Self-Care of Adolescents with Type 1 Diabetes Mellitus: Knowledge about the Disease

Autocuidado dos Adolescentes com Diabetes Mellitus Tipo 1: Conhecimento acerca da Doença

Abstract

Background: Type 1 Diabetes Mellitus (TIDM) is an increasingly prevalent disease in adolescence. Self-management of diabetes is highly important for adolescents to gain autonomy and to reduce associated risks.

Objectives: To identify the knowledge of adolescents with TIDM about the disease and respective care; to analyze the relationship between the knowledge of adolescents with TIDM about the disease and respective care and age and gender.

Methodology: Descriptive-analytical and cross-sectional study. The sample was composed of a total of 51 adolescents aged between 12 and 18 years being followed-up in diabetes consultations in the center region of Portugal. A knowledge test was applied.

Results: Although most adolescents had a good level of overall knowledge about diabetes and in 3 of the 5 dimensions, the study revealed some misconceptions, as well as adolescents with a low level of knowledge. Positive correlations were found between the adolescents’ knowledge and age.

Conclusion: It is important to correct misconceptions and identify the adolescents with insufficient knowledge so as to provide a more targeted intervention.

Keywords: adolescent; type 1 diabetes mellitus; self-care; autonomy; nursing

Resumen

Enfoque: La diabetes tipo 1 es una enfermedad cada vez más prevalente en la adolescencia. El manejo autónomo de la enfermedad es de gran importancia para que los adolescentes adquieran autonomía y reduzcan los riesgos asociados.

Objetivos: Analizar el conocimiento de los adolescentes con diabetes tipo 1 y los cuidados; comprobar la relación entre el conocimiento de los adolescentes con diabetes tipo 1 y la edad y el sexo.

Método: Estudio descriptivo-analítico y transversal. La muestra estuvo compuesta por un total de 51 adolescentes entre los 12 y 18 años que se seguían en consultas de diabetes en la zona centro de Portugal. Se realizó un test de conocimientos.

Resultados: Aunque la mayoría de los adolescentes mostraron un nivel de conocimiento alto, se identificaron algunos conceptos erróneos y se registró a adolescentes con un bajo nivel de conocimiento. Se verificaron correlaciones positivas entre el conocimiento y la edad.

Conclusión: Es importante corregir los conceptos erróneos e identificar a los adolescentes con conocimiento insuficiente, para intervenir de forma dirigida.

Palabras clave: adolescente; diabetes mellitus tipo 1; autocuidado; autonomía; enfermería

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Introduction

Type 1 diabetes mellitus (T1DM) “is an autoimmune disease characterized by the progressive destruction of pancreatic beta cells which will result in the interruption of insulin production and, consequently, severe metabolic imbalance” (Miculis, Mascarenhas, Boguszewski, & Campos, 2010, p. 276).

In Portugal, the number of new cases of diabetes diagnosis increases every year. According to the National Observatory of Diabetes, the incidence of diabetes in 2014 was 17.5% (261 new cases) for each 100,000 inhabitants aged 0-14 years, whereas in 2000, the incidence was 9.5% (160 new cases; Sociedade Portuguesa de Diabetologia, 2015). These results are in line with the international trend of increase of T1DM at increasingly younger ages.

T1DM is associated with several complications, particularly increased mortality and high risk of micro and macrovascular complications. Diabetes is a predisposing factor for retinopathy, neuropathy and nephropathy, cardiovascular diseases and diabetic foot (Santos, Silva, & Cardoso, 2009). As a chronic disease, it is also responsible for a significant health burden, as well as for reduced work capacity and lower life expectancy (Góes, Vieira, & Júnior, 2007).

Well-controlled diabetes reduces the associated complications and underlying social and economic costs, namely those related to health care, loss of income, social expenditure, loss of productivity, and also costs associated with missed opportunities for economic development (Sociedade Portuguesa de Diabetologia, 2015).

In this study, we focus on the concept of adolescence as defined by the World Health Organization, which adopts the chronological criterion that covers young people aged between 10 and 19 years (World Health Organization, 2011). Due to its very specific developmental characteristics, adolescence is a period of major changes that require from the adolescents and their families a significant effort of adapt to chronic illness, as well as a differentiated intervention by the health care teams. Diabetes demands a reorganization of the personal and family routines at several levels, implying not a cure, but rather a daily management (Ribeiro, 1998).

