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Self-care in the context of childhood diabetes: challenges of the process of transfer of autonomy

O autocuidado no contexto do diabetes infantil: desafios do processo de transferência da autonomia

El autocuidado en el contexto de la diabetes infantil: desafíos en el proceso de transferencia de autonomía

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ABSTRACT

Objective: to analyze the process of transferring autonomy to self-care for children and adolescents with type 1 diabetes, from the perspective of the mother-child binomial. **Method:** convergent care research, carried out with 16 pairs, assisted in a specialized clinic in the southern region of Brazil. The collection took place in 2017 through interviews and observation that were transcribed and analyzed according to the steps of the proposed method. The ethical precepts were followed. **Results:** some mothers had difficulty delegating autonomy for their children's self-care, and some children did not feel safe to develop self-care. Difficulties in care were related to food, glycemic self-monitoring, medication and physical exercises. **Conclusion:** the self-care transfer process is complex, with difficulties in overcoming the posture of (super) maternal protection and promoting the children's autonomy, due to the recurrence of carelessness and lack of commitment, with impacts on adequate control of the disease.

Descriptors: Nursing; Diabetes Mellitus, Type 1; Child Health; Adolescent Health; Self Care.

RESUMO

Objetivo: analisar o processo de transferência de autonomia para o autocuidado das crianças e adolescentes com diabetes tipo 1, sob a ótica do binômio mãe e filho. **Método:** pesquisa convergente assistencial, realizada com 16 binômios, atendidos em ambulatório especializado na região sul brasileira. A coleta ocorreu em 2017 através de entrevistas e observação que foram transcritas e analisadas conforme as etapas do método proposto. Seguiu-se os preceitos éticos. **Resultados**: algumas mães apresentaram dificuldade em delegar autonomia para o autocuidado dos filhos, e alguns filhos não se sentiam seguros para desenvolver o autocuidado. As dificuldades no cuidado estiveram relacionadas a alimentação, automonitoramento glicêmico, medicação e exercícios físicos. **Conclusão:** o processo de transferência do autocuidado é complexo, com dificuldades para contornar a postura de (super)proteção materna e promover a autonomia dos filhos, em função da recorrência nos descuidos e da falta de comprometimento, com impactos ao controle adequado na doença.

Descritores: Enfermagem; Saúde da Criança; Saúde do Adolescente; Diabetes Mellitus tipo 1; Autocuidado.

RESUMEN

Objetivo: analizar el proceso de transferencia de autonomía al autocuidado de niños y adolescentes con diabetes tipo 1, desde la perspectiva del binomio madre-hijo. **Método:** investigación de atención convergente, realizada con 16 pares, atendidos en una clínica especializada en la región sur de Brasil. La recolección se llevó a cabo en 2017 a través de entrevistas y observación que fueron transcritas y analizadas según los pasos del método propuesto. Se siguieron los preceptos éticos. **Resultados:** algunas madres tuvieron dificultad para delegar autonomía para el autocuidado de sus hijos, y algunos niños no se sintieron seguros para desarrollar el autocuidado. Las dificultades en la atención se relacionaron con la alimentación, el autocontrol glucémico, la medicación y el ejercicio físico. **Conclusión:** el proceso de transferencia del autocuidado es complejo, con dificultades para superar la postura de (super) protección materna y promover la autonomía de los niños, debido a la recurrencia del descuido y la falta de compromiso, con impactos en el adecuado control de la enfermedad.

Descriptores: Enfermería; Diabetes Mellitus Tipo 1; Salud Infantil; Salud del Adolescente; Autocuidado.

INTRODUCTION

Type 1 Diabetes *Mellitus* (DM1) is a chronic and progressive disease characterized by absolute deficiency of insulin secretion by the pancreas. People with this disease become dependent on insulin use, presenting a higher risk of developing secondary complications, in addition to a reduction in quality and duration of life[1].

