

Children and adolescents living with diabetes and celiac disease

Crianças e adolescentes que convivem com diabetes e doença celíaca

Niños y adolescentes viviendo con la diabetes y la enfermedad celíaca



Bianca de Cássia Alvarez Brancaglioni^a
 Grasielle Caroline Rodrigues^a
 Elaine Buchhorn Cintra Damião^b
 Márcia Silva Queiroz^c
 Márcia Nery^c

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ABSTRACT

Objective: To understand the experience of children and adolescents living with type 1 diabetes and celiac disease.

Method: This is a qualitative exploratory-descriptive study. The participants were 3 children and 2 adolescents. The data were collected by means of semi-structured interviews between January and September 2012 at the participant's residence or at the diabetic outpatient clinic of the Hospital das Clínicas, Faculty of Medicine, University of Sao Paulo in São Paulo, Brazil. The content analysis technique was used to process the data.

Results: The key aspect of the illness experience of the patients was their diet, but with different meanings. The children had difficulty following the diet, while the adolescents reported that they had greater difficulty coping with the social and affective aspects of their diet.

Conclusion: The results reinforce the importance of nurses who seek strategies, together with the patients and their families, that help minimize the difficulties of these patients, especially with regard to managing the diet imposed by both diseases.

Keywords: Children. Adolescent. Diabetes mellitus, type 1. Celiac disease.

RESUMO

Objetivo: Compreender a experiência de crianças e adolescentes que convivem com diabetes mellitus tipo 1 e doença celíaca.

Método: Estudo qualitativo, exploratório e descritivo. A coleta de dados ocorreu entre janeiro e setembro de 2012, com 3 crianças e 2 adolescentes, em um ambulatório de diabetes do Hospital das Clínicas da FMUSP ou na residência dos participantes na cidade de São Paulo, por meio de entrevistas semiestruturadas. Utilizou-se a Análise de Conteúdo como método de tratamento dos dados.

Resultados: A dieta aparece como foco da experiência dos participantes, porém com diferentes significados. As crianças têm dificuldade em seguir a dieta, enquanto os adolescentes referem que os aspectos sociais e afetivos são os mais afetados.

Conclusão: Reforça-se a importância do enfermeiro buscar estratégias em parceria com as crianças, os adolescentes e suas famílias a fim de minimizar as dificuldades encontradas principalmente no manejo da dieta imposta por ambas as doenças.

Palavras-chave: Criança. Adolescente. Diabetes mellitus tipo 1. Doença celíaca.

RESUMEN

Objetivo: Comprender la experiencia de los niños y adolescentes que viven con diabetes tipo 1 y la enfermedad celíaca.

Método: Estudio cualitativo exploratorio y descriptivo, se incluyeron 3 niños y 2 adolescentes; los datos fueron recolectados de enero a septiembre de 2012, en la clínica de diabetes del Hospital de Clínicas de la Facultad de Medicina de la Universidad de São Paulo o en la residencia de los participantes en São Paulo, a través de entrevistas semi-estructuradas. Para el tratamiento de los datos se utilizó la técnica de Análisis de Contenido.

Resultados: La dieta es el foco de la experiencia de los participantes, pero con diferentes significados. Los niños tienen dificultad para seguir la dieta, mientras que los adolescentes reportan que los aspectos sociales y afectivos son los más afectados.

Conclusión: Los resultados refuerzan la importancia de la enfermera buscar estrategias en colaboración con los niños, adolescentes y sus familias para minimizar dificultades encontradas principalmente en la gestión de la dieta impuesta por ambas enfermedades.

Palabras clave: Niños. Adolescentes. Diabetes mellitus tipo 1. Enfermedad celíaca.

^a Universidade de São Paulo (USP), Escola de Enfermagem. São Paulo, São Paulo, Brasil.

^b Universidade de São Paulo (USP), Escola de Enfermagem. Departamento de Enfermagem Materno-Infantil e Psiquiátrica. São Paulo, São Paulo, Brasil.

^c Hospital das Clínicas da Faculdade de Medicina da Universidade de São Paulo, Serviço de Endocrinologia e Metabologia. São Paulo, São Paulo, Brasil.

■ INTRODUCTION

Healthcare for children and adolescents with chronic diseases and their families is very challenging, especially in relation to obtaining support for coping with the difficulties of disease⁽¹⁾.

Diabetes mellitus type 1 (DM1) mostly starts during childhood and adolescence and requires complex, daily insulin treatment, monitoring of capillary blood glucose, a healthy diet and regular exercise⁽²⁾.

