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Emotional Challenges of a Parent Caring for a Type 1 Diabetes Mellitus Child

Constanta URZEALA^{1*}, Roxana BEJAN-MURESAN²

Abstract

The purpose of this research work is to emphasize the emotional challenges of a parent caring for a type 1 diabetes mellitus child. We used different research methods such as: biographic study, observation, case study. The interview was taken to a parent, a 37 years old mother of a girl who was diagnosed 10 years ago. The parent is the primary caretaker of the child. She works in an economic field and she is representing of The Association Help for Diabetes from Bucharest. The interview was a structured one, and had four directions: everyday routine, social challenges, emotional challenges, other important aspects identify by the interviewee. The research work was conducted between August-October 2017 and the work reflected that the parent caring for a child with type 1 diabetes feels a lot of pressure in managing the medical treatment and her working day is influenced by the time table of the glycolic check and insulin administration. The emotional charge of the parent is related to the future of the child, child's responsible towards her treatment administration and social acceptance. The interviewee needs are related to limited medical information about paediatric diabetes, the role of the telemedicine, and the lack of support from the public health system.

Keywords: *Paediatric diabetes, parent, emotions.*

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1. Introduction

Statistics shows that Europe has one of the highest incidence rates of type 1 diabetes mellitus (T1DM) in children, with an estimated 21,600 new cases per year. World Health Organization data about the incidence of this disease, for the next decade, are alarming, expecting to be doubled the number of T1DM patients until 2020 [13]. The most rapid increase is registering in the very young and those with moderate genetic susceptibility, but the mechanisms of the major determinants remain elusive [12]. Despite advances in the treatment of T1DM, this chronic metabolic disorder represents a major burden, both for children and their families [3].

2. Problem Statement

The management of the glycaemia oscillations in children differs from adults' diabetes manifestations due to specific characteristics of each developmental stage, fact that influences the standards of care for these individuals. In order to diminish the risks of diabetes complications, educational demarche for the entire family unit are necessary, until the child grows and develops self-care and functional independency [9].

The most feared "enemy" for the T1DM patient is hypoglycaemia. Hypoglycaemia may result in a variety of signs and symptoms depending on the severity of decreased glycaemia value, starting with feeling hungry, headaches, difficulties with concentration and speech, blurred vision, dizziness and culminating, if not recognised or timely approached, with confusion, loss of consciousness, seizures or death [2]. Nocturnal hypoglycaemia is recognized as one of factors responsible of the "Dead in bed" syndrome [9], respectively sudden nocturnal death that accounts for 5%-6% of all deaths among young people with T1DM. Any hypoglycaemia episode diminishes the psychological well-being and quality of life, knowing that repeating hypoglycaemic events generate powerlessness, anxiety, irritability, depression, limitations in mobility and daily activities for the patients and their families [1]. In case of repeated hyperglycaemia values, the patient finds himself in long-term complications risks, such as macro and micro vascular, retinal, renal, and peripheral neural disorders [4]. Playing, running, jumping, cycling, physical exercising are just some of the most common child's activities that can lead to hypoglycaemia, by dropping the glycaemia values during physical effort and several hours after. Too often, avoiding hypoglycaemia is directly linked to hyperglycaemia, because of

overprotection and anxiety. The insulin therapy and diet must be always correlated with the child's activities and effort energy consumption.

- For a balanced diabetes, the entire family must change its lifestyle, putting in centre the T1DM child's needs and activities. Thus, it becomes the adults' responsibility to respect the insulin therapy, the diet and the physical activities. Even if the complex treatment of T1DM is precisely followed, the emotional charge of this chronic disorder may psychologically affect children development. Specialists draw attention over the fact that some psychological and social conditions disturb the glycaemia control and leads to poor self-management [11]. Statistics demonstrate that T1DM adolescents are facing the challenge of developing psychiatric (10–20%) or eating disorders (8–30%), as well as substance abuse (25–50%) [7]. Knowing the major role of the family in the child's development and evolution, it becomes easy to identify the psychological pressure felt by the parents in avoiding any diabetic complications, any psychological disturbances, any social issue that might trigger more sufferance and pain. The families have an important role in managing the kids' treatment for diabetes that is why the life-regime of the families is drastically changed and their weekly schedules become more demanding, and they need to be more organized. Simultaneously with the diabetic control, the parents must be an active part of the diabetes care team, despite the feelings of guilt, frustration, helplessness in dealing with their child's chronic disease. One can notice that emotions are the driving force behind the activities and they create the energy that sustains the activity [6]. The T1DM child's future development, passing through puberty, teen aging, youth, adulthood, may generate parent's anxiety and overprotection. This is the reason why the parents' emotional charge must be controlled, so that the child can develop an adequate diabetes self-management.

