SOCIAL SUPPORT FOR THE CHILD WITH TYPE 1 DIABETES AND THEIR FAMILY

APOIO SOCIAL DA CRIANÇA COM DIABETES TIPO 1 E SUA FAMÍLIA

APOYO SOCIAL DEL NIÑO CON DIABETES TIPO 1 Y SU FAMILIA

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ABSTRACT

Objective: to gather evidence in the literature about social support for children with Type 1 Diabetes Mellitus and their families. **Method:** integrative review, based on the guiding question: << What are the evidences in the literature about social support for children with Type 1 Diabetes Mellitus and their families? Research conducted in the MEDLINE and LILACS databases, without time limitation, primary articles, published in Portuguese, English or Spanish, through the descriptors Social Support, Diabetes Mellitus and Child. **Results:** 17 articles were found in four categories: Social support sources; Social support in meeting quality of life and mental health; Research innovations for the promotion of social support and Conflicts of social support. **Conclusion:** it was possible to collect evidence in the literature on social support for children with type 1 diabetes mellitus and their families. One of the main sources of social support was the groups formed in social media. This should arouse the interest of the professionals in a special way, given the impact and the ease in the interactions that they can provoke. In addition, due to the greater number of international papers, it is desirable to publish more articles in the national context, better characterizing the country's reality and resulting in more appropriate interventions. **Descriptors:** Social Support; Diabetes Mellitus; Child; Pediatric nursing; Diabetes Mellitus, Type 1; Family.

RESUMO

Objetivo: levantar as evidências, na literatura, sobre o apoio social à criança com Diabetes Mellitus tipo 1 e suas famílias. **Método:** revisão integrativa, a partir da questão norteadora: <<Quais são as evidências, na literatura, sobre o apoio social à criança com Diabetes Mellitus tipo 1 e suas famílias?>>. Pesquisa realizada nas bases de dados MEDLINE e LILACS, sem limitação de tempo, artigos primários, publicados em português, inglês ou espanhol, por meio dos descritores Apoio Social, Diabetes Mellitus e Criança. **Resultados:** foram encontrados 17 artigos descritos em quatro categorias: Fontes de apoio social; Apoio social em encontro da qualidade de vida e saúde mental; Inovações em pesquisa para a promoção de apoio social e Conflitos do apoio social. **Conclusão:** foi possível levantar as evidências, na literatura, sobre o apoio social à criança com Diabetes Mellitus tipo 1 e suas famílias. Uma das principais fontes de apoio social foram os grupos formados em mídias sociais. Isto deve despertar o interesse dos profissionais de forma especial, dado o impacto e a facilidade nas interações que elas podem provocar. Além disso, devido ao maior número de trabalhos internacionais, é desejável que se publiquem mais artigos no contexto nacional, caracterizando melhor a realidade do país e resultando em intervenções mais adequadas. **Descritores:** Apoio social; Diabetes Mellitus; Criança; Enfermagem pediátrica; Diabetes Mellitus Tipo 1; Família.

RESUMEN

Objetivo: levantar las evidencias, en la literatura, sobre el apoyo social del niño con Diabetes Mellitus tipo 1 y sus familias. **Método:** revisión integrativa, a partir de la cuestión orientadora: ¿Cuáles son las evidencias, en la literatura, sobre el apoyo social del niño con Diabetes Mellitus tipo 1 y sus familias? Investigación realizada en las bases de datos MEDLINE y LILACS, sin limitación de tiempo, artículos primarios, publicados en portugués, inglés o español, a través de los descriptors Apoyo Social, Diabetes Mellitus y Niño. **Resultados:** se han encontrado 17 artículos, descritos en cuatro categorías: Fuentes de apoyo social; Apoyo social en relación con la calidad de vida y la salud mental; Innovaciones en investigación para la promoción de apoyo social y Conflictos del apoyo social. **Conclusión:** fue posible levantar las evidencias, en la literatura, sobre el apoyo social del niño con Diabetes Mellitus tipo 1 y sus familias. Una de las principales fuentes de apoyo social fueron los grupos formados en las medias sociales. Esto debe despertar el interés de los profesionales de forma especial, dado el impacto y la facilidad en las interacciones que ellas pueden provocar. Además, justificado un mayor número de trabajos internacionales, es deseable que se publiquen más artículos en el contexto nacional, caracterizando mejor nuestra realidad del país y resultando en intervenciones más adecuadas. **Descriptor:** Apoyo Social; Diabetes Mellitus; Niño; Enfermería Pediátrica; Diabetes Mellitus Tipo 1; Familia.