As DM1 is an autoimmune disease, it can be associated with other autoimmune diseases like celiac disease (CD) and/or hypothyroidism⁽³⁾. Celiac disease is a chronic immune-mediated enteropathy that affects the small intestine of genetically predisposed individuals and is precipitated by the ingestion of food containing gluten. Treatment consists of a gluten-free diet to control the signs and classic symptoms of the disease and prevent the onset of malign neoplasias⁽⁴⁾.

The prevalence of CD among children and adolescents with DM1 varies between 1 and 10%, with an incidence of approximately 8 cases for every 1000 patients per year⁽⁵⁾. Consequently, research on CD among children and adolescents with DM1 should be conducted at the moment of the DM1 diagnosis and every 1 to 2 years, insofar as the result is negative⁽³⁾.

Although the experience of children and adolescents with DM1 is described in scientific literature⁽⁵⁻⁶⁾, we did not find any national or international studies on the experience of people who suffer from DM1 and CD.

It is common knowledge that the DM1 diagnosis has a huge impact on the lives of children and adolescents. The diagnosis is usually unexpected and the disease causes sudden changes in their lives and daily routines due to the procedures required for treating this disease⁽⁵⁻⁶⁾.

In the case of CD and despite the scarcity of studies, feelings such as isolation and shame, difficulties in maintaining social relationships and carrying out daily activities, such as choosing food and planning trips, have been reported⁽⁷⁾.

Considering the difficulty of coping with DM1 or CD separately⁽⁵⁻⁷⁾, the interesting question is how do children and adolescents cope with both diabetes and celiac disease? This guiding question was used as a basis for the entire study. Knowing how children and adolescents cope with two chronic diseases will help nurses and the healthcare team plan their interventions together with these patients and meet their needs more efficiently. Therefore, the object of this study is to understand the experience of children and adolescents who cope with diabetes mellitus type 1 and celiac disease.

■ METHOD

This is a qualitative exploratory-descriptive study. The reference framework adopted for this study was Symbolic Interactionism and the methodology was Content Analysis. We also used the COREQ script⁽⁸⁾ to present the results.

Symbolic Interactionism is a theory on human behaviour that is based on the assumption that the human experience is mediated by interpretation⁽⁹⁾. This framework helps us understand the meaning the children and adolescents with DM1 and CD attribute to the experience of coping with two chronic diseases. During data analysis, we sought to understand the meaning that children and adolescents attribute to their experience, contained in each code and in the formation of the categories and subcategories.

Content analysis is a set of research techniques that includes the analysis of documents in search of a meaning⁽¹⁰⁾. In this study, we followed the stages proposed by Campos⁽¹⁰⁾ for data analysis, as follows: 1) Skimming the text, 2) Selecting analysis units, and 3) Categorization and subcategorization.

Data were collected from January to September 2012. The participants were selected according to the following criteria of inclusion: a) Between the ages of 9 and 18; b) Undergoing treatment for DM1 for at least one year and for CD for any period. The period of at least one year was selected for the DM1 diagnosis to ensure that the participants had recovered from the impact of the diagnosis and had experienced coping with the disease. In relation to CD, a specific period was considered unnecessary because we were interested in the experience of a second diagnosis of a chronic disease that included the initial period of CD and its treatment; and c) No diagnosis of a cognitive and/or sensorial impairment. There was no criterion for exclusion.

The object of this study was explained to the eligible participant and the person responsible. Once the parent had authorized the research and the child/adolescent had agreed to participate, individual interviews were conducted in a private room of the outpatient unit on the same day or scheduled at the patient's residence, as preferred by the patient and parent. All the participants were accompanied by a parent at the time of the interview, and one interview was conducted with each child or adolescent. The anonymity of the participants was preserved by identifying the interviews with the letter A (Adolescent) or C (Child) followed by the order of the interview (1, 2 or 3).

All the children and adolescents who met the criteria for inclusion accepted to participate in the study, however, in order to expand the sample, we contacted two other institutions to identify possible participants. Unfortunately,

no other children or adolescents who met the criteria were found, which led us to question whether children and adolescents with DM1 are being tested for CD as recommended by literature⁽³⁾. Three children and two adolescents between the ages of 10 and 16 participated in this study.

At the beginning of the interview, the instruments "Profile of the child/adolescent with DM1 and family"⁽¹¹⁾, the genogram and the ecomap⁽¹²⁾ were completed to familiarize ourselves with the child or adolescent and the family members, and to identify any familiar factors that could influence how the participants deal with their chronic diseases on a daily basis.

