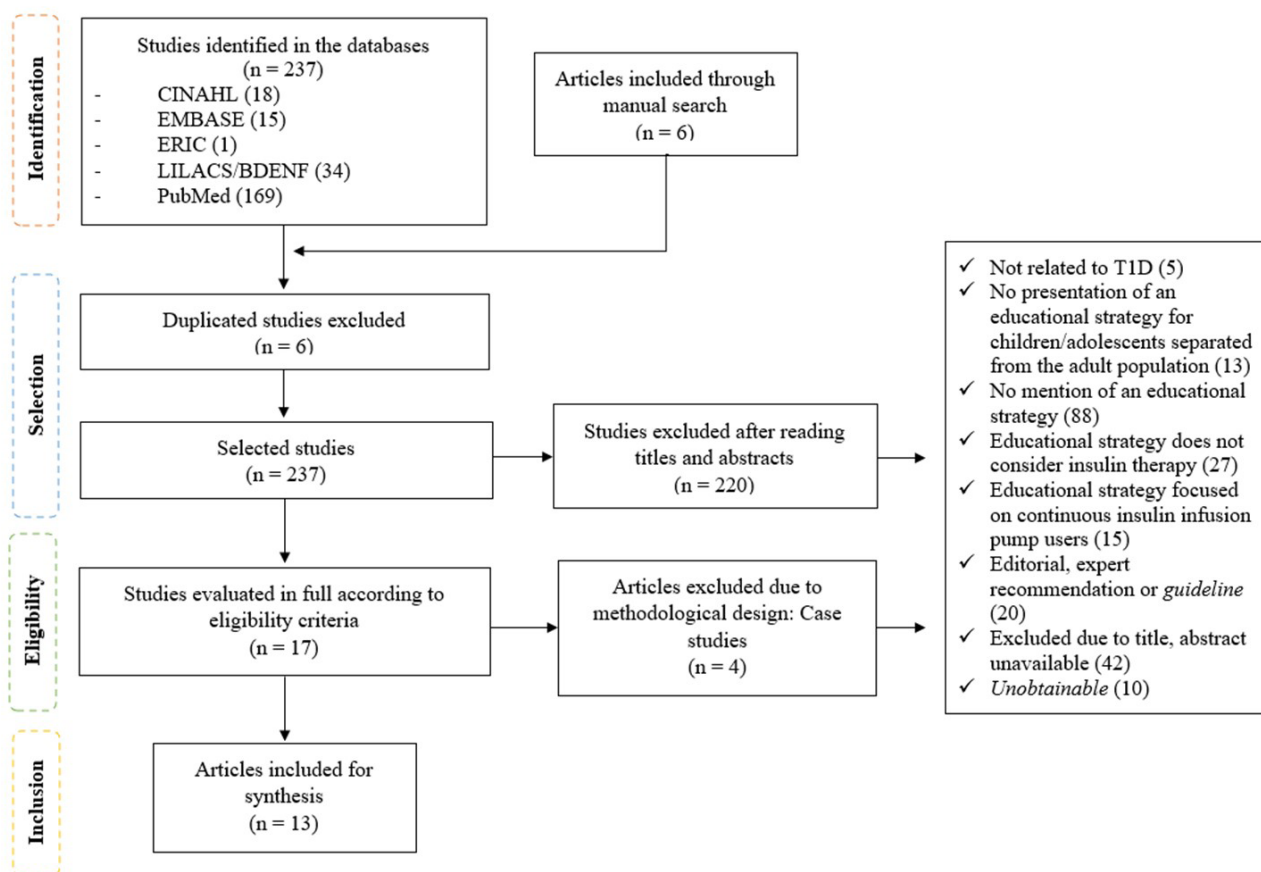
Figure 1 – database search flowchart.

In total,1,219 children, adolescents and young adults between five and 24 years of age participated in the analyzed studies. The inclusion of young people up to 24 years old in three studies[14,19–20] is justified by the fact that it is common to include those over 18 years old in pediatric clinics. Consequently, the educational programs developed in these pediatric settings also target these young people. In two other studies, it was impossible to determine the minimum age of the participants, because the authors presented the age of the participants in age groups from zero to four years old.[11,23] The detailed summary of the studies included is shown in Chart 2.

