

Type 1 diabetes mellitus: evidence from the literature for appropriate management in children's perspective

DIABETES MELLITUS TIPO 1: EVIDÊNCIAS DA LITERATURA PARA SEU MANEJO ADEQUADO, NA PERSPECTIVA DE CRIANÇAS

DIABETES MELLITUS TIPO 1: EVIDENCIAS DE LA LITERATURA PARA SU ADECUADO MANEJO, EN LA PERSPECTIVA INFANTIL

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ABSTRACT

The objective of this study was to identify the evidence available in the literature that address, for children's perspective, factors that are relevant for an appropriate management of type 1 diabetes mellitus. An integrative review was performed on the PubMed, CINAHL, LILACS, CUIDEN and PsycINFO databases, covering the period from 1998 to 2008 and using the following keywords: type 1 diabetes mellitus, child, prevention and control, triggering factors, emergencies, self care, learning and health education. Nineteen of the surveyed articles were selected, and their analysis revealed the following categories: living with diabetes; self care and glucose profile; the actions of family, friends and health professionals; and school. The evidence show that children appreciate the support they receive from their relatives, which have a direct relationship with being prepared for self care. Other members apart from their network are also valued. Areas that deserve attention are the school, the personal experience of each child, and health education.

DESCRIPTORS

Diabetes mellitus, type 1
Child
Pediatric nursing
Self care
Health education

RESUMO

O estudo objetivou identificar as evidências disponíveis, na literatura, que abordem, na perspectiva de crianças, os fatores relevantes para o adequado manejo do diabetes mellitus tipo 1. Realizou-se uma revisão integrativa, nas bases de dados PubMed, CINAHL, LILACS, CUIDEN e PsycINFO, com as palavras-chave diabetes mellitus tipo 1, criança, prevenção e controle, fatores desencadeantes, emergências, autocuidado, aprendizagem e educação em saúde, no período de 1998 a 2008. Dos artigos levantados, selecionaram-se 19, e sua análise permitiu a identificação das categorias: vivendo com o diabetes; autocuidado e perfil glicêmico; atuação da família, amigos e profissionais de saúde; e escola. As evidências apontam que a criança aprecia o apoio recebido por seus familiares os quais têm relação direta com o preparo para o autocuidado. Outros membros externos à sua rede também são valorizados. A escola é um espaço que merece atenção, bem como a experiência particular de cada criança e a educação em saúde.

DESCRITORES

Diabetes mellitus tipo 1
Criança
Enfermagem pediátrica
Autocuidado
Educação em saúde

RESUMEN

El estudio objetivó identificar las evidencias disponibles en la literatura que aborden, en la perspectiva infantil, los factores relevantes para el manejo adecuado de la diabetes mellitus tipo 1. Se realizó revisión integradora en bases de datos PubMed, CINAHL, LILACS, CUIDEN y PsycINFO, con los descriptores diabetes mellitus tipo 1, niño, prevención y control, factores desencadenantes, emergencias, autocuidado, aprendizaje y educación en salud, en período 1998 a 2008. Del total, se seleccionaron 19, su análisis permitió identificar las categorías: viviendo con la diabetes; autocuidado y perfil glucémico; actuación de la familia, amigos y profesionales de salud; y escuela. Las evidencias determinan que el niño aprecia el apoyo recibido por sus familiares, los cuales tienen relación directa con la preparación para el autocuidado. Otros miembros externos a su red también son valorizados. La escuela merece atención, así como la experiencia particular de cada niño y la educación en salud.

DESCRIPTORES

Diabetes mellitus tipo 1
Niño
Enfermería pediátrica
Autocuidado
Educación en salud

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INTRODUCTION

Among chronic childhood illnesses, type 1 diabetes mellitus (Type 1 DM) is one of the most common, representing approximately 2/3 of all diabetes cases in children⁽¹⁾. Today, an estimated number of five million diabetics exist in Brazil, about 300 thousand of whom are younger than 15 years⁽²⁾. The consequences of having a child with diabetes in the family have been widely debated upon in the Brazilian and international contexts⁽³⁻⁴⁾. Adequate disease management in this population has shown to be a challenge, mainly for the children themselves, due to the presence of inadequate behaviors skills and knowledge that collaborate towards non-adherence to treatment and to a significant increase in long-term complications⁽⁵⁾.