Once the instruments were completed, the following question was asked: *"Tell me what it's like to cope with two diseases: diabetes and celiac disease"*. Based on this question, other questions were formulated to obtain further insight into the experience of disease of the children and adolescents with DM1 and CD. The interviews lasted 20 minutes on average.

The first step to process the statements of the subject consisted of precisely transcribing the recordings and analysing the transcribed statements according to the stages of the method⁽¹⁰⁾. The material was read several times, during which the codes were extracted and grouped according to similarity of meaning. In the current study, non-aprioristic categories were used, which are those that fully emerge from the text created by interviewing the subjects. Once the categories and subcategories were defined, they were grouped according to the theme⁽¹⁰⁾. The process resulted in the emergence of themes that explained the experience of children and adolescents who cope with DM1 and CD.

The ethical procedures specified in Resolution 196/96⁽¹³⁾ of the Conselho Nacional de Saúde were observed. The research projects were approved by the Comitê de Ética da Escola de Enfermagem of the USP (CAAE 0055.0.196.015-11 and 0097.0.196.015-11) and the partner institution. The parent signed an informed consent statement and the child/adolescent signed an agreement to participate in scientific research. Both statements were signed in two copies, one of which was given to the family and the other to the researcher.

■ RESULTS AND DISCUSSION

Five individuals participated in this study: 3 children and 2 adolescents between the ages of 10 and 16, of which 3 were girls and 2 were boys. Most of the interviewees used carbohydrate counting (n=4) and an insulin application pen (n=3). Most of the parents had finished school or higher education.

During the interviews and the analysis, we tried to identify the interactional experience of the child or adolescent in relation to having two chronic diseases. Based on this perspective, we present a description of the explanatory categories and subcategories of the experience of the participants when coping with diabetes mellitus type 1 and celiac disease.

Difficulty receiving another diagnosis of a chronic disease

This category gathers the findings that refer to the moment of the diagnosis and the start of living with celiac disease. The subcategories **Fearing the consequences of celiac disease** and **Family receiving the diagnosis of celiac disease** carry a meaning that the interviewees attribute to a phase of new restrictions. A lack of knowledge on celiac disease increases the anguish and concerns of the participants and their families. The fear of developing other diseases, especially cancer, is also present due to the intake of gluten before the participant was aware he or she suffered from celiac disease. A recent study corroborates the results found for this category in relation to the difficulties parents have in managing the complications of both diseases⁽¹⁴⁾.

The reaction of families when receiving the diagnosis of celiac disease can be observed in the following statement:

Oh, diabetes, my dad has type 2 diabetes, so the diabetes was bearable. But celiac disease, I didn't even know what it was. At first, when I told them, my sister cried, my mother cried, my dad cried [...] (A2)

Difficulty coping with a gluten-free diet

The participants stressed that the main difficulty coping with celiac disease is the gluten-free diet. For these children, this diet restricts their food choices, and for the adolescents the diet causes embarrassment and difficulties in their social lives.

When they narrate their experiences of coping with both diseases, the children and adolescents compare the diet for diabetes and the gluten-free diet. In the diet for diabetes, they are allowed to eat sweets insofar as intake is moderate and they follow some strategies, such as carbohydrate counting and the recommended dosage of insulin to control blood sugar. However, the treatment for celiac disease fully excludes the intake of gluten, which restricts their food choices. These concerns were detailed in the subcategories **Cutting out food with glu-**

ten, Feeling like eating something I cannot eat and Ashamed of exposing myself

The period after the CD diagnosis is reported as a difficult stage for the participants due to the continuous restrictions of the gluten-free diet. Consequently, the participants perceived the start of their experience with celiac disease as a stage in which their range of choice was drastically reduced, like paths that closed before them. The desire to eat a specific food item that does not have a gluten-free equivalent is also reported as a difficult moment for the participants:

[...] at first it was tough [...], I have to cut out Trakinas®, pizza, too, lots of things, at school and in several other places [...] then the path started opening up again (A1)

It's annoying sometimes, because there is something I cannot eat. With diabetes, I can eat it and correct it with insulin, but I can't eat just anything either. (C1)

As reported in other studies on coping with celiac disease^(7,15), the adolescents stated they felt embarrassed when they went to places where people did not know they had DM and CD. They feel embarrassment due to the undesired attention they receive when they have to ask questions about how food is prepared or the content of food:

[...] it's a little embarrassing [...] I go to a restaurant, and I feel like eating something there, but I don't know if it has flour or not. Asking is embarrassing [...] I prefer not to eat something than ask. (A2)

Coping with celiac disease

We perceived that the children and adolescents need to go through an adaptation process after receiving the diagnosis of the disease. This process involves understanding what it means to have celiac disease, as specified in the following subcategories: **Not knowing what celiac disease was at first, Understanding celiac disease, Getting used to celiac disease** and **Unknowingly asking for something with gluten**.