In this review, the following educational strategies were evidenced: group lectures[18,20–21]; individual education[11,17,20,22–23] including the donation of *care* kits[22] and dinners;[17] dramatization,[12–13] educational camp,[19] telephone contact with the health care team[14–15] and texting by mobile phone.[16–17] The following themes were addressed: insulin dosage adjustment in daily situations[12–15,19,21,23] and insulin management education associated with the nutritional strategy of carbohydrate counting,[17–18,20] diabetes education with a specific module on insulin therapy[16,22] and intensive insulin use, that is, three or more doses per day.[11]

In most studies, the pediatric nurse specialist or diabetes educator was part of the team responsible for the intervention, including pediatricians, diabetologists, pediatric endocrinologists, dieticians, psychologists and social workers. The category of the health care professional responsible for elaborating the educational intervention was not highlighted in a single study.[16]

Chart 2 – Studies included in the synthesis.

Authorship, country and year	Objective, type of study and participants	Educational intervention	Clinical and behavioral outcomes
Simell et al, Finland (1991)[11]	To report the effects on metabolic control of an educational intervention developed during hospitalization. RCT. 61 children and adolescents, 0 to 14 years, newly diagnosed with T1D.	**Theme:** intensive use of insulin Group 1 (G1): daily educational program from the 2nd to the 7th day of hospitalization. Outpatient follow-up for three weeks, with 3-4 visits. Group 2 (G2): educational program started on the 7th day of hospitalization, continued two times a week until discharge in the 4th week. Professionals involved: pediatrician, dietician, social worker, psychologist, hospital nurse with diabetes training and nurse from the outpatient clinic specialized in diabetes. Both groups: availability of telephone appointments with a senior pediatrician during the two years of the study. Monthly and quarterly follow-up. After two years, the participants were evaluated for two days, looking at the circadian variation in diabetes control and endogenous insulin secretion.	**Clinical outcomes only:** HbA1c: improvement after one month in G1 (p=.01). After two months, both groups reached mean values comparable to healthy individuals. In two years, there was an increase in HbA1c from 7.4% at 3 months to 9% in the 21st month of treatment in G1; increase from 7.8% to 8.8% at 18 months in G2. Significant correlation between the time of diagnosis of the disease and increase in HbA1c (p=.004), constant in the two years of study. C peptide: undetectable after 6 months in G1 and after 12 months in G2, occurring first in children aged 7 to 10 years and, last, in adolescents. There was no correlation between HbA1c and C peptide after two years of study. Insulin use: lower mean for G1 in the two years of study. Changes related to the time of diagnosis and not to the period of hospitalization.

Chart 2 – Cont.

Authorship, country and year	Objective, type of study and participants	Educational intervention	Clinical and behavioral outcomes
Grey et al, United States (1998)*,[12]	To determine whether Coping Skills Training (CST) combined with intensive diabetes treatment improves metabolic control (MC) and quality of life (QoL) of adolescents starting intensive therapy regimens. RCT. 65 adolescents, 13 to 18 years old, on insulin therapy for at least one year.	**Theme:** coping skills in the management of intensive insulin therapy. Control group (CG): intensive treatment (multiple-dose insulin therapy). Experimental group (EG): intensive treatment and CST, which consisted of dramatization of everyday situations (food choices, conflicts, decision making), to train coping skills. Participants were evaluated and the scene was repeated until the expected behavior was identified. Groups of 2-3 adolescents; average duration 1-1.5 hours. The adolescents participated in an average of six weekly sessions, followed by monthly consultations at the pediatric diabetes clinic for three months.	**Clinical:** decrease in HbA1c after three months, faster and greater one month after the start of intensive treatment, maintained until the end of the study in the EG. In both groups, intensive therapy associated with a higher number of monthly visits led to a decrease in HbA1c at three months (p<.01). The results suggest that intensive treatment improves MC, which can be intensified through the CST. CST has an immediate beneficial effect on the adolescent's ability to obtain MC in the short term. There was no difference between the groups in terms of insulin doses or number of blood glucose monitoring checks performed per day. The intervention did not affect the decrease in acute complications. BMI increased in the overweight participants in both groups. **Behavioral:** improved self-efficacy (Self-Efficacy for Diabetes scale), depression (Children's Depression Inventory), QoL (Diabetes Quality of Life Youth scale), and coping with T1D (Issues in coping with IDDM) during the three months of study in EG.