Three-quarters of all DM1 cases in the world are diagnosed in individuals up to 18 years of age and the estimates point to a global annual increase of 3% to 4% in cases of the disease during childhood[1-3]. Brazil records nearly 9,600 new cases of the disease per year, ranking third in the world, with the largest number of children and adolescents with DM1, along with the USA and India[1].

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Diabetes control is essential to enable better quality of life and minimize short- and long-term harms to the health[4]. Care measures such as daily insulin administration, self-monitoring of capillary glycaemia (SMCG), changes in the diet patterns and physical activity are indispensable, along with recognition of the symptoms caused by hypo- and hyperglycemia[1,5].

Parental involvement in DM1 care during childhood is essential in order to maintain children's and adolescents' adherence to the treatment and prevent glycemic control deterioration[6]. When the child is diagnosed, the parents must assume responsibility for daily management of the disease, as children have difficulties perceiving symptoms, in addition to being more susceptible to undesirable and dangerous effects[7]. In relation to adolescents, considering their ability to understand the disease and their needs for independence, the responsibilities for DM1 care should be negotiated and shared with the parents[6-8].

Therefore, it is during childhood that the care transfer process should be initiated, so that children and adolescents are gradually prepared to develop autonomy to assume DM1 self-care[9,10].

Thus, for the process to occur successfully, it becomes necessary to identify the skill and responsibility levels for DM1 that children and adolescents are able to assume, as self-care transfer at the appropriate age guarantees those involved a calm and reliable process, facilitating a full and adequate care transition from childhood to adulthood[6,8,10].

Equipped with relevant information about the transformations that occur in individuals at different life phases, nurses who work with people affected by diabetes can assist in action strategies for care, aiming to minimize the harms that the disease may cause, as well as assist in the development of skills that may favor the care process[4].

Thus, it is believed that identifying the participants' knowledge about DM1 care and the way in which the disease should be managed contributes to the process of transferring care in childhood and to the construction of self-care autonomy. Given the above, the study aimed at analyzing the process of transferring autonomy for the self-care of children and adolescents with Type 1 diabetes, from the perspective of the mother-child dyad.

METHOD

A convergent care research study conducted at an Outpatient Pediatric Endocrinology Service of a university hospital from a municipality in southern Brazil. The *Consolidated criteria for reporting qualitative research* (COREQ) was used to design this study[11].

Data collection took place between April and October 2017. The study was conducted with children and adolescents who have DM1 and their mothers, registered and undergoing monitoring in the aforementioned service.

The inclusion criteria for the children and adolescents were as follows: having been diagnosed with DM1 for at least two years, being monitored by the reference outpatient service, being aged between seven and 19 years old, being literate and having a primary caregiver. Inclusion of the mothers was according to their children's eligibility.

The lower age limit was established based on studies that indicate this age group as cognitively competent for this type of design[12], and the upper age group, for being defined as the end of adolescence[13]. The determination of two years since onset of the disease was due to the fact that the participants would have already gone through the DM1 Partial Remission or Honeymoon Phase[14].

A participant observation was performed for data collection whereas a structured questionnaire was applied to record the sociodemographic data, followed by an interview script. The guiding questions for the mothers sought to understand their perception of the children's self-care and, for the children and adolescents, to know the perceptions about self-care.

After the evaluation by the Pediatric Endocrinology outpatient team about the need for interventions with the children and adolescents assisted in the service, who mostly had a deficit in DM1 care, it was decided to use convergent care research. The care practice was initiated in the outpatient service where the patients were undergoing monitoring and it was continued at their homes.

The study was developed in two stages. The first one consisted in collecting data from the medical charts and the second was devoted to conducting home visits in which educational actions were developed. Home visits were made according to the availability of those involved, they lasted a mean of 2 hours and 15 minutes and nearly three meetings were held with each participant. Data collection was ended when no new information was reported, achieving the objective proposed.

