Benefits of participation in a summer camp to self-care for children and adolescents with diabetes: the perception of mothers

Benefícios da participação em um acampamento no autocuidado de crianças e adolescentes com diabetes: percepção das mães

Beneficios de la participación en un campamento en la autoatención de niños y adolescentes con diabetes: la percepción de las madres

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ABSTRACT
Objective: To understand the mothers' perception of the benefits of self-care in the routine of their children, after participating in a summer camp for young people with diabetes. Methods: A qualitative descriptive study was performed, in which individual semi-structured interviews with seven mothers were carried out. The themes emerged were coded and grouped by similarity into categories and subcategories, totaling twelve categories. Results: This study showed the importance of the camp to promote self-care. It also revealed that the benefits of such camp extended to all participants involved in this activity. Final considerations: The summer camp proved to be important to promote self-care for children and adolescents with diabetes and it enabled the reflection on how to improve this type of education, so that the knowledge and skills in diabetes developed by children and adolescents can be even more effective and long-lasting.

Keywords: Type 1 Diabetes mellitus; Health Education; Camping; Mothers; Pediatric Nursing.

RESUMO
Objetivo: Compreender a percepção das mães a respeito dos benefícios na rotina de seus filhos em relação ao autocuidado, após estes participarem de um acampamento de férias para jovens com diabetes. Métodos: Estudo descritivo qualitativo, realizado à luz do Interacionismo Simbólico e da Análise Qualitativa de Conteúdo, com sete mães que foram entrevistadas. Os dados foram codificados e agrupados por similaridade, emergindo as categorias temáticas. Resultados: Revelaram a importância do acampamento para promover a educação do autocuidado da criança/adolescente com diabetes, e os benefícios decorrentes dessa experiência, como promoção da independência, melhor controle e aceitação da doença, prazer em participar e extensão dos benefícios à família. Considerações finais: O acampamento mostrou-se importante para promoção do autocuidado da criança/adolescente com diabetes e possibilitou a reflexão sobre como aprimorar essa modalidade educacional para que os conhecimentos e habilidades em diabetes desenvolvidos pela criança/adolescente possam ser ainda mais eficazes e duradores.

Palavras-chave: Diabetes mellitus Tipo 1; Educação em Saúde; Acampamento; Mães; Enfermagem Pediátrica.

RESUMEN
Objetivo: Comprender la percepción de las madres a respecto de los beneficios en la rutina de sus hijos en relación con el autocuidado, después de su participación en un campamento de verano para jóvenes con diabetes. Métodos: Estudio descriptivo y cualitativo, llevado a cabo a la luz del Interaccionismo Simbólico y del Análisis Cualitativo de Contenido, con siete madres que habían sido entrevistadas. Los datos fueron codificados y agrupados por similitud, lo que originó categorías temáticas. Resultados: Se reveló la importancia del campamento para la promoción de la educación del autocuidado del niño/adolescente con diabetes, así como los beneficios de esta experiencia, tales como la promoción de la independencia, un mejor control y aceptación de la enfermedad, el placer de participar y la ampliación de los beneficios para la familia. Consideraciones finales: El campamento se mostró importante para promover el autocuidado del niño/adolescente con diabetes y permitió la reflexión sobre cómo se puede mejorar esta modalidad educativa de manera que los conocimientos y las habilidades en diabetes desarrollados por el niño/adolescente puedan ser aún más eficaces y duraderos.

Palabras clave: Diabetes mellitus Tipo 1; Educación en Salud; Campamento; Madres; Enfermería Pediátrica.
INTRODUCTION

Diabetes mellitus (DM) is becoming the epidemic of the 21st century; according to the International Diabetes Federation (IDF), in 2015, there were approximately 415 million people with diabetes worldwide, of which 542,000 were children. This disease is characterized by a heterogeneous group of metabolic disorders that have hyperglycemia in common, the result of defects in insulin action, insulin secretion or both. Among the types of diabetes, type 1 is present in 5% to 10% of cases and it is caused by the destruction of beta cells in the pancreas, regulated by self-immunity in the majority of cases, with a resulting deficiency in insulin production by these cells. Although this condition can occur at any age, it affects children and young adults more frequently, with a global incidence that has been increasing nearly 3% per year.