Therefore, we believe that there is an urgent need for a more interventive action among adolescents, which represents a challenge for health care services and in particular for nurses. An early and sustained intervention by the health care teams will impact the well-being and quality of life of diabetic adolescents and their families by reducing their anxiety and debilitated emotional status (Aguir & Fonte, 2007).

Based on this problematic background, a descriptive and analytic study was conducted with a population of adolescents with T1DM, with the following objectives: to identify the knowledge of adolescents with T1DM about the disease and respective care; and to analyze the relationship between the knowledge of adolescents with T1DM about the disease and respective care and age and gender.

Background

T1DM is an increasingly prevalent chronic disease in adolescence, whose diagnosis and treatment results, in most cases, in a strong emotional impact on patients, particularly adolescents (Aguir & Fonte, 2007). As regards the impact of diabetes on adolescents and their families, this disease can affect the behavioral, somatic, social and financial areas. This is a phase where adolescents become more independent from their parents’ responsibility and start to define their self with the consolidation of the sense of belonging to groups of peers. Here, they try to define their personal identity, deepen their relationships with peers, intensify intellectual interests, and develop a sense of social belonging (Sampaio, 2010).

In addition, the knowledge of diabetic adolescents about the disease is determinant to the adoption of behaviors. According to Karlsson, Arman, and Wikblad (2008), the lack of knowledge about the physical processes related to diabetes promotes insecurity in adolescents concerning the treatment based on the triad of diet, physical exercise and insulin therapy, and also concerning their accountability and autonomy.

Knowledge is conditioned by the social and cultural beliefs of the environment where adolescents are...
inserted, negatively or positively influencing disease management. According to the self-regulation model of illness representation, individuals create mental representations, namely disease-related beliefs which condition the behaviors and, consequently, the outcomes (Leventhal et al., 1980, cited by Nouwen, Urquhart Law, Hussain, McGovern, & Napier, 2009). As for self-care, “it is a regulatory human function that individuals deliberately perform for themselves or have performed for them to maintain life, health, development and well-being” (Tomey & Alligood, 2002, cited by Queirós, Vidinha, & Filho, 2014). Thus, self-care is based on the activities that individuals perform in an effective and responsible way to maintain life, health and well-being (Araújo & Damasceno, 2010). The provision of nursing care sustained by the Self-Care Theory has proved to be an effective alternative to encourage patients to actively participate in their treatment, increasing their accountability for the outcomes (Peixoto, 1996). Nursing is particularly concerned with the need for the individual to perform self-care activities on a permanent basis to sustain life and health, recover from disease or cope with its effects (Orem, 1991). With regard to diabetes self-care, adolescents with T1DM are encouraged to periodically attend consultations for urine and blood testing, insulin administration, adjustment of insulin in relation to the consumption of carbohydrates and physical exercise (Rosalind, 2006). Thus, self-care includes: insulin administration, blood glucose monitoring, maintaining records of insulin administration and glucose levels, management of hypoglycemia and hyperglycemia, complying with meal plans and exercising regularly (Chien, Larson, Nakamura, & Lin, 2007). In view of the above, it is relevant to understand how each adolescent interprets, apprehends and builds the illness process in terms of the therapeutic demands, but also the adaptation to the social context.

**Research questions**

How is the knowledge of adolescents with T1DM characterized in general terms and in the relevant dimensions of self-care?

Is there an association between this knowledge and the adolescents’ age and gender?

**Methodology**

Before the application of the questionnaire, we requested written authorizations from the board of directors of the District Hospital of Figueira Da Foz, EPE (HDFF, EPE), the board of directors of the Baixo Vouga Hospital Center, EPE (CHBV, EPE), and an association for patients with diabetes (AD). The study began after the favorable opinion from the ethics committees of these institutions. This is a quantitative, descriptive-analytical and cross-sectional study. According to the model of analysis proposed, our key variable was the knowledge about T1DM and associated care. As regards the other variables, we considered the adolescents' demographic characteristics of age and gender.