The social support network, family relations⁽⁶⁾ and the relationship of trust with health professionals⁽⁷⁾ influence self-care and self-control behaviors⁽⁷⁾, besides enhancing treatment adherence, resulting in better glucose control⁽⁶⁻⁷⁾. Studies have demonstrated that understanding the life experiences of children in their different spaces, valuing them and seeking greater approximation, can contribute to knowledge sharing on diabetes management and to the child's greater involvement in care^(6,8-9). Besides, nursing practice, health care, research and new knowledge creation can also be benefitted⁽⁹⁾.

OBJECTIVE

This research aims to identify available evidence in literature on factors interfering in adequate management of Type 1 DM, from children's perspectives, published between 1998 and 2008. The researchers expect to contribute to the synthesis of available knowledge and to appoint its applications for nursing practice and future research.

METHOD

This integrative review⁽¹⁰⁾ comprised the following steps: problem definition; article search and selection; definition of data for extraction and analysis; result discussion and interpretation and, finally, knowledge synthesis. The guiding question to elaborate the review was:

What scientific knowledge has been produced on relevant factors for adequate Type 1 DM management, from the perspective of children living with this illness?

The following preselected keywords were used, based on the Health Sciences Descriptors (DeCS) and Medical Subject Headings (MESH), in their different combinations: type 1 diabetes mellitus; child; prevention and control: precipi-

tating factors; emergencies; self-care; learning; health education. The inclusion criteria were: published articles whose theme corresponded to the research problem and involving children up to 13 years of age. Articles in English, Portuguese and Spanish, published between January 1998 and July 2008; with abstracts indexed in PubMed, CINAHL, LILACS, CUIDEN and PsycINFO. The combination of the descriptors used in each database resulted in 1,001 references. Two authors independently performed exhaustive reading of the titles and abstracts and, in case of doubts about the selection, the publication was included for final decision together with all authors. The first confrontation with the references selected at this moment resulted in 88 papers. Then, new meetings among the authors resulted in the exclusion of reviews, theses, dissertations and publications on genetic and epidemiological questions, specific treatments, among others, so that 44 articles remained. As from this step, the copies of these 44 papers were obtained and their contents were fully read and discussed, during face-to-face meetings among the authors. The goal was to check

The social support network, family relations and the relationship of trust with health professionals influence self-care and self-control behaviors, besides enhancing treatment adherence, resulting in better glucose control.

that they actually covered the guiding question and complied with the inclusion criteria. New studies were found that focused on adolescents, laboratory exams and neurological and cognitive complications only, which were excluded. In the same step, the authors identified studies involving children and young people at the start of adolescence (three papers with participants aged 8-15 years and one with adolescents aged 12-14 years), which were also included due to the contribution of their results to this review. We also included one single study involving subjects aged 8-19 years, but which presented results on factors interfering in Type 1 DM management per age range, permitting the identification of child-related factors. The final sample included 19 articles. To analyze the selected articles, a script was used with the following indicators: activity area of the researchers, publication year and country, place where the study was developed, method, participants, central theme and results.

RESULTS

The analysis of the selected publications revealed that for children, the main actors in this process, the factors interfering in diabetes management take the form of issues facilitating and hampering this management. Picture 1 summarizes these factors, divided in four categories.

Living with diabetes: coping with the illness and valuation of the child's experience

The children's lack of knowledge about the disease and its implications entails fear of suffering prejudice and isolation, impairing adequate diabetes management⁽¹¹⁾. Support-

ing themselves on beliefs and having positive feelings that offer comfort collaborate to cope with these issues, relieving their suffering and improving their quality of life⁽¹¹⁻¹²⁾. On the other hand, further understanding on the disease, obtained through their experience during the diagnosis, hospitalizations and their own bodies' reactions are positive factors that enhance good control⁽¹³⁾. Besides, the children's participation as research subjects, favoring greater contact between the children and health professionals or researchers, can contribute to expand this knowledge, as it offers opportunities for greater mutual interaction, improving their education on the illness and its management and, consequently, achieving better glucose control⁽¹⁴⁾.