The participants reported not knowing what celiac disease was or what changes this new diagnosis would bring to their lives:

I laughed when they told me I had celiac disease! I thought it was a good thing [...] I thought we couldn't eat salt [...] (C2)

However, in time and with the help of health professionals, the children and adolescents began to understand celiac disease and got used to the diet. The suffering and difficulties encountered in their daily activities are minimized when the participants have access to gluten-free versions of the food they are used to eating. Thus, this moment is perceived as a period in which participants understand the new options of gluten-free versions of the food to which they were accustomed. This perception was reported as a path that opened before them:

[...] then, the path opened up [...] because of the shop, because there are lots of gluten-free products. (A1)

[...] is it normal to have celiac disease, it's the same as before, we just changed the type of food, changed the school lunches, the type of flour [...] (C3)

In the case of households with fewer financial resources, the children suffer more with the gluten-free diet. A diet consisting of foods without gluten is approximately 44% more expensive than a diet with conventional food items⁽¹⁶⁾. The participants are deprived of eating food that the diabetes diet allows, such as biscuits, bread and pasta, because the family cannot purchase the gluten-free alternatives.

A more economical alternative to maintaining the gluten-free diet would be food prepared by the families of the children and adolescents⁽¹⁷⁾. However, in proposing this measure, the families must have the time and skill to prepare gluten-free alternatives. They must also be instructed on precautions during cooking to avoid cross-contamination, and receive indications on sources from where to obtain gluten-free recipes.

The children and adolescents also showed that they are generally concerned about their diet, despite not being too happy about the restrictions. There were situations in which the participants ingested food that contained gluten thinking the food was gluten-free.

Having a social life

In spite of the difficulties of coping with two chronic diseases, the participants do have social lives, as reported in the following subcategories: **Getting on well at school, Telling friends, Going out with friends, and Difficulties during trips**.

Some participants reported they did not have problems coping with both diseases and going to school. The children and adolescents stated they ate the gluten-free items from

the school canteen or took packed lunches from home to maintain their gluten-free diet, as reported below:

I have lunch at school, so when there is something I can't eat, like spaghetti, I take my own spaghetti and they prepare it for me. (C1)

The children and adolescents have a normal and close relationship with their school friends, and reported telling some of their friends about the DM1 and CD or about one of the diseases. The participants also reported that when they visit friends at their homes, they take their own meals to avoid eating food with gluten, as stated below:

[...] I take my stuff when I'm going to spend the day at a friend's house. My mum takes bread, biscuits [...]. (C3)

Because normally when I go out, when I go to their house, I go to a birthday party, so I take everything. But then, with them, with everyone like that I don't feel embarrassed. I eat my food, normally. (A2)

Again, the adolescents stated that they have greater difficulties in social situations, especially with their peers, which is highly valued during adolescence⁽¹⁸⁾. This was also highlighted in other studies^(6, 7). For the adolescents, living with celiac disease means coping with frequent difficulties during trips due to the small number of shops that cater to their needs in Brazil, which makes it hard for them to stick to their diet on some occasions.

A similar finding was reported in a qualitative study conducted in Sweden. This study had 117 adolescent participants with celiac disease and explored how the diagnosis impacted the quality of life of this population. Some adolescents reported they were exposed to several situations that made them feel vulnerable, alone or unsupported, leading to a certain isolation from their friends in order to maintain the right diet⁽¹⁵⁾.

Coping with diabetes

Living with both diseases seems to make the problems related to diabetes treatment a little less important in comparison with the difficulties in managing CD, thus attributing a new meaning to DM, as follows:

It was really tough at first. I used to say that it was alright with diabetes, I could correct it and eat everything, but it's different with celiac disease, it was really bad because I couldn't eat much. (A2)

The only study we found on the experience of parents with children who suffered from both diseases corroborates the findings of this study in that it reports that the experience of adolescents with CD was more difficult due to the gluten-free diet. The parents perceived that their children felt more isolated and suffered from bullying and jokes due to their diet after the CD diagnosis⁽¹⁴⁾.