Treatment must be incorporated into the daily life of individuals with diabetes in order to be effective, requiring important changes in behavior. This is a great challenge for health professionals, as patients must be educated so that good adherence to therapy can be achieved, apart from considering the beliefs and values that can influence self-care.

Education on diabetes promotes the development of the skills required for self-care and disease management. IDF protocols emphasize it as an integral part of diabetes care. Based on this principle, there are different types of educational approaches such as summer camps. Educational camps for children and adolescents with diabetes promote the experience of a traditional summer camp in a safe and prepared environment. Furthermore, they enable participants to share their experiences and learn how to have more autonomy over their condition. Evidence in the literature shows the benefits to specific knowledge, self-care and self-esteem.

These summer camps combine leisure and knowledge and they are performed by a multi-professional team, enabling this population to acquire knowledge, improve self-monitoring and accept their condition more easily.

A recent review study sought to identify the effectiveness of summer camps for individuals with diabetes. It found out that, although influenced by several factors, they are effective in many aspects, such as the acquisition of knowledge, psychological aspects, better understanding of diabetes and children themselves by professionals. The same article argues about the need for more studies on this theme, including its long-term effects.

The authors of the present study, who participated in a multi-professional summer camp as part of the nursing team, observed how interdisciplinary health education was performed in this environment, based on several pleasurable and playful activities such as games, drama, dance, contests and therapeutic toy sessions. During the summer camp, it could be noted that the knowledge and skills for self-care for children and adolescents changed, enabling them to become more independent regarding diabetes care.

Based on this observation and the benefits described in the literature, the following question arose: Could participation in a summer camp bring changes to the self-care routine of these children/adolescents after they return home? We realized that one of the possible ways to answer this question would be the perception of mothers who, although following the changes that occurred during the summer camp from a distance, interact with their children on a daily basis and can thus perceive whether such changes had an effect on their routine.

Therefore, the present study aimed to understand the mothers’ perception of the benefits of self-care in the routine of their children, after they participated in a summer camp for children and adolescents with diabetes.

METHODS

A descriptive qualitative research project was performed, justified by the object of study. This is because such approach focuses on descriptive data, considering the fact that listing, measuring and using statistical methods with the data collected does not enable the meanings permeating social relations to be achieved. In qualitative research, the meaning given by individuals to things and their life is the key concern of investigators.

The theoretical framework used was Symbolic Interactionism, a perspective of analysis of human interactions that focuses on the nature of interactions and the dynamics of the social activities taking place among individuals.

A total of seven mothers agreed to participate in this study and were subsequently interviewed. Their children had been in the ADJ-UNIFESP summer camp between 2012 and 2014, supervised by the non-governmental organization (NGO) that promotes education on diabetes through campaigns and lectures and performs the follow-up of many children and adolescents participating in this camp.

Mothers were selected based on the list provided by the institution, including their telephone numbers so they could be contacted and invited and interviews could be set up. These interviews were conducted in different public locations that facilitated the meetings for participants, such as food squares at shopping malls, bakeries, coffee shops and waiting rooms of clinics, according to suggestions and choices made by the mothers themselves. Individual semi-structured interviews were performed, recorded on a portable voice recorder and fully transcribed by one of the researchers subsequently.

The present research project was submitted to and approved by the Research Ethics Committee of the Universidade Federal de São Paulo (UNIFESP - Federal University of São Paulo), under number 691.534/2014, and participants signed an Informed Consent Form to agree to participate in this study.
As this is a qualitative study, the criterion used to define the number of individuals was saturation. It is employed to establish the final sample size, interrupting the inclusion of new participants when the data obtained begin to show, according to the researchers' assessment, a certain redundancy or repetition, and when the data collection stops being relevant, as the information provided by new participants would add little to the material already obtained.12

In the present study, the following guiding question was used in the interviews: How do you perceive the self-care routine of your child after her/his participation in the summer camp? Other questions were designed during these interviews, aiming to further understand the concepts and expressions used by the mothers to achieve the research objective.

The data collected during interviews were submitted to conventional Qualitative Content Analysis, an analytical and interpretative method that aims to describe and promote knowledge of a phenomenon based on empirical data directly extracted from participants’ speech. To achieve this, after interviews were fully transcribed, data were analyzed according to the following three stages: Reading, Coding, and Categorization. With this approach, relevant theories or other results of the investigation were dealt with in the Discussion section.13

RESULTS AND DISCUSSION

Data analysis revealed 12 categories, which will be described as follows through extracts from the mothers’ speech. In order to maintain their anonymity, participants were identified by the letter I (Interviewee) and their number in the sequence of interviews.