Chart 2 – Cont.

Authorship, country and year	Objective, type of study and participants	Educational intervention	Clinical and behavioral outcomes
Grey et al, United States (2000)*[13]	To determine if the initial effect of CST on MC and QoL, combined with intensive care, can be maintained in young people who are starting treatment. RCT. 77 adolescents, 12 to 17 years old, on insulin therapy for at least one year.	**Theme:** coping skills in the management of intensive insulin therapy. Control group (CG): intensive treatment (multiple-dose insulin therapy). Experimental group (EG): intensive treatment and CST, which consisted of dramatization of everyday situations to train coping skills. Participants were evaluated and the scene was repeated until the expected behavior was identified. Groups of 2-3 adolescents: average duration of 1-1.5 hours. The adolescents participated in an average of six weekly sessions, followed by monthly appointments at the Pediatric Diabetes Clinic for 12 months.	**Clinical:** decrease in HbA1c after 12 months in EG. Better MC in EG with better self-efficacy related to diabetes and medical treatment (*Self-Efficacy for Diabetes scale*), with statistical significance during the six months. **Behavioral:** less negative impact on QoL (Diabetes Quality of Life Youth scale) after 12 months, with the best results observed in the first three months of intervention.
Howells et al, Scotland (2002)[14]	To evaluate the changes in self-efficacy of young people with T1D who participated in the Negotiated Telephone Support (NTS) intervention. RCT. 79 young people, 12 to 24 years old, on conventional insulin therapy.	**Theme:** problem-solving concerning T1D. Group 1 (G1): conventional treatment (quarterly consultation at the diabetes center). Group 2 (G2): conventional treatment and NTS, consisting of a phone call by a dietician specialized in pediatrics and diabetes over a one-year period. Adolescents decided on the theme of the call, which took place every two to three weeks, with the option of extra calls upon the youth's initiative. Home visits by one clinical psychologist for active instruction and delivery of a leaflet on problem-solving. Group 3 (G3): NTS and consultation at the diabetes center once/year, HbA1c every three months (at home or collection at the center). Most chosen themes in NTS: diabetes (general), performance at work, friendship, relationship with parents and siblings, health, social life and leisure, school/university, and others. On average, each participant received 16 calls, lasting nine minutes each, at three-week intervals.	**Clinical:** the NTS did not improve glycemic control in G2 and G3. G1, G2 and G3 showed an increase in BMI during the study. There was a statistically significant correlation (p<.01) between the participant's age and the average duration of the telephone contact in G2 and G3. Fewer consultations at the diabetes center in G3. G1, G2, and G3 showed no statistically significant differences (p=.84) in the number of emergency hospitalizations due to diabetes complications during the study. **Behavioral:** there was no statistically significant difference between the groups in the self-efficacy scores (Self-Efficacy for Diabetes), treatment adherence barriers (Environmental barriers to Adherence Questionnaire) problem solving (Social Problem Solving Inventory), and diabetes knowledge (Diabetes Knowledge Scale). Self-efficacy increased significantly in the combined intervention and in individuals with HbA1c under 8%.

Chart 2 – Cont.