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INTRODUCTION

Diabetes Mellitus (DM) is a heterogeneous group of metabolic disorders due to the action and / or secretion of insulin, and they commonly, present hyperglycemia.¹ It is a chronic disease that affects more and more citizens around the world. Currently, the world population with diabetes is estimated to be 387 million people and reaches 471 million in 2035. Of these, 80% live in developing countries with an increasing proportion of younger people. The incidence of type 1 DM has increased in children under five years ¹, causing concern in health professionals and researchers working with chronic diseases due to the challenges in their control and adherence to the therapeutic regimen, together with the inherent challenges of growth and development to childhood and adolescence.

Chronic disease in childhood is seen as a stressor that affects the child's normal development and social relationships within the family. In addition, it can have implications such as dysfunction of physical conditions, developmental disabilities, learning difficulties and mental illness.²

The family plays a fundamental role in the management of chronic conditions in childhood. It is through this that the human being learns to live, to love, to feel, to take care of and to care for the other, therefore, it is the primary socializing agent.³ The family routine of a child with chronic illness changes through frequent consultations, and hospitalizations, affecting, all family members, to varying degrees. The psychological resources of the parents, the child and the family structure influence and can help in the adaptation of the child to the disease. This is because the family can be a moderator to mitigate the negative effects of the disease on the child.²

When faced with a health problem, the family creates its own coping mechanisms with the means built in its trajectory, with variations in the supply and availability of resources.⁴ Essential factors for the management of the disease are the appreciation of the role of family and experience of the child, the work of the health team, as well as the identification of social support, of the social network.⁵

Recently, the interest, of the scientific community, in the study of social support has grown. This is a term that is difficult to define, because it is multifaceted and complex to measure. In some of the definitions, it is pointed out as a temporal

term, that is, it has meaning and variable significance with the course of life.⁶

A theoretical essay, that reflected on the main concepts of network and social support, shows that there is no consensus among the authors on the concept of social support, but it is defined as functional aspect of social relations.⁷ In this perspective, it can be subdivided into four categories: reinforcement support (expressions and feelings of recognition), emotional (affection, love), informational (suggestions, information) and instrumental (financial assistance, availability of time and resources).⁶

The social network is the personal or group structure through which social support can flow. This social network of families with children with chronic diseases is made up of different people and institutions, and the social support provided by this network is significant, but, it is not always continuous and in keeping with the needs of families.⁴

Such needs, in the context of type 1 DM, are many. Mothers point out that they may be related to the restructuring of the family's food menu, motivation of the child to practice physical exercises, school adaptation, relationship with the other siblings, and relationship with the health team.⁸

With DM being a disease with a high global morbidity, with all the adaptations that the family must make due to the chronic illness and the increasing appreciation of social support, it is of great importance to understand what are the sources of social support that the child with DM and his family have the influence of social support in the management of the disease, as well as what has already been produced in the literature on these issues increasingly present in this context.

OBJECTIVE

- To gather evidence in the literature about social support for children with Type 1 Diabetes Mellitus and their families.

METHOD

This is an integrative review. Based on evidence-based practice, the PICO strategy was used to organize the research question. This strategy represents an acronym for Patient (child with Type 1 Diabetes Mellitus and their families), Intervention (social support), Comparison and Outcomes (evidence on social support of children with type 1 DM and their families). Thus, the guiding question was: "What is the evidence, in the literature,

about the social support of the child with Type 1 Diabetes Mellitus and their families?"