In order to guide the research, the following guiding question was asked to the family members: “What does your child know about the DM1 care measures and how do you perceive their responsibility towards self-care?”; and the question for the children and adolescents was as follows: “Which self-care actions can you perform and how do you perceive your responsibility towards self-care of your disease?”.

Data analysis followed the stages proposed by Convergent Care Research (CCR), which are as follows: apprehension of all the information through readings and re-readings of the meetings and interviews; data coding; selection of the codes related to DM1 self-care; elaboration of categories; and interpretation of the findings[15].

The data analysis process generated three thematic categories: Self-care practices developed by mothers and children with DM1 and ability to recognize symptoms; Main differences between mothers and children regarding DM1 care; Mothers' perception of the transfer of children's responsibility and autonomy for self-care.

To present the study results, the participants were identified as S (Schoolchildren: from 8 to 11 years old), YA (Young Adolescents: from 12 to 15 years old) and A (Adolescents: from 16 to 18 years old), followed by the number that represented their age in ascending order, among the other participants of their age subgroup. The mothers were identified by the letter C (Caregiver), followed by the letter and number corresponding to their child. The study was developed in accordance with the guidelines regulated by Resolution No. 466/12 of the National Health Council, and approved by the Committee of Ethics in Research with Human Beings of the institution involved.

RESULTS

The study had 32 participants: 16 children and adolescents and their mothers. The age subcategories consisted of five schoolchildren aged between eight and 11 years old, nine young adolescents aged between 12 and 15 years old, and two adolescents aged between 16 and 18 years old. The mothers' mean age was 46 years old, with predominance of Incomplete Elementary School (n=6).

The participants' age at the time of diagnosis varied between two and 13 years old. The time since diagnosis varied between two and 11 years, being the mean value 4.9.

The data on the self-care activities, obtained according to the mothers' and children's perceptions, were organized to reflect the three categories emerging from the study.

Self-care practices developed by mothers and children with DM1 and ability to recognize symptoms

The DM1 self-care patterns presented by children and adolescents, in their respective age groups, were described in three forms of participation – Predominant Parental Participation (PPP); Shared Participation with the Child (SPC); and Self-Care Autonomy (SCA), as shown in Table 1.

TABLE 1: Age groups by age, time since diagnosis and self-care pattern. Maringá, PR, Brazil, 2017.

Age groups	TD (years)	Self-care pattern
Schoolchildren (8-11 years old)		
8 years 3 months old	3	SPC[‡]
8 years 4 months old	4	PPP[§]
8 years 9 months old	6	SPC[‡]
10 years 11 months old	2	SPC[‡]
11 years 4 months old	8	PPP[§]
Young Adolescents (12-15 years old)		
12 years 4 months old	2	SPC[‡]
12 years 5 months old	7	SPC[‡]
12 years 11 months old	5	SPC[‡]
13 years 8 months old	5	SPC[‡]
14 years 1 month old	3	SPC[‡]
14 years 2 months old	2	SPC[‡]
14 years 6 months old	3	SPC[‡]
14 years 6 months old	11	SPC[‡]
14 years 9 months old	6	SPC[‡]
Adolescents (16-19 years old)		
16 years 1 month old	3	SCA[‖]
18 years 1 month old	8	SCA[‖]

TD: Time since Diagnosis; [‡]: Shared Participation with the Child; [§]: Predominant Parenteral Participation; [‖]: Self-Care Autonomy.

In turn, Table 2 presents the competencies and readiness for the main self-care actions among the children and adolescents, by age group.

TABLE 2: Self-care actions, according to the pillars that comprise the DM1 care measures Maringá, PR, Brazil, 2017.

Self-care needs	**Self-care actions**		
	IP*	**SP†**	**NP‡**
Schoolchildren (8-11 years old)			
Glycemic self-monitoring	-	3	2
Food/Carbohydrate control	-	-	5
Insulin preparation/dose	-	-	5
Insulin application	-	2	3
Performance of physical activity	-	1	4
Young Adolescents (12-15 years old)			
Glycemic self-monitoring	4	5	-
Food/Carbohydrate control	3	3	3
Insulin preparation/dose	4	2	3
Insulin application	-	-	-
Performance of physical activity	3	-	6
Adolescents (16-19 years old)			
Glycemic self-monitoring	2	-	-
Food/Carbohydrate control	1	-	1
Insulin preparation/dose	2	-	-

*: Individual Performance; †: Shared Performance; ‡: Not Performed.