**Population and Sample**

Of the total sample, 32 adolescents (62.7%) were recruited in the endocrinology consultation of CHBV, EPE; 11 adolescents (21.6%) being followed-up in hospitals of the central region were recruited during the field activities of an AD; and eight adolescents (15.7%) in the endocrinology consultation of HDFF, EPE. An accidental sampling method was used, since the adolescents were being integrated into the study as they attended the consultations/AD meetings and only when the researcher was present. Data were collected between September 2012 and February 2013.

In relation to gender, the sample is balanced as 25 adolescents (49%) were girls and 26 adolescents (51%) were boys. As regards age, the mean age of the group was 15 years ($SD=2.07; Md=15$). The selected age groups, of similar size, show a homogenous distribution. However, there is a higher prevalence of adolescents aged between 12-14 years. The 12-14 age group is composed of 21 adolescents (41.2%), followed by the 15-17 age group with 19 adolescents (37.3%), and the >17 age group with 11 adolescents (21.6%). All the respondents lived in the central region of Portugal.

**Instrument**

We designed a knowledge test about T1DM and associated care (Table 1). This is a multiple choice test in which one answer is correct out of three alternative answers. It is subdivided into five areas of knowledge about the disease: nature/pathophysiology of the
disease (25%), acute and chronic complications of T1DM (30%), insulin administration (15%), measurement of capillary blood glucose (10%), and health maintenance (20%).

Table 1

Domains of knowledge included in the test

| Nature/pathophysiology of the disease (25%) | Concept of DM1 |
|                                           | Causes for DM1 |
|                                           | Organ that produces insulin |
|                                           | Symptoms of hyperglycemia |
|                                           | Causes for variations in blood sugar levels |
| Acute and chronic complications of the disease (30%) | Concept of hypoglycemia |
|                                           | Causes for hypoglycemia |
|                                           | Symptoms of hypoglycemia |
|                                           | Procedures in case of hypoglycemia |
|                                           | Concept of hyperglycemia |
|                                           | Complications of poorly managed diabetes |
| Insulin administration (15%) | Sites for insulin administration |
|                                           | Storage and conservation of insulin |
|                                           | Measures to be taken while administering insulin with an insulin pen |
| Measurement of capillary blood glucose (10%) | How to measure capillary blood glucose |
|                                           | How to change the lancet to measure capillary blood glucose |
| Health maintenance (20%) | Number of daily meals |
|                                           | Practice of physical exercise |
|                                           | Measures to be taken before practicing physical exercise |
|                                           | Diet of diabetic adolescents |

In addition to the level of knowledge about the disease, we calculated the percentage of answers to the various alternatives in order to identify any misconceptions. Misconceptions are interpreted as answers that, despite being wrong, were considered as being correct by more than 25% of the adolescents. The content validity of the instrument was assessed by experts in the area of diabetology, in particular a pediatrician, a diabetology nurse, and an endocrinologist, and adjustments were made according to their suggestions. We also analyzed the dispersion of the answers, by calculating the means between 0 and 1 and the standard deviation of the answers to each item. We found that all questions discriminated with very close standard deviation values, which revealed low heterogeneity. The level of knowledge was assessed for the total score and for each domain. The following scores were calculated: (No. of correct answers / Total no. of items) x 100. Thus, the level of knowledge can vary between 0% (minimum) and 100% (maximum), being that values under 50% correspond to a low or insufficient level of knowledge, between 50 and 80% to a reasonable level of knowledge, and above 80% to a good level of knowledge. The normality tests did not confirm the normal distribution of the variable Knowledge about the disease in the overall knowledge or in the different domains (p<0.05), as can be seen in Table 2.

Table 2

Normality tests of the knowledge about the disease in the several domains of knowledge and in the overall knowledge (n=51)

| Knowledge about the disease       | Kolmogorov-Smirnov Tests |
|-----------------------------------|--------------------------|
|                                   | Score | p     |
| Nature of the disease             | 0.38  | 0.000 |
| Complications of the disease      | 0.27  | 0.000 |
| Disease management                | 0.35  | 0.000 |
| Insulin administration            | 0.25  | 0.000 |
| Health maintenance                | 0.28  | 0.000 |
| Overall knowledge                 | 0.17  | 0.001 |
Data Collection
The specific days for application of the instrument were previously scheduled with the nursing teams of the institutions and with the person responsible for the AD. Before applying the instrument, the adolescents and legal guardians were explained the nature of the study, its objective and purpose, as well as ensured of the data anonymity. The instrument was applied after the adolescents and the legal guardians signed the informed consent. The questionnaires were answered on an individual basis during approximately 15 minutes.