The data collection was carried out in October 2016, using the following databases and their descriptors:

- MEDLINE (*Medical Literature Analysis and Retrieval System*): "Social Support" AND "Diabetes Mellitus" AND "Child", according to Medical Subject Headings (MeSH).
- LILACS (Latin American and Caribbean Literature in Health Sciences): "Social support" AND "Diabetes Mellitus" AND "Child", according to the descriptors in Health Science (DeCS).

At first, we found 264 articles, and, then, "social support" was selected as a subject filter and found 92 articles. From these, the research articles were selected in which the

title or abstract allowed in advance to conclude that they were specifically related to the theme of the study, leading to the exclusion of 33 articles.

Inclusion criteria were: originary articles published in Portuguese, English or Spanish, with a theme related to the social support of children with type 1 DM and their families, without time limitation.

In order to extract the data of the articles selected in the integrative review, a validated instrument¹⁰ was used, in a way adapted to the theme of the research. After this step, seven articles were excluded because they did not relate specifically to the theme, resulting in a survey of 17 articles in total, as shown in figure 1.

Figure 1. Process of identification, selection, eligibility and inclusion of studies included in this study. Campinas (SP), Brazil, 2016.

Data were analyzed in two ways. For the characterization of the publications, the articles were analyzed quantitatively in relation to the published periodical, year of publication and place where the research was carried out. The objectives, methodology, main results and conclusions were analyzed qualitatively, allowing the creation of four categories. The categories were: Sources of social support; Social support in meeting quality of life and mental health; Innovations in research to promote social support and Conflicts of social support.

RESULTS

The survey allowed a sample of 17 articles eligible for this study. As for the publication period, they covered the period between 2008 and 2016, most of which (n = 10) were published in the last five years. As to the place of studies, most of them were performed in the United States (n = 5), followed by Brazil (n = 4). We also found studies in Germany (n = 2), Chile (n = 1), the Netherlands (n = 1), Switzerland (n = 1), Iran (Amsterdam and Miami). Regarding the

characterization of study participants, it is important to highlight that 11 of the 17 studies addressed adolescents; as for the others, one addressed pre-adolescents, two other studies investigated school-age children, one was made with parents of preschoolers and one with professionals only.

The analysis of the objectives and results allowed the identification of four categories, described below, that allow to obtain a panorama about how the subject has been discussed in the current literature.

♦ Sources of social support

The work listed in this category identifies the sources in which the child and his family receive social support.¹¹⁻⁶ National and international research describes the nuclear family itself as an important source of social support for the child and for themselves.

An Iranian study¹³ reinforces the importance of the family in this regard, noting that family members support adolescents to lead a normal life. When health is stable, parents empower teenagers, improving independence and self-care skills.

In a significant way, friends are described as important sources of social support, being mentioned in all the significant environments of everyday life. In addition, disease management has been influenced by positive and negative attitudes of friends.¹⁴ Young people with type 1 DM and their healthy friends at a camp agree that friends should have more information about the medical consequences of having DM in order to help maintenance of the disease.¹⁶

In addition to family and friends, school, religion, health staff, social media groups and sites¹¹⁻⁶ are mentioned as important resources in this context, because they are sources in which the child and family can interact with peers and find support there, a sense of belonging, and resources for coping with the disease.

A national study,¹² that aimed to understand the influence of the network and social support in the care of school children with type 1 DM showed a positive repercussion in the family context, generating well-being and trust because the social network favored the sharing of information and experiences, moments of relaxation and aid in the acquisition of inputs for the treatment.

♦ Social support and its relationship with quality of life and mental health

The effects of social support have been described primarily in terms of the impact and benefits they can bring to the child and his

family in terms of their quality of life and biopsychosocial functioning.