Authorship, country and year	Objective, type of study and participants	Educational intervention	Clinical and behavioral outcomes
Lawson et al, Canada (2005)[15]	To determine the effect of telephone contact on MC, treatment compliance, and QoL of adolescents with T1D. RCT. 43 adolescents, 13 to 17 years old. T1D for at least 1 year, insulin therapy 2-3 times/ day and inappropriate glycemic control in the last 6 months.	**Theme:** adjustments to insulin dosages. Control group (CG): standard care (two or three doses of NPH and regular insulin, or glycemic corrections with ultrafast insulin; meal plan with a dietician once per year; quarterly medical return with diabetologist and HbA1c). Experimental group (EG): standard care and telephone contact for six months. Two diabetes nurse educators each contacted about 11-12 adolescents weekly, to discuss the blood glucose diary of the previous week and necessary adjustments in insulin dosages.	**Clinical:** decrease in HbA1c in 29% of participants in EG and increase in 19% (p=.015) of the participants in EG. Increased HbA1c in CG. Increased BMI in EG. There were no changes in insulin dosages or severe hypoglycemic episodes in both groups. **Behavioral:** Improvement of QoL (Diabetes Quality of Life Youth scale) and family functioning (Family Environment Scale) scores of the experimental group at three months. The intervention showed gaps in the knowledge about T1D.
Franklin et al, Scotland (2006)[16]	To describe the Sweet Talk RCT. 92 young people, 8 to 18 years old, with T1D for at least one year.	**Theme:** T1D self-care tasks. Group 1 (G1): standard care (2-3 doses of premixed insulin). Group 2 (G2): standard care and *Sweet Talk*. Group 3 (G3): basal therapy-bolus and *Sweet Talk.* (automated system that stores and sends, according to a previous schedule, about 400 text messages by mobile phone, guided by behavioral theories). It includes: a weekly reminder of the successful goals agreed at the clinic; daily messages with tips, information, or reminders to reinforce the goals agreed upon with the health care team concerning insulin application, blood glucose self-monitoring, healthy eating, and exercise.	**Clinical:** improvement of HbA1c in G3 (p<.001). No significant changes were identified in DKA and severe hypoglycemia episodes. The BMI increased in G3. The use of the health service was greater in G2 and G3 (p=.016). Emergency contacts with the health care team were more frequent in G3 than G2 (p=.02). **Behavioral:** improved self-efficacy (Self-Efficacy for Diabetes score) in G2 when compared to G1 (p=.003); increased adherence to the treatment, measured using a visual analog scale (p=.042). There was no change in knowledge levels (Diabetes Knowledge Score). The social support (Diabetes Social Support Interview) provided by the health care team increased when *Sweet Talk* was used in G2 and G3 (p<.05).

Chart 2 – Cont.

Authorship, country and year	Objective, type of study and participants	Educational intervention	Clinical and behavioral outcomes
Coates et al, Northern Ireland (2013)[17]	To evaluate the impact of a diabetes education program for adolescents with T1D (CHOICE): HbA1c, BMI, hypoglycemia and hyperglycemia episodes, and adherence to the diet. RCT. 135 adolescents, 13 to 16 years old. T1D for at least one year.	**Themes:** interaction between carbohydrate consumption and insulin requirement; meal times and effects of physical exercise on blood glucose and insulin. Control-group (CG): standard care every three months, with the professional from the clinic; to solve problems. Experimental group (EG): CHOICE, consisting of four weekly educational sessions, involving one nurse and two dieticians with experience in diabetes at seven hospitals. The duration of the sessions was three hours, plus one dinner to practice carbohydrate counting. These included a curricular guide, plates to standardize the meals, images of individual portions to build custom meals and cards to promote the dialogue. During the breaks between the sessions and at two, four and five months after the intervention, text messages were sent to assess the progress and encourage communication.	**Clinical:** improved HbA1c in EG after 24 months. Greater variation in BMI in CG at 12 months. Average of six days of hyperglycemia in the 24-month period, without DKA episodes, in both groups. No difference between the groups in the number of hypoglycemic episodes. **Behavioral:** greater adherence to the diet (Diabetes Care Profile) after one, three, and six months in EG.

Chart 2 – Cont.