Using the resources

The participants reported the resources they use and how they help them adapt to the diseases. They mentioned institutions, healthcare professionals, commercial establishments and the internet, among other resources they use to better cope with both diseases, as stated below:

[...] The internet also helped a lot. I searched for recipes on how to make coxinha without gluten [...] and cake, too [...]. (A1)

In Brazil, internet access is not available to the entire population, although this tool is widely used by adolescents. A recent study recommends that nurses provide reliable sites that help patients obtain information and share their experiences⁽¹⁴⁾. In this sense, the nurses must also prepare and carry out educational activities to inform and help the children and adolescents adapt to the disease^(11, 19).

Getting support

The children and adolescents in general mentioned the support they get from their families since the start of their experience with the disease to the present day:

[...] My mum does everything for me. It gets a lot better. When my brother goes home and wants to eat something that has gluten, he waits for me to go to school to eat it. (A2)

As reported in literature^(6, 7, 18-19), the support provided by family members, friends, healthcare professionals and other people that the children and adolescents consider important is an effective coping strategy. These people provide the emotional support and the help they need to solve problems and follow the treatment. Consequently, the social support seems to greatly influence the experience of children and adolescents when coping with two diseases.

Not getting support

Although some participants mentioned the support they got from people and family members, others felt

alone and unaided even within their family circles, which makes coping with the disease even harder for them and affects their self-esteem, as reported below:

My step-father would rather I just died, you know? Because he gave me loads of things, biscuits and bread with gluten. (C2)

In general, the children and adolescents seemed somehow supported by their families, although there were situations in which they did not get any support and felt they were a burden to their friends, as revealed by adolescents in another study. These children tend to isolate themselves from their peers and do not follow the treatment correctly⁽¹⁴⁻¹⁵⁾.

Still adapting to the diseases

The process of adapting to the disease is not linear and varies according to the situations experienced by the participants, that is, in certain moments, they feel they have adapted to the situation to a greater or lesser extent.

[...] with diabetes, I took around two years to adapt [...] with celiac disease, I adapted after a year more or less, and I've already adapted well. (A1)

The difficulties of adapting to a chronic disease are highly documented in literature^(1, 5-7, 11, 14-15, 18-19), although we did not find studies on the experience of children and adolescent who suffer from more than one diagnosed chronic disease.

In this sense, the results obtained in this study are highly relevant, as they allow us to understand for the first time how the children and adolescents who participated in the study attribute meaning to the interactions of the process of coping with two chronic diseases. DM1 and CD (Figure 1).

The graphic representation shows that the children and adolescents already coped with the situation of having DM1 and were used to the demands of diabetes treatment (lightly dotted circle). With the CD diagnosis, the children and adolescents also start the treatment (dotted circle), that is, the total exclusion of gluten from their diet. The diet (intersection - chequered) is a common factor between the two pathologies and the focus of the disease experience of