In the two studies¹⁷⁻⁸ that investigated correlations between quality of life and social support in adolescents, it was found that girls reported lower means in the dimension of quality of life. They conclude that health services must go beyond physical treatment, thinking about psychoeducational interventions and strengthening the sources of social support as part of the treatment.

An article, that identified and analyzed the main emotional characteristics that can affect the psychic functioning of adolescents with type 1 DM, indicated that the disease changes the family dynamics in biological, psychological and social aspects, configuring elements that interfere in the confrontation of the disease. However, the disease was not identified by the subjects as a central factor in their lives, but, rather, as an attribute. In addition, it is described that having type 1 DM does not interfere directly with dreams, planning, self-perception and self-image.¹⁹

When agreeing on the coping of the disease, a cross-sectional study, investigating psychiatric characteristics in a group of adolescents with type 1 DM showed that most psychological problems were seen in girls and the patients' anxiety status was a significant risk factor for depression. It also indicated that, although parental social support has no effect on depression, it appears to be effective in anxiety.²⁰

A multi-centered study that has determined whether and how the consensus guidelines of clinical practices for the psychological care of young patients of the ISPAD (*International Society for Pediatric and Adolescent Diabetes*) are being implemented in routine care at pediatric clinics and diabetes clinics around the world.²¹

In it, it was shown that only 54% of mental health professionals received training in diabetes care. The role of the mental health professional is in the screening, assessment and delivery of mental health interventions, such as depression, as well as, interventions for adherence problems. These respondents reported difficulty with lack of ability in relation to diabetes.²¹

In addition to this fact, the study shows that only 40% of non-mental health professionals, have had training in counseling techniques and even fewer have received training to recognize mental health problems or more serious psychiatric problems.²¹

◆ Research innovations for social support promotion

Some innovative strategies seeking new resources to promote social support have been found, such as validation of social support measure in DM, through the *Modified Diabetes Social Support Questionnaire-Family (M-DSSQ-Family)*, for Dutch adolescents. Thus, it was possible to validate the questionnaire with 40 items and not 70, as in the original. These items are related to the social support of the parents of adolescents on insulin administration, blood glucose, assists during hypoglycemia and hyperglycemia, following the diet plan, regular exercise and emotional support. In it, it was observed that one of the factors, the orientation and supervision of parents, improves glycated hemoglobin, but worsens the adherence of adolescents.²²

Another study reporting an innovation described the implementation of a telephone intervention with parents of children with type 1 DM. The research team developed a program based on social cognitive theory, in which five sessions were made over the phone, addressing psychosocial factors that influence the engagement in health behaviors described in social cognitive theory. It was promising for the intervention group because it significantly reduced the difficulty and stress of the parents, and showed a tendency to increase perceived social support.²³

◆ Conflicts of social support

Surprisingly, the literature has brought indications that the same source that can be important social support, for children and their families, can also generate conflicts and even hinder the management of the disease.

The interaction between support relationships with parents and metabolic control in adolescents with diabetes was investigated in families with different approaches to disease management, that is, more or less rigid families in the supervision and control of care. This article concludes that it is not recommended that parents do not supervise the treatment of their children, but suggest that the excess of control and the lack of flexibility and of communication with the adolescent end up triggering a negative reaction in the adolescent children, interfering in the healthy behavior.²⁴

A cross-sectional study, that analyzed associations between direct and indirect caregiver responsibility in the management of DM with glycemic control and capillary glycemia frequency in adolescents, showed that the perception of responsibility shared by adolescents, particularly when characterized

by greater responsibility of the caregiver, is fundamental for better management. Shared responsibility, in this sense, can be seen as desirable in the management of the disease in adolescents.²⁵

Another study examined whether the negative effects of conflicting relationships with family members can be minimized when children feel supported by individuals from other support networks.²⁶ It is evident that parental support and participation in physical activities were related to greater exercise rates in adolescents with type 1 DM. Parents may be encouraged to participate in physical activities with children, help participate in sports teams, and find ways to enable children to become more involved.²⁶ In another study with preadolescents, it is suggested that intervention programs be developed to emphasize family support and reduce family conflict.²⁷