Other measures also collaborate to obtain good disease management, such as attempting not to think about it and trying to live in harmony, assuming it and adjusting it to their lifestyle^(11-12,15). Performing the necessary care, including eating well, performing self-monitoring of blood glucose, staying active and taking medications to avoid medical complications, hospitalization or death are other actions that, from the children's perspective, add up efforts to achieve good disease control^(11-12,15). For some children however, facing diabetes becomes a "daily struggle with themselves", like a constant probation⁽¹¹⁾.

Chart 1 – Factors facilitating and hampering diabetes management, from children's perspective - Ribeirão Preto - 2009

Factors interfering in Type 1 DM management, from children's perspective		
Categories	Facilitate	Hamper
Living with diabetes	Value the child's experience; get to know, face and accept the illness; positive beliefs and feelings.	Not knowing about the illness: facing it as a "daily struggle"; prejudices; isolation.
Self-care and glucose profile	Glucose levels within normal range; help for self-application and decision to choose foods.	Privation of foods; interruption of activities to deal with the illness' demands; fear and deficiency in self-application technique; insufficient resources.
Family, friends and health professional	Support from family, friends and professionals; family involvement; bonding and valuation of the child: multiprofessional team.	Lack of support from parents; family conflicts and stressing environment; difficulties to relate with friends.
Role of school	Support from friends; adequate place to store materials; information to friends and teachers; school visits by health professionals; educative activities.	Inadequate place for self-care; interruption of school activities; inadequate canteens; lack of knowledge; indifference of school team; inflexibility of school rules; fear of being judged by friends; bullying

The importance of self-care and glucose profile

The daily tasks needed for self-care often provoke the children's annoyance, hampering adequate disease management⁽¹⁵⁾. The pain mentioned to perform capillary glucose testing can contribute for children to avoid it, thus leaving one important care act aside. They even report that fear of self-applying insulin is a feeling they need to face every day⁽¹¹⁾.

Diet care also represents a challenge for the children. Dealing with the desire to have sweets and the guilt of giving in to this desire are examples of barriers for self-care⁽¹¹⁾. In the school context, this situation can be intensified, as they are forced to eat appropriate snacks for their condition, which they generally bring from home. Besides, for school snack breaks are times that enhance group interaction among the children and, consequently, their snacks, contributing to increase this challenge⁽¹⁶⁾. Despite these difficulties, glucose and diet control are responsibilities which children in the age range from 8 to 11 years should gradually start to assume, first sharing them with their parents and, over time, under the children's own supervision⁽¹⁷⁾. To start this responsibility process, having someone to remind

the children to perform capillary glucose monitoring⁽¹⁸⁾ and insulin application⁽¹⁷⁾, to discuss what would be good or not to avoid glucose variations, and also regarding sweets received at school, helps them to manage the illness, thus achieving a good glucose profile^(13,19). In this phase, the children see the maintenance of glucose test results within normal limits as a positive factor. Health professionals, however, need to heed to the possibility that maintaining glucose levels within adequate parameters is much more related to the family and health team's acceptance of the child than to the treatment and control of the illness⁽²⁰⁾.

Attempts to achieve adequate disease management minimally involve diet control, capillary glucose testing and maintenance and prescribed insulin applications. Besides the correct application technique⁽²⁰⁾, the success of this self-care first depends on the purchasing of materials like insulin, syringes and needles⁽²⁰⁻²¹⁾. The children appointed non-provision or lack of insulin at public institutions and delivery of insufficient syringes and needles for all applications needed as factors that make self-care unviable. This situation is aggravated even further when the family has insufficient financial resources to purchase these materials⁽²¹⁾.