Authorship, country and year	Objective, type of study and participants	Educational intervention	Clinical and behavioral outcomes
Price et al, United Kingdom (2016)[18]	To analyze the effect of Kids in Control of Food: KICk-OFF on the biomedical and psychological outcomes of young people with T1D. RCT. 370 adolescents, 11 to 16 years old, T1D for at least 1 year.	**Themes:** carbohydrate counting and adjustment of insulin doses in daily life; management of hypoglycemia, ketones, and long-term complications. Control-group (CG): standard care. Experimental group (EG): KICK-OFF (five-day course taught at 17 medical centers). Group education strategy, including written material, support questionnaire and evaluation. Developed by a diabetes nurse and a dietician with expertise in diabetes, and by a member of the local team. The professionals were trained during a five-day course on teaching skills, developed during the pilot study.	**Clinical:** HbA1c levels without statistically significant differences between the groups over the 24 months (p=.38). EG participants with high HbA1c at the beginning of the study showed better results after two years when compared to the CG (p=.03). After 24 months, the CG presented worsening of HbA1c levels compared to the EG, in which the decrease continued. There was no significant change in the rates of DKA and severe hypoglycemia. **Behavioral:** improved general QoL scores (PedsQL-G) in the experimental group at six- and twelve-months post-intervention (p=.04) and improved scores in physical and psychosocial domains at six months (p=.04). There was a decrease in disease symptoms (PedsQL-D) at six months (p=.008). After 12 and 24 months, the CG presented high treatment adherence scores (p=.02) and, at six and 12 months, high self-efficacy scores (p=.01 and p=.02).
Semiz et al, Turkey (2000)[19]	To evaluate the effectiveness of camps for children with diabetes, using objective parameters. Quasi-experiment. Young people from 8 to 20 years old, T1D for at least 1 year. 28 participants in Camp 1; 29 participants in Camp 2; 14 participated in both.	**Themes:** teaching the insulin injection technique; recognition and management of hyperglycemia and DKA; adjustment of insulin doses based on diet and activities; importance of control and new therapies. Camps: 10 days long, a health care team comprising pediatric endocrinologists, diabetes nurses and dieticians. Assessment before/after the intervention: participants completed a knowledge questionnaire on diabetes and nutrition before, immediately after and six months after both camps.	**Clinical:** there was no difference in the mean annual HbA1c level before and after the first camp in all participants (p>.05). No difference in the HbA1c level before the first and after both camps (p>.05). After the first camp: Weight gain of 1.2 kg in 18 children considered underweight, and weight loss of 0.9 kg in 8 children who were overweight. **Behavioral:** increased knowledge, more noteworthy after the second camp (p<.05). Knowledge decreased after six months when compared to immediately after the camps. Nevertheless, the levels still remained higher than the knowledge levels before the camps (p<.05).

Chart 2 – Cont.

Authorship, country and year	Objective, type of study and participants	Educational intervention	Clinical and behavioral outcomes
Lawson et al, Canada (2000)[20]	To compare the short-term results of the Intense Diabetes Management Program (IDM). Quasi-experiment. 28 young people, 11 to 20 years old, with nephromegaly detected by ultrasound.	**Themes:** action and adjustment of insulin doses; daily glucose monitoring and on days of illness; causes, treatment, and prevention of hypoglycemia episodes; food plan and carbohydrate counting. Group 1: customized education on IDM + intense clinical follow-up for three months; six-eight hours of educational intervention, distributed in three-four sessions conducted at a diabetes center by a diabetes nurse, a dietician and a researcher. Weekly telephone contact initiated by the researcher. Group 2: IDM as part of the diabetes care routine, educational sessions in groups of up to 20 people, conducted by a diabetes nurse specialist, a dietician, and a diabetologist. Encouraged telephone contact (patient's initiative). IDM: multiple-dose regimen of regular (IR) or ultrafast insulin before meals and NPH before bedtime. IR doses were adjusted according to the pre-prandial glucose level, amount of carbohydrates ingested and planned physical exercise after the meal. All participants were instructed to monitor blood glucose levels four times a day.	**Clinical outcomes only:** Group 1: mean decrease in HbA1c of 2.5% in the first three months (p<.0001). Episodes of severe hypoglycemia occurred. Group 2: mean HbA1c decreased by 0.9% in the first three months (p=.05). There were no episodes of severe hypoglycemia. Considerable increase in HbA1c in both groups one year after the intervention. There was no difference between the mean HbA1c in both groups at 15 months after the beginning of IDM (p=.8). No episodes of DKA were observed in both groups.

Chart 2 – Cont.