DISCUSSION

By the survey of the articles, we can see an increase of published works related to social support in the last five years, confirming the initial idea of this article that the topic is gaining importance in the scientific community and relevance in the national and international scenario.^{11-5,17, 20-1,24,28}

In identifying the sources of social support available to children and families, it must be noted, how much the family itself is the main source of support and support not only for the child, but also for the child. Thus, the idea that the family is a system and, as such, relies on and seeks to rebalance in times of mismatch, using its own strengths, such as acquired skills for managing the disease, mutual support, union, communication and negotiation skills of family tasks and roles was reinforced.²⁹ Findings in this category also corroborate those of articles developed in other contexts of chronic child illness,³⁰ and reinforce the importance of thinking about the family throughout the assessment, planning, implementation and follow-up of the process of caring for the child with diabetes.

However, literature has also brought evidence that sources that are thought to be socially supportive may sometimes have a reverse effect. The work, which indicated that there is interference in the adolescent's healthy behavior when parents exercise strict control,²⁴ exposes the fact that all social support must be done professionally, with sensitivity and recognition of the individuality of children and their families, with accompaniment for the early detection of any

problems such as the one mentioned in this study. It should not be judged that a particular source of support, serving in some cases, will serve for all. Therefore, the careful investigation of each child, their family situation, through precise evaluation instruments, such as the genogram and ecomap, is essential if the risks of offering resources that end up as a burden or sources of conflict are to be eliminated. the family, but that promote the good development and their quality of life.

According to the World Health Organization (WHO), quality of life (QoL) is defined as: "the individual's perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns."³¹

QoL has been directly evaluated in terms of the child's access to social support networks in the context of childhood diabetes, as seen in the works that used KID-SCREEN. This scale, which evaluates ten dimensions of the child's life and correlates them with the child's quality of life, considers physical, psychological, mood and emotional well-being, self-perception, autonomy, relationship with parents and family life, resources, peers and social support, school environment and bullying.¹⁷⁻⁸ Thus, this concept and the dimensions evaluated in this scale corroborate with the sources of social support identified in this study, which reinforces the importance of recognizing them as essential for the life of the child and its family, and the responsibility of health professionals to promote opportunities to meet them with such sources of support.

As for the innovations to promote social support, the articles found dealt with interventions carried out in the international context.²²⁻⁷ Although they have achieved satisfactory results in their realities, it is important to highlight that, in Brazil, access to technological resources is still a challenge for a large portion of the population.³² Thus, thinking about intervening in order to increase the offer of social support involves the cautious development of strategies that are easy to achieve, understand and reach for the Brazilian sociodemographic profile.

CONCLUSION

This literature review sought to identify evidence in the literature on the social support of children with type 1 DM and their families. It was evident the predominance of international work, which evidenced the need

for more work on social support for children with type 1 DM and their family in the Brazilian context, characterizing the peculiarities of the national culture and implying more appropriate innovations and interventions.

As sources of social support, the literature describes the family, school, friends, religion, health team and groups formed in social media and websites as the main. The latter should arouse the interest of professionals in a special way, given the impact that social networks exert on people of all ages today and the ease in the interactions it can bring about. Further studies are suggested in order to explore the influence of these groups in the management and control of the disease, so that new treatment strategies can be considered, with a multidisciplinary approach.

The literature has indicated a strong association between the quality of life of these children and their families and the availability of social support, and suggest that professionals should continue to move towards proposing psychoeducational interventions that go beyond conventional treatment. This suggestion is reinforced by the examples of innovations already available on the international scene, which indicate that facilitating social support for children and their parents can reduce the stress of the whole family in managing the disease, reducing the feeling of isolation and promoting autonomy to achieve satisfactory levels of quality of life.

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