Results
In relation to the knowledge of adolescents with T1DM about the disease and associated care, we analyzed the overall knowledge and the knowledge per domain, and identified the misconceptions existing in the population of diabetic adolescents.

Level of Knowledge of Diabetic Adolescents about the Disease and Care:
In relation to the knowledge about the disease by domain of knowledge, an analysis of knowledge was performed in the five domains (Table 3), with a variation from 0% to 100%, and the median for each domain ranged between 66.7% and 100%. As regards the average knowledge in each domain, it ranged from 73.9% to 88.2%. In general, the level of knowledge of this population varied between reasonable and good. As regards the overall knowledge about diabetes and associated care, 50.9% (Md=85) of the adolescents has a good level of knowledge. Most adolescents showed a good level of knowledge in the following dimensions: acute and chronic complications of the disease (76.4%) and nature/pathophysiology of the disease (60.8%). On the other hand, few adolescents showed a good level of knowledge in the following dimensions: health maintenance (29.4%) and insulin administration (39.2%). The measures of central tendency point in the same direction, with higher mean and median scores found in the dimensions related to the chronic and acute complications of the disease and the nature/pathophysiology of the disease. The greatest variation was found in the domain related to the measurement of capillary blood glucose. A worrying aspect is the percentage of adolescents with insufficient knowledge, where 17.6% and 13.7% of adolescents show a low level of knowledge regarding insulin administration and chronic and acute complications of the disease, respectively.

Table 3
Levels of knowledge about the disease by domain of knowledge and overall knowledge

| Domain of knowledge about the disease | <50% | 50-80% | 80-100% | 0% a 100% | Md   | X    | SD  |
|--------------------------------------|------|--------|---------|----------|------|------|-----|
| Nature/pathophysiology of the disease| 0    | 20     | 31      | 100.0    | 88.2 | 16.0 |
| Acute and chronic complications of the disease | 7    | 13.7   | 9.8     | 39       | 76.4 | 83.3 | 19.0 |
| Insulin administration               | 9    | 17.6   | 43.1    | 39.2     | 66.7 | 73.9 | 24.0 |
| Assessment of capillary blood glucose| 1    | 2.0    | 45.1    | 52.9     | 100.0| 75.5 | 27.0 |
| Health maintenance                   | 4    | 7.9    | 62.8    | 29.4     | 75.0 | 74.0 | 23.0 |
| Overall knowledge                    | 3    | 5.9    | 43.0    | 50.9     | 85.0 | 80.5 | 13.0 |

Misconceptions
Another relevant aspect concerning the knowledge about diabetes is the identification of misconceptions. To this end, we analyzed the adolescents’ answers to each question (Table 4).

With regard to the observed misconceptions regarding the procedures in case of a symptomatic hypoglycemia, 25.5% of the adolescents believe that they must take a sugar packet and reassess blood glucose within 10 to 15 minutes, undervaluing the subsequent ingestion of slowly absorbed carbohydrates. These adolescents do not recognize the ingestion of slowly absorbed carbohydrates as a way to maintain their blood glucose levels. When asked about the practice of physical exercise, 39.2% of the adolescents mention that it is important to measure blood glucose and ingest rapidly absorbed carbohydrates. These adolescents undervalue the correct alternative related to the management of insulin before the practice of physical exercise. In relation to insulin storage,
most adolescents (51%) believe that, after opening the cartridge, it must be kept in the fridge. There is clearly an underlying misconception here regarding the insulin preservation in the cartridge in use. When asked about the replacement of the lancet, 27.5% of the adolescents referred that it must be replaced after each puncture. Here, adolescents reveal a poor management of the consumables.