Authorship, country and year	Objective, type of study and participants	Educational intervention	Clinical and behavioral outcomes
Von Sengbusch et al, Germany (2005)[21]	To evaluate the effectiveness of standardized and structured diabetes education, developed by a remote team. Quasi-experiment. 107 children with mean age 11.1 ± 2.5 years old and T1D for at least six months.	**Theme:** function of insulin and parent empowerment to adjust doses according to daily events and challenges. Five-day course (Monday to Friday), which three researchers conducted at eight state hospitals in cooperation with the local health team. Group education, including four to six children of the same age group. Individual or group education for parents, one to two times a week. Data collected before (t0), at six weeks (t1), and at six months (t2) after the intervention.	**Clinical:** children with HbA1c > 8% before the intervention significantly improved MC between t0 and t1, and t0 and t2, regardless of changes in insulin therapy and the number of glucose monitoring checks per day (p<.01). Children with HbA1c <6.8% increased the level between t0 and t1(p>.05), and between t0 and t2 (p<.05). There was no significant difference in HbA1c at the three measurement times (P>.05), nor in the number of severe hypoglycemia episodes (p>.05), but there was a significant reduction in the number of hospital admissions (p<.05). **Behavioral:** diabetes knowledge increased at t1 and t2 compared to t0 (p<.05). Adolescents who lived with a single parent obtained a higher knowledge score when compared to those who lived with both parents (p<.05). Improved QoL (German KINDL R quality-of-life questionnaire) at t1 (p<.05) and t2 (p<.01). Satisfaction with the intervention (German CSQ-8 Client Satisfaction Questionnaire) was high: 57.4% of children rated it as 'very good' at t1.

Chart 2 – Cont.

Authorship, country and year	Objective, type of study and participants	Educational intervention	Clinical and behavioral outcomes
Qayyum et al, Pakistan (2010)[22]	To evaluate the effectiveness of Diabetes Self-Management Education (DSME) in glycemic control of Pakistani children with T1D. Quasi-experiment. 50 children, mean age 10 years, and age of diagnosis 8.15±3.02 years.	**Theme:** specific module on insulin therapy that addressed types of insulin, preparation of the injection, application sites and forms, where/how/for how long insulin can be stored. DSME: educational program of a pediatric diabetes clinic, organized in four modules consisting of 1.5-hour lectures, offered for groups of 10 children and their parents/caregivers. At the end, the participants received a glucose meter with reagent strips, a blood glucose diary, educational leaflets, nutritional diary, and an identification card and bracelet, as well as a doll with highlighted application sites. Monthly follow-up with a pediatric endocrinologist, a pediatrician, a dietician, a diabetes nurse after the intervention, with telephone reminders one week before the appointment.	**Clinical outcomes only:** no differences were identified in the insulin regimen or mean insulin dosage during the study. Decrease in HbA1c after participation in the DSME (p<.001).
Mukama et al, Tanzania (2013)[23]	To analyze the impact of a diabetes education and management program: glycemic control and chronic complications of children and adolescents in Tanzania. Quasi-experiment. 81 participants, 0 to 17 years old, with T1D for at least six months.	**Themes:** prevention and treatment of hypoglycemia; prevention of hypoglycemia due to incorrect insulin application; caution with excessive physical activity and skipping meals; calculations of insulin dosages and storage methods; recognition and prevention of DKA. Individual educational intervention developed in a hospital by two pediatric endocrinologists, nurses, dieticians and psychologists. Duration of the study: six months.	**Clinical outcomes only:** there was no improvement in HbA1c at six months after the intervention (p=.1). There was no statistically significant association between the results of HbA1c and gender (p=.06), nor with medical returns (p=.89) or insulin dosage (p=.17). The number of hypoglycemia episodes dropped by 2/3 at six months (p=.65). DKA episodes were associated with the lack of insulin doses (p<.05) and blood glucose monitoring at home.

* The articles Grey et al (1998) and Grey et al (2000) are results from the same study.

All studies examined the effect of the educational intervention on glycated hemoglobin (HbA1c), but other outcomes of interest were the effects of the intervention on the Body Mass Index (BMI);[12,14–17,19] number of injections and insulin dose per day;[12–13,15,17,23] episodes of hyperglycemia with ketoacidosis (DKA), and severe hypoglycemia;[11,15–16,23] number of blood glucose monitoring checks at home;[11] number of emergency contacts with the health care team by telephone;[15–16] and attendance at medical appointments.[11,16]

Self-efficacy, depression, coping difficulty, barriers to treatment adherence, quality of life, social support, family dynamics, knowledge about diabetes, adherence to diet and medical return visits, and satisfaction with the intervention were measured in ten studies,[11–19, 21] using specific scales to evaluate these constructs. However, only seven of them mentioned the validation processes of the scales in the contexts in which they were used.[12–16,18] The verification of endpoints varied among the studies. In the majority, the endpoints were three, six, and twelve months after the intervention.