The schoolchildren were able to recognize at least two hypoglycemia symptoms, and most of them (n=3) were capable of correcting their glycemic level in these episodes. Two children failed to identify any of the hyperglycemia signs, and it was their mothers that implemented the due corrections.

> *I always have to do it well (blood glucose), otherwise it's dangerous that it goes down a lot and I faint, or that it goes up a lot and I don't know how to take the insulin. (S1)*
>
> *When it (blood glucose) is low, I feel something, I don't know, I think I get sweaty. Then I tell my mothers. (S5)*

As for the care actions, two mothers reported taking full care of their children's diabetes, while the others shared some actions, always supervised.

> *I do everything for him. He's still not interested in taking care of himself, he doesn't care, he doesn't want to learn. Despite the insulin, I wouldn't let him do it anyway, because the boy makes the wrong dose [...]. (CS2)*
>
> *As soon as she wakes up she comes to my bed with the devices and shows me the reading (blood glucose). Then I tell her how much insulin she needs. She prepares the pen and applies it. (CS3)*

As for food control, three mothers performed carbohydrate counts and the others followed the glycaemia correction schemes predefined by the physician. Physical activities were performed without previously controlling the glycaemia values.

> *At school, I explained everything well. She (child) makes the measurement at 10 o'clock, and they need to call me so that I tell them how much she should eat for lunch. (CS1)*
>
> *Before they measured his blood glucose before lunch at school, but now they don't, and then we'll only see again when he gets home. (CS2)*

Regarding the young adolescents, all of them were able to recognize a mean of two symptoms characteristic of hyper- and hypoglycemia. Most of them presented autonomy for the corrections in both situations (n=6).

> *It's already been 20-something twice (blood glucose). But I don't feel anything too strong. I just get dizzy, and I get shaky. (YA1)*
>
> *When there's hypoglycemia at dawn, I notice it and eat a fruit or honey. I don't even need to measure. But it's already reached 39 (blood glucose), and I felt nothing. (YA4)*

All the young adolescents performed the SMCG procedure, with a daily mean of five tests. However, some mothers reported performing the tests for their children at some times during the day, or supervise such action.

> *[...] I say, "Do the test so you can have lunch. My role is boring. Sometimes he says "Today I'm lazy, do it on me?". (CYA1)*

> *I do the test about three or four times a day. Sometimes I forget to do it. I only do the control before bed, if it's high (blood glucose) before dinner. (YA5)*

Insulin application was a self-care measure performed by the young adolescents; however, at some point of the day, all of them requested their mothers' help, in general, to apply it in places of the body that were difficult to access for them.

> *My mother talks to me at breakfast and lunch (via the cell phone), I tell her the blood glucose reading, and she tells me how much insulin I need. (YA2)*
>
> *She (daughter) takes charge of the insulin stuff. She prepares the pen, for example, but sometimes she asks: "How much do I need, Mom?" I think it's more to confirm. (CYA6)*

In relation diet control and carbohydrate count, although all the young adolescents had the autonomy to choose which food products they would eat, only a few (n=3) had autonomy to perform the carbohydrate count independently.

> *He asks every time about carbohydrates, he doesn't calculate and won't even look at the table, the way I leave it in the drawer, it stays. (CYA2)*
>
> *I do the carbohydrate count. I only need the cell phone [...] to calculate it. (YA4)*
>
> *I don't always do it. My mom does it more for me. (CYA5)*

Among the young adolescents, exercises, necessary to assist in glycemic control maintenance, were not performed in an adequate manner, only in physical education classes at school.