Children become more aware

Mothers reported that their children were more aware of diabetes when they returned from the summer camp, especially with regards to the consequences of not following the treatment, in addition to the importance of the diet and calculation of carbohydrates.

She became more aware, you know? When treating diabetes, you know? [...] she is more aware of what could happen if she doesn’t treat it. [...] she’s beginning to become aware of this as well, of calculating the carbohydrates (I4).

She actually became much more aware of what diabetes is, of the importance of her diet. [...] she came back more aware (I5).

Corroborating this finding, the literature emphasizes that the use of summer camps as an opportunity to teach is an invaluable way for children/adolescents to acquire disease control skills, as a result of their interaction with the camp staff support.6

Children begin to teach what they learned at the summer camp

Regarding specific knowledge, mothers reported that their children learned several things at the summer camp from both friends and nurses/instructors and began to teach what they learned there. They also reported the desire to participate in one of these camps with their children, aiming to acquire the same knowledge and, as a result, not to feel excluded from their care.

[...] that she also brought me a little information. [...] so she learned a lot there (I7).

[...] These are the things that came from the summer camp, from what he learned there with his friends, nurses, instructors, leaving us out of this, so he doesn’t need us anymore. [...] because they come back and start teaching us what they learned. [...] Well, I’d like the next summer camp to be only for parents or for parents and their children, because it’s worth it, nobody will be there doing nothing, don’t you think? [...] because we feel lost, they come back with all this information and we know nothing (I3).

Diabetes requires children and families to acquire knowledge and develop skills and attitudes to overcome the challenges posed by this disease. In a study performed in Argentina, it was possible to involve children/adolescents and their families in a summer camp to consolidate and strengthen the learning process on diabetes.14

In the present study, mothers reported that their children’s willingness to teach was so great that they expressed their desire to be young leaders5:

She wants to participate in the young leaders and we’ve been encouraging her to go, I think it’s super important that she takes part in it (I1).

Children manage to use insulin on their own

Mothers’ reports pointed to improvements in their knowledge and self-care skills. After participating in a summer camp, children were not afraid of self-administering insulin, becoming more prepared to do this and neither requiring nor accepting their parents’ administration.

[...] because she even cried once, she said she was afraid of taking insulin. Then, when she came back, she was more prepared (I7).

[...] so that we don’t inject insulin in her anymore, she does it herself, both the quick and Lantus®️, the regular one [...] I often asked her: do you want me to do it? But since she came back from the summer camp, she’s never accepted my help anymore. So this was excellent! (I1).
In addition to overcoming the fear of administering insulin, mothers observed that their children also lost their fear of hypoglycemia resulting from the insulin administration.

She would inject insulin before the summer camp, but she was afraid of insulin having a stronger effect than expected and causing hypoglycemia. Now, she’s not afraid anymore, she’s not even aware of this (I7).

Another self-care skill that could be improved was the rotation between insulin administration and catheter insertion, although it was also reported that this was not always performed adequately.

[...] today, she does the rotation, something she’d never do before (I1).

[...] or to do the injecting rotation, she knows she can’t keep doing it only on the belly, for example, but as this is easier for her, she sometimes does it on her belly. Not that she doesn’t know, but she does it because she’s naughty at times (I2).

[...] She does the rotation. Well, the pump doesn’t allow you to do this too far away, you know? Because it’s more like this, where we inject it more often, on the belly (I4).

Additionally, mothers reported that their children became more confident when administering insulin, a fact attributed to camp nurses that supervised the administration.

[...] you have to inject it (insulin) in front of everyone there. So, perhaps, it gave her the freedom to inject it on herself and to let someone watch her to see if it’s right. I said it was cool, because the nurses were there. As I wasn’t looking, I couldn’t tell if it was right, you know? Because she’d inject it and wouldn’t let us look. [...] so, she became more confident to inject the insulin, much more confident, you know? (I7).