As for the risk of bias, in five of the clinical trials, the randomization method was properly reported,[14–18] while four studies mentioned concealing the participants' group allocation.[14–15,17–18] The masking of participants and professionals is liable to bias, as both know who will be included or not in the group that will receive the education, except for the texting intervention (Sweet Talk)[16], in which professionals do not know which adolescents will receive the messages. All clinical trials reported masking of the participants, which did not occur in the quasi-experiments. Regarding the masking of the outcome evaluators, only four reported measures to hide the results from the researchers involved in the data analysis.[11–14]

Seven studies mentioned data losses and exclusion, such as participants' withdrawal or incompleteness of data for the analysis of HbA1C, characterizing a low risk of bias for incomplete outcomes.[12–16,18–19] Only three of the clinical trials showed the intervention protocol or correctly included the publication of the desired outcomes in its description.[15,18,21]

DISCUSSION

This study identified several educational strategies for the teaching of insulin therapy to children and adolescents with T1D, developed in different contexts, such as pediatric clinics, diabetes centers, hospital environments, educational camps and distance education. The diversity of contexts shows that diabetes education does not take place only in hospitals or at the time of diagnosis in health care settings but positively helps in the treatment as, like the educational camps, the environment favors the promotion of autonomy, which leads to the internalization of self-care behaviors.[24] The design of the strategies in these contexts should be appropriate to their clients' educational needs and, in the case of children and adolescents, the school setting deserves attention in future research.[25]

The literature recommends that diabetes education aimed at the pediatric clientele must be planned in such way that age, developmental stage and socio-cultural issues are taken into account.[25] Resources such as dramatization,[12–13] development of educational[14] and illustrative[22] leaflets were used in some studies in this review. In only one study, a doll that highlighted the insulin application sites was used in the strategy.[22] The remaining educational programs did not mention how the information was given to the participants, highlighting a gap in the studies concerning how the educational programs have been developed.

Despite the efforts the health care professionals have made, three out of four young people with T1D report at least one factor that inhibits their treatment adherence and that may be associated with improper glycemic control, i.e., HbA1c levels superior to 7.5%.[26] Aspects such as fear and pain are barriers to the achievement of intensive treatment, but can be overcome by implementing effective educational strategies. The team should be attentive to the educational diagnosis of the pediatric population and define whether the strategies implemented consider these individual aspects.[25]

Beyond encouraging adherence to insulin therapy, the nurse's role is to empower the young person with T1D for self-care in a planned manner, so that the transition from childhood to adult life takes place without negatively affecting the follow-up care. The health care team should conduct the treatment of young people until the transition to adulthood, as some studies have pointed out.[27–28] Aware of these clients' preferences, researchers have used technology as a diabetes education resource. The telephone contacts with the health care team and the text messages sent to the patients by mobile phone are examples found in this review.[14,16]

These interventions do not depend on family involvement, as they focus on the adolescent's learning needs. In younger children, however, family-centered care is more appropriate.[29] A review on the use of video games and virtual environments in diabetes education for self-care highlighted that studies on medication adherence are still numerically scarce and, as highlighted in the findings of this review, strategies need to be better outlined in order to objectively measure their effect.[30]

Although the implementation of recreational strategies such as Therapeutic Play and interactive technologies are based on the guidelines for diabetes education, aiming to influence the educational particularities of the young clients[2], these were not addressed in the articles retrieved in this review. Only two studies evidenced appropriate strategies for younger children, an age group in which the number of new cases of T1D has grown exponentially,[1] which is another gap that needs attention in the future.