> *Physical exercises are also good, right? I tell her. At school there's only physical education, but it's only two days a week and she never wants to do it. (CYA6)*

The adolescents included in the study had total autonomy in self-care actions, performing the SMCG procedure, determining their own insulin doses, implementing blood glucose corrections, defining the application sites, planning their meals and performing the carbohydrate counts.

> *My parents haven't helped me with diabetes since I was diagnosed (3 years since diagnosis). I do everything alone. My dad cries when he sees me stinging, and my mom says she doesn't know. I've already told them that I think they needed to learn some care, because if something serious happens to me, like hypoglycemia, they won't know what to do. (A1)*

The adolescents showed the ability to recognize most of the hypo- and hyperglycemia symptoms, as well as to implement the glycemic corrections. For the adolescents, rotation in the insulin applications did not present a defined sequence and control of carbohydrates and performance of physical exercises were implemented by only one of them.

> *I always do everything (care actions), but some days I don't, I wake up and I don't feel like it. Some days I don't apply insulin. It sickens me to do it every day [...] (laughs). (A1)*

Despite understanding that self-care is important for maintaining the glycemic levels, some essential care measures were omitted, contributing to a less effective metabolic control. The participants were accompanied by their mother to all the medical consultations or, in special situations, by their father.

Main differences between mothers and children regarding DM1 care

Some conflicts in relation to the DM1 care measures were identified between the mothers and their children, in all age groups. For the group of schoolchildren, the main conflicts mentioned were lack of control over food (n=4), followed by difficulties with rotation of insulin application (n=3).

> *He doesn't take care of himself. The other day he had breakfast here at home and said that he ate some fruit there (at school). When he got home, he had 400 (blood glucose). (CS2)*

Among the young adolescents, the greatest divergence was in relation to omission of the SMCG procedure, especially in the periods when they were at school; however, all other care measures caused moments of tension, as they were neglected by most of the young individuals.

> *He doesn't control his blood glucose at school. At home, I have to remind him that 1 hour after he eats, he has to measure it. I have to remind him all the time, because he doesn't remember. (CYA2)*

Among the adolescents, only one of them presented family differences as a result of DM1 self-care failures.

> *He doesn't do the controls. If he does, he doesn't mark it on the map, he doesn't take the insulins every time. See how rebellious he is? He only does the controls to go to the doctor. (CA2)*

In this case, specifically, all the care measures were neglected by the adolescent at some point of the day, generating complete lack of control over the glycemic levels and, consequently, apprehension and conflict between mother and child.

Mothers' perception of the transfer of children's responsibility and autonomy for self-care

Self-care autonomy transfer was more frequent among children and young adolescents aged between 11 and 13 years old. In all age groups, the mothers highlighted SMCG as the first self-care measure implemented for their children.

> *I do everything carefully for him. If necessary, I think he even knows how to do it [...] But, you know? At his age, he doesn't want to do it. And also, I wouldn't let him do anything related to control, no way. (CS4)*
>
> *I've already tried to teach her, but she doesn't seem to understand, she doesn't seem to want to learn. I tell her that she also has to take care of herself. It can't just be just Mom. (CS5)*

Although young adolescents assumed DM1 self-care to some extent, according to the maternal perception, they did not have any initiative and autonomy to perform it in full. All the mothers attributed the high HbA1c levels to the children's neglect and irresponsibility in managing the disease.

> *Nothing has changed since we discovered the disease... He'd have to take responsibility. I do the monitoring, but it's his life. He's the one who'll suffer, and I can die tomorrow [...]. (CYA2)*
>
> *How can I let him take care of himself alone? His glycated (hemoglobin) is 12. That's why I have to keep reminding him. (CYA8)*

Among the adolescents and their mothers, the perception of self-care autonomy was complete. One of the mothers reported concern about the care actions performed by her child in controlling the glycemic levels and attributed the negative results of the tests to neglect in self-care.