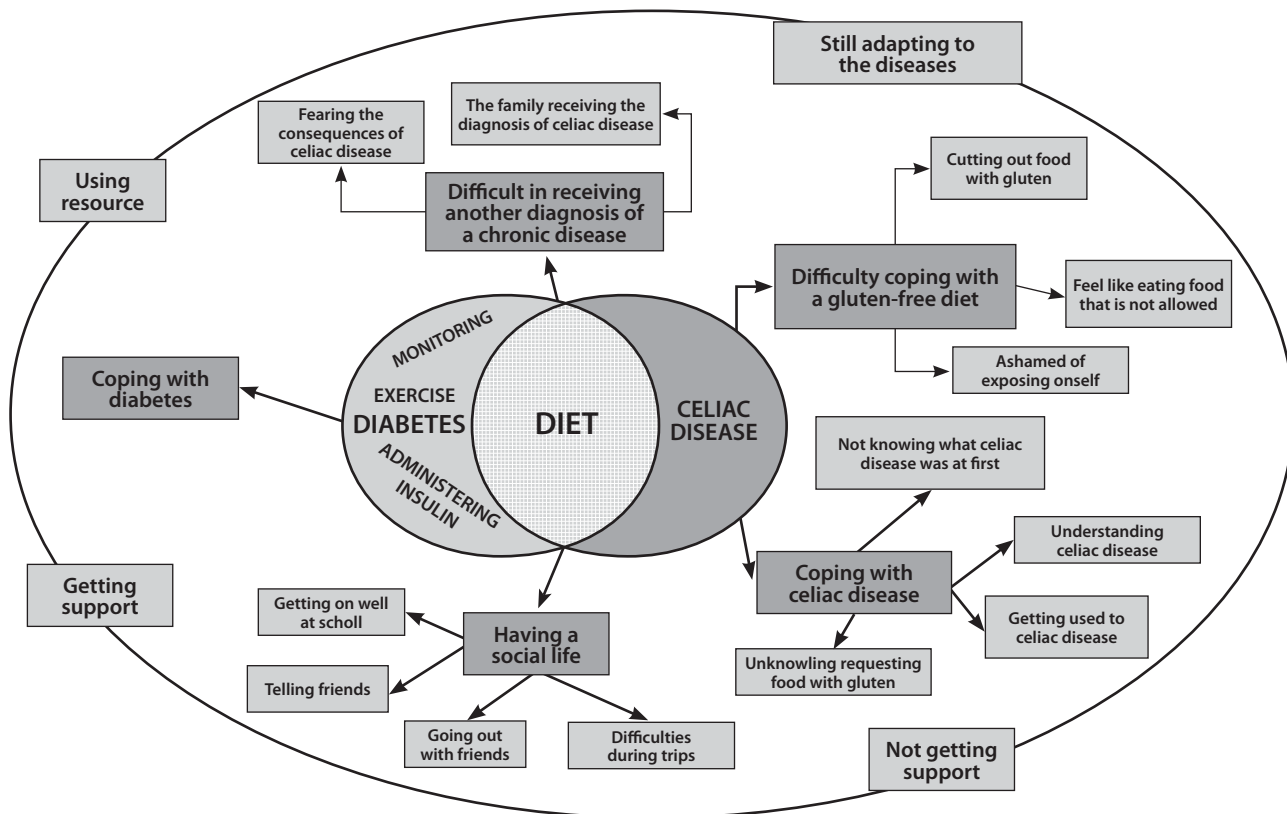


Figure 1 – Graphic representation of the experience of disease of children and adolescents with diabetes mellitus type 1 and celiac disease

the children and adolescents; and managing celiac disease is considered the greatest difficulty they encounter in their daily lives. We can also see an eclipse that represents aspects of the experience that influence the way the children and adolescents cope with both diseases.

■ FINAL CONSIDERATIONS

The current study provided for the first time the opportunity for children and adolescents who cope with two diseases, DM1 and CD, to narrate their experiences. Their statements helped us understand that the diet is the focal point of the experience of their disease and the main difficulty of the children who must maintain a gluten-free diet. Similarly, the main difficulties reported by the adolescents were the social and affective aspects related to the limitations of their diet.

It is apparently more difficulty for the children and adolescents to cope with celiac disease than with diabetes due to the restrictions of a gluten-free diet. These restrictions led to the adoption of strategies that facilitate disease management, like taking a packed lunch from home to trips and visitations, physical activity, the support of family and friends, the use of resources such as support from healthcare professionals, sports and the internet.

The results reinforce the importance of nurses during the planning of care for children and adolescents with DM1 and CD, the need to seek strategies with these patients and their families to minimize the stress and suffering caused by the diet, and the need to promote adherence or maintenance of the diet and the other treatment measures. A wide range of resources can be used by nurses, such as social networks and exchanging messages on applications such as Whatsapp to establish and consolidate bonds, and, above all, to become available in case of doubts related to managing DM1 and CD. Educational workshops using games and toys to teach the skills and techniques for treating the disease are also quite effective for the care of children and adolescents with chronic diseases. However, the most important tools are still therapeutic communication and the true involvement of nurses when interacting with these children and adolescents. These tools also increase the effectiveness of the strategies mentioned above.

Furthermore, nurses must be able to identify the social support of these children and adolescents in order to help establish and strengthen this support.

It should also be highlighted that the social and economic characteristics of the participants and the small number of children and adolescents interviewed for this study can be considered study limitations. Most of the persons responsible for the participants had finished school

or university, and the children and adolescents used carbohydrate counting, which indicates that the participants probably had a good social and economic condition that favoured the maintenance of treatment.

The small number of children and adolescents with DM1 and CD is probably due to the different criteria for diagnosing celiac disease adopted by the healthcare institutions and the absence of a protocol to investigate CD among patients with DM1.

We also stress the need for further studies on the subject with a higher number of participants in order to better understand how these patients experience and cope with two diseases.

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■ Corresponding author:

Elaine Buchhorn Cintra Damião
E-mail: buchhorn@usp.br

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