Therefore, across the various domains of knowledge, the diabetic adolescents revealed that some of their self-care practices were based on misconceptions. We can infer that there is a significant percentage of adolescents with misconceptions about T1DM and respective care, with the exception of the domain related to the nature/pathophysiology of the disease.

Table 4

| Conhecimento acerca da doença: distribuição das respostas por item (n=51) |
|-------------------|-----|-----|-----|-----|
|                  | A   | B   | C   |
| Nature/pathophysiology of the disease |     |     |     |
| 1. What is T1DM? | 46  | 90.2| 4   | 7.8 | 1  | 2.0 |
| 2. What are the causes for T1DM? | 8   | 15.7| --  | 0.0 | 43 | 84.3|
| 3. What is the organ than produces insulin? | 51  | 100.0| --  | 0.0 | -- | 0.0 |
| 4. What are the symptoms of a high level of sugar in the blood (hyperglycemia)? | 43  | 84.3| 8   | 15.7| -- | 0.0 |
| 5. The variation of blood glucose is related to: | 42  | 82.4| 8   | 15.7| -- | 0.0 |
| Acute and chronic complications of the disease |     |     |     |
| 6. What is hypoglycemia? | 10  | 19.6| 40  | 78.4| 1  | 2.0 |
| 7. One of the causes for hypoglycemia is: | 6   | 11.8| 2   | 3.9 | 43 | 84.3|
| 8. The symptoms of hypoglycemia can be: | 44  | 86.3| 4   | 7.8 | 3  | 5.9 |
| 9. What to do in case of symptomatic hypoglycemia (blood glucose <70 mg/dl): | 37  | 72.5| 13  | 25.5| 1  | 2.0 |
| 10. You are hypoglycemic if: | 2   | 3.9 | 3   | 5.9 | 46 | 90.2|
| 11. What are the complications of poorly controlled diabetes? | 45  | 88.2| 3   | 5.9 | 3  | 5.9 |
| Insulin administration |     |     |     |
| 12. Sites for insulin administration: | 49  | 96.1| 1   | 2.0 | 1  | 2.0 |
| 13. How should insulin be stored and preserved after opening the cartridge? | 1   | 2.0 | 26  | 51.0| 24 | 47.1|
| 14. Measures to be taken while administering insulin using an insulin pen: | 40  | 78.4| 1   | 2.0 | 9  | 17.6|
| Measurement of capillary blood glucose |     |     |     |
| 15. In the measurement of capillary blood glucose, you should: | 1   | 2.0 | --  | 0.0 | 50 | 98.0|
| 16. The lancet used to measure capillary blood glucose should be replaced: | 14  | 27.5| 27  | 52.9| 9  | 17.6|
| Health maintenance |     |     |     |
| 17. How many meals should a diabetic adolescent have per day? | 4   | 7.8 | 44  | 86.3| 3  | 5.9 |
| 18. Can a diabetic adolescent practice physical exercise? | --  | 0.0 | 6   | 11.8| 45 | 88.2|
| 19. Before practicing physical exercise, the adolescent should: | 24  | 47.1| 20  | 39.2| 7  | 13.7|
| 20. The diet of a diabetic adolescent should include: | 38  | 74.5| 9   | 17.6| 4  | 7.8 |

Correct answer
Bold: Misconceptions

Relationship between Knowledge and Age
An additional statistical analysis was performed in order to investigate the existence of a relationship between the knowledge about the disease and age (Table 5). A positive relationship was found between age and knowledge about the disease. This trend of knowledge increasing with age is particularly significant concerning the awareness of complications \( p<0.001 \) and the nature of the disease \( p<0.05 \).
Table 5

Knowledge about the disease and age

| Knowledge about the disease                  | Age  |
|---------------------------------------------|------|
|                                             | $r_s$| $p$             |
| Nature/pathophysiology of the disease       | 0.304*| 0.030          |
| Acute and chronic complications of the disease | 0.580**| 0.000          |
| Insulin administration                      | 0.090| 0.531          |
| Assessment of capillary blood glucose       | 0.020| 0.891          |
| Health maintenance                          | 0.103| 0.473          |
| Overall knowledge                           | 0.405**| 0.003          |

Spearman's correlation; *Significant at $p<0.005$; **Highly significant at $p<0.01$

Relationship between Knowledge and Gender

Another statistical analysis was performed in order to investigate the existence of a relationship between the knowledge about the disease and gender. To this end, we applied Mann-Whitney U tests (Table 6), with no significant differences being found in any of the dimensions or in the overall knowledge ($p > 0.05$).