The fact that the study was performed with a small sample induced limitations; however, it exposes important information about DM1 self-care actions in childhood and adolescence, for care autonomy through knowledge.

DISCUSSION

The difficulty maintaining the children's glycemic levels in the appropriate standards was a concern that permeated the mothers' reports. This concern is justified because HbA1c levels higher than those recommended for each age group increase the chances of chronic complications related to diabetes[16,17].

Assuming DM1 self-care in childhood is a necessity of any person affected by the disease. Care autonomy will be possible to the extent that the developmental stage of each individual is considered[18,19], as the competence for diabetes management is related to the skills that will be developed, in general, around 12 years of age[17].

Parents should start out preparing their children for the self-care transition during childhood and remain doing so throughout adolescence, so that it may occur naturally and safely[18].

As in previous findings[19-21], the young adolescents included in this study had autonomy for DM1 self-care. The study also pointed out to the young individuals' neglect in the face of essential care actions for glycemic control maintenance, as reported in a previous study, which highlighted that adolescents present less effective metabolic control than other age groups[17,22].

In all age groups, the main self-care action developed by children and adolescents was the SMCG procedure, corroborating with another study in which it was the control measure performed by most of the adolescents[23].

Insulin application and dose definition and carbohydrate counts were only performed by children and adolescents, and other actions were shared with the mothers. This maternal care with insulin preparation and application is justified, as this is a drug considered potentially dangerous, being among those that present an increased risk of causing significant harms due to failures in their use[24].

90% of the participants revealed conflicts between children/adolescents and their family members were revealed in the current study. In all age groups, the divergences were generated due to the difficulty adhering to the treatment and in being able to maintain glycemic control and the HbA1c levels within the goals. The divergences are related in a higher number to less effective metabolic control for adolescents than for other age groups[17,25].

Conflicts between mothers and younger children were generally related to food control, mainly during the periods when they were at school and, in the case of the adolescents, they were due to decrease in authority over the child to maintain adherence and prevent glycemic control deterioration. Adolescence is considered a troubled phase, where young individuals can develop risk behaviors, the sense of identity is strengthened and the adolescents suffer direct interference from their peers and are often influenced by them, at which time parents lose control over their care[12].

Balance of the actions aimed at transferring self-care to children and adolescents with DM1 is necessary, as the parents' excessive demand can lead young people to less adherence to care, as a form of protest or rebellion. On the other hand, overprotection can impose limitations on actions towards independence, making young people with DM1 to be less competent to assume responsibility for their own health[17,26].

For the care responsibility transfer to occur, children must learn the basics about DM1 management, and it is equally important that the parents remain involved in diabetes control, preparing their children for self-care in adolescence[18-20,27].

As adolescence progresses, individuals become more vulnerable, sometimes leading to lapses in health care and glycemic control deterioration[19-20]. Therefore, self-care should be a continuous process, and self-care transfer will only be successful when both the individual and the family are able to implement it[18-20,27].

Study limitations

The fact that the study was conducted with a small sample induced limitations; however, it exposes important information about DM1 self-care actions in childhood and adolescence, for care autonomy through knowledge.

CONCLUSION

Most of the children's mothers reported assisting in everyday DM1 care, allowing some self-care. Although they recognized their self-care ability in some actions, the young adolescents reported more confidence if supervised by their mothers. Regarding the adolescents, they showed autonomy for all the care measures.

In all age groups, most of the mothers did not feel safe in delegating total autonomy to their children due to recurrence of carelessness and lack of commitment, which would guarantee them adequate care. Although the self-care autonomy transfer was present in some way in the actions of most of the mothers, complete self-care only occurred among adolescents over 15 years of age.

In view of the increase in DM1 diagnoses among children and adolescents and the difficulty maintaining care in this life phase, developing research studies for this specific population segment is justified, which should receive special attention from nurses, in the search for the maintenance of continuous care and through diabetes education, seeking to provide better quality of health throughout life, stimulating public policies that subsidize development of these actions.

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