As members of the camp nursing team for several years, the researchers of this study were also responsible for the promotion of self-care of children and adolescents. Therefore, they encouraged these young individuals to administer insulin and, when they began to do so, supervised and guided them according to need. This skill that children/adolescents acquired was reported by the mothers in this study.

Despite the advances in the technologies involved in insulin administration, such as the continuous subcutaneous insulin infusion pump, the literature in this area emphasizes the importance of education and empowerment of individuals for self-care as a key part of a successful therapy.15

Parents and the health team must provide learning opportunities for children/adolescents to develop the skill of self-administering insulin and home control, aiming to enable their independence.16

Children start performing the glycemic control

In the present study, mothers reported that their children began to perform capillary glycemia (CG) by themselves, understanding the meaning of the values found, in addition to recognizing the symptoms of hypoglycemia and hyperglycemia.

She started doing the dextro on her own, you know? To know when it's low, high, or too high, you know? (I5).

[...] she does it alone, [...] gets up, already does the controls, notes them down. [...] she used to be afraid (of performing the control) (I2).

Mothers reported that, after the summer camp, their children began to recognize the symptoms of hypoglycemia and hyperglycemia, performing the required measures to correct them.

[...] especially her care for the symptoms she’s been having, she can notice when she’s hypoglycemic or not, so as she notices this, she understands and does the Dextro. [...] when she begins to feel bad, she already tells us and does the Dextro. She sees what she’s going to eat and how much insulin to inject (I2).

In agreement with the refusal to perform capillary glycemia, mothers reported that, even after participating in the summer camp, their children still showed some reluctance. Thus, mothers must demand this from them, something attributed to adolescence. Additionally, they must be reminded of how to adequately monitor diabetes, including antisepsis of the punctured area for capillary glycemia.

[...] sometimes, we keep asking, because she’s an adolescent, so she’s a bit inattentive. So, we have to push her: ‘Go monitor it, go check the Dextro’ [...] (I1)

[...] or when she does the Dextro, she feels lazy to do the hand hygiene, so she skips it at times, she knows she’s got to do it, but sometimes she doesn’t, you know? (I2).

[...] We always ask her to wash her hands, you know? But, sometimes, she doesn’t want to and I’ve already seen a difference of up to 40mg/dl, you know? On her fingertip (capillary glycemia), doing it when her hand is dirty and then when it’s clean. [...] And she feels lazy, you know? So my inspection is annoying her more (I5).
Monitoring capillary glycemia is essential for the treatment of diabetes. The results obtained enabled us to reassess the established therapy, aiming to achieve good glycemic control and to prevent acute and chronic complications caused by this disease.\textsuperscript{2} However, the literature warns that, due to a number of factors such as pain and inconvenience, many children and adolescents do not accept the frequent punctures on the fingertip, they feel unwilling to take the measurements and hide their disease from their peers, thus neglecting the treatment.\textsuperscript{17,18}

Children become interested in diet management

Mother perceived that, after the summer camp, their children became interested in diet management, distinguishing and balancing foods, looking at food labels and being willing to know the effect of foods on their organism, especially the glycemic level.

[...] and her interest in looking at the label and trying to understand the harm that such food can do to her. [...] she began to notice the influence of her diet on the Dextro. It was really nice! I want her to continue like this, noticing the differences. It was very good! (I5).

I think she is even more interested in foods and knowing what has more carbohydrates, what has more proteins. So, now, she knows how to distinguish foods: this has more proteins, this doesn't raise the blood sugar. So she can balance her diet better (I1).

The new interest in diet management is a positive aspect of the summer camp experience that reflects on the routine at home, as observed through the mothers' reports. This behavior differs from the findings of a literature review performed in 2009 that affirms that the eating habits of children with diabetes do not meet the recommendations of guidelines and that, in some aspects, they are even less healthy than the habits of children without DM.\textsuperscript{19}

Nutritional therapy in diabetes aims to achieve a good nutritional status, physiological health and quality of life, enabling a healthy diet that should be consumed by all, whether they have diabetes or not. Additionally, it is a required tool for diabetes control, prevention and treatment of short- and long-term complications.\textsuperscript{2,20}

Children learn about, overcome their fear of and begin to perform the calculation of carbohydrates

Mothers pointed to the calculation of carbohydrates as one of the aspects that their children learned during the summer camp and began to perform at home, including overcoming their fear of doing this. This was regarded as an important benefit in their daily care routine, as the calculation of carbohydrates is viewed as positive and necessary in the treatment of diabetes.