Activities of family, friends and health professionals

Families' involvement, supporting the children as early as the diagnosis and promoting a healthy family environment, is an important factor for treatment adherence and glucose control⁽²²⁾. In case of a negative and critical relation with the parents and lack of support, when nobody assumes the responsibility for disease management or when tasks related to the regime are not shared, metabolic control gets worse⁽²³⁾. Stress-loaded environments, inside or beyond the family context, can entail behavioral problems that, consequently, interfere in self-care, affecting, among other issues, the children's diet⁽⁴⁸⁾, who can be more anxious and depressed⁽²⁴⁾. Health professionals should pay attention to the constant need for family assessment and follow-up, as children who are not closely supervised by their parents require special attention, mainly regarding the frequency of meals⁽²⁴⁾. Likewise, in daily experiences with the disease, single-parent families can present difficulties to support these children, so that relatives and friends need to be mobilized to share care⁽²²⁾.

Friends and health professionals were also reminded as factors interfering in disease management, offering emotional support and other types of help on different occasions^(12,15-16,19). Friends' companionship, offering moments of fun and relaxation, makes the children feel accepted in their condition, collaborating towards successful disease management^(12,15-16,19). They particularly emphasized the presence of a friend who knows about their disease and is able to acknowledge bad times; immediately performing care when necessary, warning close relatives and supporting the children to seek help⁽¹⁵⁻¹⁶⁾.

The children reminded the involvement of a multiprofessional team to be of help in physical, diet and socialization limitations as an important factor for adequate management⁽²¹⁾. Professionals were mentioned because of their actions, valuing and supporting the children in the hospital environment^(11,20,25), at Basic Health Units⁽²¹⁾, during clinical follow-up⁽¹⁵⁾, in education programs⁽²⁶⁻²⁷⁾, research⁽¹⁴⁾ and at school^(19,28). In all of these cases, the professionals' actions directly interfere in the children's experience, mitigating their fears and anxieties, performing educative actions, increasing knowledge on diabetes and the children's needs⁽¹¹⁾ and intensifying self-care⁽²¹⁾ and the expression of their experiences, emotions and feelings⁽²⁶⁻²⁷⁾.

Role of the school

The school was highlighted as an important factor that influences adequate diabetes management. For many children, the school structure revealed lack of preparation to help them with some self-care actions. Private rooms are missing for insulin administration, which is often performed at inappropriate and tight places, such as the children's bathroom⁽¹⁶⁾, which can impair metabolic control results⁽¹⁹⁾. Offering an adequate place for the children to store the materials they need for self-care⁽¹⁹⁾, with easy

access in case of need, was an important aspect these children reported⁽¹⁶⁾.

The school team's indifference towards the conditions, symptoms and difficulties of diabetic students was also reported. In addition, lack of knowledge among school professionals also collaborates to impair disease management^(16,19).

In the school context, colleagues often are the main sources of support for the children^(16,19). Many children, however, are afraid of classmates who, uninformed about the disease, react negatively to the need to interrupt school activities for care delivery⁽¹⁶⁾. In many cases, they report being victims of bullying⁽²⁹⁾. They believe that offering appropriate information to friends and colleagues strengthens bonds of friendship and enhances understanding of their condition⁽¹⁵⁾. The development of educative programs, permitting discussions and the search for solutions to these difficulties, involving health professionals, parents, students and teachers, was appointed as an important strategy for disease management⁽²⁸⁾.

DISCUSSION

Dealing with the demands of a chronic illness like diabetes represents a permanent challenge for the children themselves and for everyone involved. Since the diagnosis and start of their contact with the disease, the emotional commotion the children experience can be aggravated by the fact that they do not know what it means to be diabetic and its implications for their daily lives⁽¹¹⁾. Although relevant, research that seek the children's opinions and grant importance to their experiences are scarce^(13,15).