Due to the wide range of educational strategies evaluated in the articles included in this study, no single strategy could be determined that is capable of improving knowledge about insulin therapy, combined with a psychosocial or metabolic improvement. These findings are consistent with those described in a review on psychosocial interventions for children and young people in the UK.[31]

The use of validated instruments to assess the proposed constructs is the first step to ensure the methodological rigor of these interventions. The risk of bias assessment of the experimental and quasi-experimental studies in this review highlights the need for a thorough description of the study protocols. In 2014, in a study of the available instruments to assess self-care behaviors in diabetes, different weaknesses were demonstrated in the validation process.[32]

Evidencing validated instruments for the pediatric population is one of the knowledge gaps that needs to be reviewed, as in a study published in 2011[33]. Investments are also needed in the assessment of other extremely important aspects of education involving insulin therapy, such as recognizing a possible increase in the number of injections after participating in an educational strategy, assessing the occurrence of less hypo- and hyperglycemia episodes related to intensive medication, increased frequency of capillary glucose tests or decrease in the number of contacts with the health care team. Although mentioned in some studies, these have not been assessed as outcomes of interest among the studies included in this review. HbA1C, a biological marker evaluated in all investigations, is a parameter that reveals glycemic control, but that, alone, does not show the necessary skills adjustments that support insulin therapy.

The engagement of different professionals in the educational strategies described was also observed, including nurses, pediatricians, diabetologists, pediatric endocrinologists, dieticians, psychologists, and social workers. The presence of the multiprofessional team in teaching children and adolescents with T1D is paramount. The team should be responsible for monitoring educational interventions in order to ensure the quality of the care provided.[25]

The training of professionals with expertise in diabetes education is a reality in countries like the United States and Brazil, guaranteeing the career development of leaderships for the multiprofessional teams that assist children and adolescents with T1D.[25,34] Nurses were present in most of the studies listed in this research, highlighting their role as health care educators and promoters of self-care in young people with T1D. Regardless the time of T1D onset the children or the adolescents are in, this professional play an important role in the disease management.[35]

The approach of different topics, such as the adjustment of insulin dosage in daily situations, education for insulin management associated with the nutritional strategy of carbohydrate counting, diabetes education with a specific module on insulin therapy and intensive insulin use, allowed important outcomes: improved HbA1c results, even if modest, especially in the long term[11–13,15,17–18,22], better self-efficacy results[12–15], better treatment adherence[16,18], increased knowledge on the disease[19,21] and its coping[12], as well as a better quality of life[12–13,15,18,21], but not maintained over time.[15] No decrease was observed in most studies concerning the number of acute complications.[12,14–18,21]

Important aspects related to insulin therapy, such as the presence of lipohypertrophy, rotation of the application sites and reuse of needles were not mentioned as issues evaluated after the educational interventions, although they are fundamental for the achievement of proper metabolic control and reduction of complications in the short and long terms.[36]

Maintaining the behavioral change related to insulin therapy also depends on the quality of the educational programs. These should prioritize not only strategies that take into account the needs and particularities of the target population, but also ongoing support[37–38] to develop and maintain self-care behaviors, progressively achieving better outcomes.

As a limitation of this review, we identify the possibility that the choice of the descriptors to perform the search strategy was not comprehensive enough to capture all the studies produced. In addition, ten studies were classified as *unobtainable*, published between 1978 and 1990, whose full texts could not be accessed, even after contact with the respective authors.

CONCLUSION

The systematic review evidenced the use of the following education strategies: group lectures; individual education with donation of care *kits* and dinners; dramatization; educational camp; telephone contact with the health care team and texting by mobile phone.

The strategies implemented for the child and youth audience and the focus on insulin therapy education took place in multiple health care contexts, developed by a single professional or multidisciplinary team. Nurses served as the leaders in most of the studies analyzed. These studies investigated clinical and behavioral outcomes, and all educational strategies measured glycemic control through HbA1C. No single strategy could be identified that managed to improve metabolic control and promote behavioral changes with regard to the insulin therapy of youth with T1D.

Methodological weaknesses were found in fundamental stages for the design of experimental studies, such as bias in planning phases of the intervention and in evaluation of its outcomes. Outlining educational strategies focused on insulin therapy for children and adolescents with diabetes has shown a gap that, once filled, will contribute to evidence-based practice and the improvement of pediatric diabetes education.

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CONFLICT OF INTERESTS

No conflicts of interest

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