[...] she more or less knows how to calculate the carbohydrates, but she doesn't know all. She knows about food. [...] she began to calculate the carbohydrates, you know? That was very positive! (I4).

[...] but I think that what really changed was the calculation of carbohydrates. [...] she was terrified of this, now she doesn't need to be afraid of this calculation anymore. [...] she'd keep a fixed dose (of insulin) as she was afraid (I7).

The method of calculation of carbohydrates is key for the nutritional treatment of diabetes. It must be included in the context of a healthy diet, aiming to quantify the carbohydrates present in a meal, thus enabling the calculation of the amount of insulin required to establish a good glycemic control.\textsuperscript{21}

Children becoming independent

The independence that children acquired during the summer camp is considered to be important by mothers as part of their care routine, enabling them to have autonomy and freedom in self-care, which is defined by these mothers as something wonderful and positive.

[...] the independence of knowing that she doesn't need her mom or dad there the whole time. [...] I think that's it, eternal gratitude, her independence, that this is important, the most important thing was her independence, her self-sufficiency (I4).

Ah! She became more independent. [...] so this was wonderful, it gave her autonomy. I would even say, "If you want to become more independent, if you want to go to a friend's place, you can't go!" So, it was very positive for her to become more independent (I2).

After participating in the summer camp, children/adolescents began to go out without their parents, although this did not mean mothers were not concerned.

[...] She has been to two parties by herself already. I wrote it, you know? The amount of carbohydrates there usually is at a party and then she left. [...] So we began to trust her more and let her participate in social events with teens. [...] but we suffer, I keep thinking if she's alright (I5).

[...] because before, if she had to go to a friend's, I was always there with her. She goes down the apartment building to play by herself. I wouldn't let her do this before. [...] I think it was her dream as well, to be alone (I4)

For mothers, the moment their children become independent and able to manage diabetes better is when they can feel more at peace.
A summer camp is a valuable experience of autonomy and independence for children/adolescents who had never been apart from their parents in the majority of cases. In a Brazilian study, children and adolescents reported that their camp promoted an independent approach to treatment, as they are encouraged to perform self-monitoring and that this experience can change and influence their routine positively when returning home.  

Children realize they are not different because they have diabetes  

Participating in a summer camp also brought about changes to the self-perception of children and adolescents, enabling them to realize that they are not different and that there are others like them. Thus, they stopped feeling excluded and rejected, a fact that improved their self-esteem and promoted friendships, developing their social interactions.  

The perception of being different in the group is described in the literature as one of the difficulties of children with DM, as the care involved in the treatment interferes with their social life and their interaction with friends can thus influence disease management.  

A study conducted with children and adolescents with diabetes in Germany, who participated in a summer camp in 2006 and 2008, also found that, based on the relationships formed with their peers, they received support in terms of reaffirmation and motivation, apart from maintaining contact with each other after returning from such camp. This shows the importance of interacting with other children with diabetes.  

Children begin to accept their disease  

The results of the present study also raise the question of acceptance of the disease. In agreement with the literature, according to the reports of mothers, their children also have difficulties accepting the disease. However, after participating in a summer camp, they began to accept themselves and their health condition.  

Children need to be reminded to maintain certain habits they have acquired  

Although recognizing all the positive changes in their children's behavior after returning from the summer camp, mothers also perceived that, regarding the maintenance of habits acquired in the summer camp, especially those not directly associated with diabetes such as care for the environment, children became more neglectful with time.
In a study that described the experience of educational camps for adolescents with diabetes in Argentina, education on this disease is pointed out as key in the treatment of children with diabetes and their families. However, it warns about the need to consider the fact that changes in habits are a slow, gradual and long-term process to achieve the objectives. Additionally, the need of continuous health care after a summer camp is pointed out, aiming to maintain the knowledge and support in the different stages involved in this disease.

**Summer camp as a gift for the children and families**

The moment the summer camp enables the care routine of children and their own behavior to change, the family routine is also affected. In the present study, according to the mothers, apart from the positive effects associated with self-care in diabetes, the summer camp provided benefits for both mother and child, representing a gift for them.

> [...] In the case of my daughter, it was like this right after she came back... in the first week, you feel like you're in heaven. [...] the gift wasn't just for her, but for me as well (I1).