Around the age of four⁽⁴³⁾, children start to understand the need to perform diabetes control and become able to make decisions on their treatment, which increases with their development, experiences⁽¹³⁾ and transfer of responsibilities parents-child⁽¹⁸⁾. Health professionals need to closely follow this process, valuing the children's and their families' potentials, and at the same time identify intervention needs, especially regarding health education. When developing educative activities, besides covering technical issues, health professionals should privilege interaction with the other, participating and understanding experiences of pain, suffering and joy, with a view to improving the patients' quality of life^(21,25). Adequate education when the disease is discovered and monitoring of the children, bonding with them and their families, valuation of their knowledge and experience exchanges among children and among relatives are essential aspects which nurses should prioritize.

The children's families and friends should also be incorporated into the care and orientation plan. Studies appoint that, in families with conflict environments and deficient involvement in diabetes issues, treatment adherence is low, self-care and metabolic control are inappropriate⁽²³⁾ and difficulties occur to transfer care skills from parents to chil-

dren⁽¹⁷⁾. Paying attention to this negative aspect, health professionals need to understand the families and children's vulnerabilities and offer adequate interventions for each case, helping to decrease conflicts, assess the self-care process⁽¹⁹⁾ and seek interventions that offer support, education and facilitate this transition⁽¹⁷⁾.

For the children, friends are important sources of support and interfere in adequate disease management. Thus, interventions including friends and classmates can complement family-oriented ones⁽¹²⁾. The involvement of friends, parents and the extended families reinforce the support needed to strengthen management, enhance the children's self-confidence and understanding about the importance of following adequate treatment. All of these factors are essential for self-care development.

The school was identified as relevant equipment in self-care development, turning into a fundamental space for the children to develop, create and strengthen bonds, as this is where they spend most of their day. The analyzed studies indicated that these young people make efforts to find ways to perform self-care and adapt their needs to the school's, in the attempt to limit the impact of their condition on school activities⁽¹⁶⁾. Like the family, the people they have contact with at school can exert positive or negative influences on their disease experience. The children also appoint great difficulties, exacerbated by the inflexibility of school routines, which do not promote good disease management⁽¹⁶⁾, or by the children's individual immaturity, or by concerns with blood derivatives in the classroom or by the maintenance of rules for all students⁽¹⁹⁾. Besides school adaptations, another difficulty in the school environment was diabetes-related bullying. Depression related to bullying can contribute to reduce treatment adherence, compromising self-care, besides permitting the appearance of long-term complications⁽²⁹⁾.

The health team's approximation with schools shows to be essential, as this environment represents a key scenario for joint actions, involving professionals, children and school actors, with a view to achieving quality health care, especially in case of diabetes demanding daily management. Training or follow-up by a health team, especially by the

nurse, advising classmates, employees and teachers, shows to be effective, improving the children's glucose control⁽²⁷⁾. Educative programs in schools is another strategy health professionals should consider, with a view to reducing cases of bullying, informing teachers, students and other people present in the school space about the disease and its consequences⁽²⁹⁾. These programs can contribute to promote greater interaction among the students, increase the self-esteem of diabetic children and improve their treatment adherence.

The children also remembered health professionals as an important source of support for adequate disease management. Hence, multidisciplinary follow-up for these young people becomes fundamental, in the different phases of their growth and development, considering each person's individuality, the context they live in, their beliefs, fears and family relations, and leading them towards a healthy life, starting from their potentials^(15,21). The authors believe that thinking about a diabetes education program needs to involve service organization⁽²⁰⁾, qualifying nurses and their team, in the attempt to improve the care delivered to these children. Simple language, games, paintings, drawings, movies and reading can be part of these programs, as these strategies are valid to enhance expression of the children's feelings, contributing to their learning⁽²⁶⁻²⁸⁾.

CONCLUSION

From the children's perspective, knowledge on the disease, self-care, daily school life, support from families, friends and health professionals can influence disease management negative or positively. In care delivery to these clients, health professionals, particularly nurses, should pay attention to assess these aspects, so as to identify care priorities and effective and creative strategies to enhance the positive aspects and decrease the gaps that hamper adequate disease management. Theoretical concepts on child development, health promotion, family nursing and specific aspects of care delivery to diabetic patients need to be used and added to the care plan, which all stakeholders need to elaborate and assess jointly.

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