Table 6

Knowledge about the disease and gender

| Gender | Mann-Whitney’s Test |
|--------|---------------------|
|        | Female ($n=25$) | Male ($n=26$) | $Z$ | $p$ |
|        | Md | 100.00 | 100.00 |     |     |
| Nature/pathophysiology | X | 88.00 | 88.46 | -0.108 | 0.914 |
| | DP | 16.33 | 16.17 |     |     |
| | Md | 83.33 | 91.67 |     |     |
| Acute and chronic complications of the disease | X | 78.67 | 87.82 | -1.415 | 0.157 |
| | DP | 22.83 | 15.32 |     |     |
| | Md | 66.67 | 66.67 |     |     |
| Insulin administration | X | 73.33 | 74.36 | -0.214 | 0.831 |
| | DP | 23.57 | 25.49 |     |     |
| | Md | 50.00 | 100.00 |     |     |
| Disease management | X | 74.00 | 76.92 | 0.540 | 0.589 |
| | DP | 25.50 | 29.09 |     |     |
| | Md | 75.00 | 75.00 |     |     |
| Health maintenance | X | 76.00 | 72.12 | -0.911 | 0.362 |
| | DP | 25.50 | 21.60 |     |     |
| | Md | 85.00 | 82.50 |     |     |
| Overall knowledge | X | 79.20 | 81.73 | -0.219 | 0.827 |
| | DP | 15.72 | 11.40 |     |     |

Discussion

The instrument was designed to operationalize the variable related to the knowledge about the disease. Most adolescents showed a good overall knowledge. As for the domains of knowledge, we observed that most adolescents have a reasonable to good level of knowledge between 50% and 100%. However, with the exception of the domain of nature/pathophysiology of the disease, we observed that adolescents had a low level of knowledge in all the domains (<50%). The largest percentage of adolescents with an insufficient level of knowledge was found in the domain related to insulin administration (17.6%), followed by the domain of acute and chronic complications of the disease (13.7%). According to Karlson et al. (2008), the lack of knowledge about diabetes-related physical processes promotes insecurity in adolescents.
regarding their ability and responsibility to manage their diet and their disease. In turn, Garcia, Brown, Kouzekanami, & Hanis (2001) argue that, although the diabetic patient’s in-depth knowledge is not a guarantee of significant behavioral changes and good self-care conduct, it is undeniable that knowledge is essential for diabetes management.