> [...] The summer camp staff speaks the language of teenagers, because I think they speak it well, and this helps the family, my daughter, so I think it's always positive (I4).

In a study that sought to understand the experience of schoolchildren with diabetes through therapeutic toys, role plays showed that diabetes is not only included in children's experience, but also in that of the family, who suffer together and provide support.

Additionally, summer camps enabled parents to experience their life as a couple, when they could go out alone, something that had not occurred since their child had been diagnosed with diabetes.

> [...] we couldn't be alone as husband and wife, as a couple, going out, going to the movies, as she (daughter) was always with us and this is something the summer camp helped us with. This camp also helps the family, this is great for parents too, we slept all night long, right, daughter? (laughter) (I4).

When children have a chronic disease, the way a family functions changes, affecting all the members as they take on new responsibilities. Thus, the couple experiences a greater number of situations and emotions that they need to cope with. This is not an easy task and they can be successful in their initiatives or not.

Mothers reported that the summer camp was good for their children, as they greatly enjoyed to participate in it and returned feeling amazed. Additionally, they noticed that their children were feeling calmer and willing to manage the disease correctly.

> [...] But our daughter liked it very much, I think this camp was the best thing in her life, when she came back, she was more amazed than when she went to Disneyland (I4).

> [...] he came back feeling well and very happy. [...] but I think the summer camp is like this, he came back full of life, willing to do so much and to get it right, I think this is good. He wants to get it right (I3).

Reflecting on children's new participation in the summer camp

Based on the recognition of all the benefits resulting from their children's participation in the summer camp, mothers reported that they would allow them to participate in this activity again, as they believed that a second time would bring even greater benefits and that their children would take more advantage of it.

> Certainly! I'm sure that if they had one every year or every six months, I'd certainly let them do it! (laughter) (I1).

> [...] So, this... I'm going to try again, let's see if we can send our daughter to a summer camp again. [...] and I think that this way, as she gets older and with her return to this camp, she'll get more information and become more and more independent (I4).

In a recent literature review, the most relevant physiological or behavioral changes were found in individuals who had participated in more than one summer camp for children and adolescents with diabetes. Reports from mothers are in agreement with the statements made by children and adolescents themselves, the majority of which, in the experience of researchers working in these camps, expressed their desire to participate in such activity again.

**FINAL CONSIDERATIONS**

The summer camps were found to be an important type of education to promote self-care for children and adolescents with diabetes, as shown in the several categories that revealed the benefits resulting from such experience. Such benefits are associated with the promotion of independence, self-control of disease and acceptance that these young individuals began to show, apart from the pleasure of participating in summer camps and the benefits for the families themselves.

Nursing, a profession committed to care, plays a key role in health education and, consequently, nurses must be included in the team caring for children/adolescents in such camps, as it is already occurring.

We should emphasize the importance of this experience in nursing qualification, as it enables professionals to acquire much learning, bringing them closer together to health education, which is very important for such qualification. Therefore, the benefits
extended to all participants involved in this activity: children, adolescents, parents, instructors, students and professionals from several areas.

To understand the mothers’ perception of their children’s participation in the summer camp was important to reflect on this type of education and how it can be developed, so that the knowledge about and skills in diabetes acquired by them can be even more efficient and long-lasting.

We hope that the results of this research project can promote the development of more studies that enable, among other things, the understanding of the long-term effects and those on glycemic indices, apart from some of the actions pointed out, such as parents thinking about the possibility of joining summer camps and researchers performing other studies on this experience, as the present one was restricted to the perspective of mothers.

In this sense, studies on fathers could be performed, which in principle would be participating as well. However, this did not occur due to their difficulties in being present during interviews with the children/adolescents themselves and with the professionals involved in their follow-up, after their participation in summer camps.

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Camp and self-care of children with diabetes

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Summer camp for children and adolescents with diabetes promoted by the Associação de Diabetes Brasil (ADJ - Brazilian Diabetes Association) and UNIFESP Diabetes Center and held at the Nosso Recanto (NR) Camp.

The Young Leaders in Training - Diabetes is an international project developed by a Brazilian NGO that aims to prepare young individuals to help others with diabetes and to educate the population, so they can have a better quality of life and prevent Diabetes mellitus type 2.