In addition to the adolescents’ level of knowledge about the disease, we aimed at analyzing the misconceptions in order to understand if self-care in diabetes is conditioned by false concepts, with some of them already being discontinued practices. As regards the procedures in case of a symptomatic hypoglycemia, 25.5% of the adolescents believe that they must ingest a sugar packet and reassess blood glucose within 10 to 15 minutes, undervaluing the subsequent ingestion of slowly absorbed carbohydrates. Hypoglycemia is commonly associated with the ingestion of sucrose. The intake of slowly absorbed carbohydrates to maintain the levels of blood glucose was less often mentioned in the answers, which denotes that this is a deeply rooted concept in the target population. The same is true when asked about the practice of physical exercise: 39.2% of the adolescents mentioned that they must measure blood glucose and ingest rapidly absorbed carbohydrates. In this question, the adolescents undervalued the correct alternative of measuring insulin before the practice of physical activity. In addition to the difficulty in managing physical exercise and insulin administration, these results suggest the belief about diabetes-related limitations to the practice of physical exercise. The adolescents’ main concern regarding the practice of exercise is the occurrence of hypoglycemia during or up to several hours after the physical activity, which can be discouraging. The diabetic patient has no physiological way of inhibiting insulin release, thus, insulin sensitivity is not affected by physical exercise. However, hypoglycemia can be controlled. It is important to define the type, intensity and duration of the physical activity and, consequently, reduce in 10% to 20% the insulin dose of the previous meal. Capillary blood glucose should be monitored before, during and after the physical activity, and adolescents should be provided with carbohydrates (Miculls et al., 2010). In relation to insulin storage, most adolescents (51%) consider that, after opening the cartridge, insulin must be kept in the fridge. There is a noticeable lack of knowledge here concerning insulin storage, because nowadays it is not necessary to store insulin in the fridge after opening the cartridge. When asked about the replacement of the lancet, 27.5% of the adolescents mentioned that it must be replaced after each puncture. Here, the adolescents reveal a poor management of the consumables. It should be noted that 15.7% of the adolescents believe that their disease is a result of bad eating habits, which can be a significant factor in how the adolescent integrates and manages the disease. We can infer that some of the adolescents’ knowledge about the disease is permeated by misconceptions that may condition disease management, with the exception of the domain related to the nature of the disease. Empirical studies have shown that the misconceptions about diabetes are associated with self-care, diet and emotional well-being. Skinner and Hampson (cited by Nouwen et al., 2009) argue that beliefs have a positive influence in diet management in diabetes. The belief about treatment effectiveness is a significant factor for the adherence of adolescents with T1DM to the dietary regimens (Griva, Myers, & Newman, 2000 as cited by Nouwen et al., 2009). Iannotti et al. (2006) have associated the effectiveness of the interventions and the beliefs of diabetic adolescents about self-care and metabolic control, and the results showed that the greater the belief in the treatment, the more effective were the self-care behaviors and the metabolic control of the disease. These concepts can be influenced by variables such as the sociodemographic, cultural and economic characteristics of the environment surrounding the adolescents. These are deep-rooted habits/beliefs taken as certain that diverge from the training received in hospital settings and that influence disease management. However, nurses are first-rate professionals and play a relevant role in the education of diabetic adolescents and their families. These results, particularly concerning misconceptions, may be related to the information provided by nurses. There is a clear need for differentiated teams composed of nurses with specialized training in the area of diabetes and with specific skills to establish an effective therapeutic relationship with adolescents and their families.

An additional analysis was also performed to observe if the gender and age variables are associated with the knowledge about the disease. In relation to gender, this association was not confirmed, whereas age seems to be directly associated with the adolescents’
knowledge about the disease, which may be justified by the level of intellectual and cognitive development and maturity. These results contradict other studies that mention that older adolescents do not believe in the efficacy of the treatment and, as such, do not comply with the treatment (Anderson, Auslander, Jung, Miller, & Santiago, cited by Nouwen et al., 2009). The study of Nouwen et al. (2009), with a sample of 150 adolescents aged 12-18 years, also contradicts these results since older adolescents attach less importance to treatment by showing a good metabolic control. The study revealed some limitations that conditioned the results obtained. We highlight the waiting time for the institutions to authorize the study. Regarding the number of participants, the sample size was considerably limited by the fact that most consultations took place every three months.

Conclusion

This study allowed us to identify how diabetic adolescents manage their self-care roles in what concerns their knowledge about the disease. The results have implications for nursing practice, namely in terms of monitoring diabetic adolescents and their families. Based on the results, we can state that adolescents with TIDM have a good level of knowledge about the disease; however, prevalent misconceptions were observed that may condition the disease self-care management, thus increasing the risk of long-term complications. These data may put into question the strategies and methods used when dealing with diabetic adolescents. The creation of support groups with specific moments for the adolescents to share their experiences outside the hospital could be a strategy used in a future approach. In terms of the level of knowledge, it is important to work toward correcting prevalent misconceptions, including those related to hypoglycemia, insulin storage, replacement of lancets, practice of physical exercise, and insulin administration. The misconceptions of the sample lead us to think about the nurses’ role as professionals with a responsibility to educate these adolescents and their families. The identification of cases with a low level of knowledge was very important: The largest percentage was found in the domain related to insulin administration (17.6%), followed by the domain of acute and chronic complications of the disease (13.7%). These domains require a more targeted nursing intervention.

As regards the implications for the care practice, we believe that the inclusion of nurses specialist in child and youth health in the diabetology team, empowered with differentiated skills to promote the adjustment of the adolescents to the process of chronic disease, would be an important strategy for the success of the education of diabetic adolescents and their families. We suggest the replication of studies in this area with the application of this instrument in other institutional contexts.

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