3. Research Questions/Aims of the research

We conducted a case study which aim is to emphasize the emotional charge felt by a parent caring for a T1DM.

4. Research Methods

The research was developed in Bucharest, during August – October 2017. The study is based on interviewing one parent, a female aged 37 years old, active from the professional point of view in economics, caring for a T1DM 10 years old girl. The adult is challenging his child's disease for

5 years, being the beneficiary of the modern telemedicine devices, as follows: CGMS, since February 2017 and wireless insulin pump, since August 2017. The family is part of a larger interdisciplinary intervention, conducted by the medical doctor taking care of the child, receiving advocacy on diabetes care, nutrition and psychological challenges, physical activities programme, social interaction demarches.

As research methods, there were used: observation, the interview method, case study.

The questions of the interview focused on the emotional charge of the parent caring for a T1DM child, starting from the diabetes diagnosing. It was applied a semi-structured interview, with open questions, focused on four main thematic axes: life regime, social issues, emotional difficulties, specific diabetes needs. The data were collected in the frame of Counselling Centre from UNEFS (CCOC), being at first recorded and then analyzed.

Taking into account the particularities of each T1DM child and his own family environment, there was applied the case study as research method, in order to underline one specific emotional tableau of the challenges triggered by this disorder. Future similar case studies are taken into account for an extended analysis on this topic.

Due to the fact that paediatric diabetes mellitus is less studied in the field of physical education and sport, the present study brings added value for the specialists involved in the educational process addressed to T1DM children. Understanding the emotional challenges of the parent is helpful for providing physical activities programs that correspond to the needs of the child and, in the same time, that diminish the adult's fears regarding the risks of glycaemia oscillations during physical effort. The role of the family is essential for the diabetes management [8], this study underlining the emotional balance of the adults in providing the complex treatment for the T1DM child.

5. Findings

5.1. Structure

- Regarding the first direction of the interview, the life regime, the parent faces different issues and challenges after the diagnosis of the child.

One of the main problems is related to the delay in diagnosis. The diagnosis of this child is delayed because there is only one hospital in Bucharest that can establish this type of paediatric diabetes. The family tries to find out what was wrong with the girl in two other hospitals before that.

This delay in diagnosis creates uncertainty for the family and the parents decide to ask for a second opinion in Vienna where the T1DM is confirmed. The Romanian state medical system has very poor resources and all the South counties rely on the Marie Curie Hospital in Bucharest, this makes very hard to create a proper data base with these T1DM patients and a proper therapy for them. It is very difficult for the families with different socio-economic backgrounds to provide a therapeutic strategy for their children.

The treatment of the T1DM child is customized based on insulin injections, diet, and physical activity. Even if the foreigner specialists advise the family to use an insulin pump since the beginning and a Continuing Glucose Monitoring System (CGMS), the Romanian specialist recommends waiting for a while until they could change the insulin therapy. After four years of therapy based on injections and classical blood check of the glucose level, the girl gets the telemedicine devices. On the other hand, the costs of the telemedicine devices are very high and some families cannot afford the costs. In other European countries the CGMS are offered to the patients by the State Health System, as standard of care, while in Romania these devices cannot be even purchased by the families but by the Clinic and the attending physician who supervises the treatment and the diabetes management of the children. The insulin pump involves other strategies for the families. The Romanian State Health System offers to the patients a wired insulin pump according to their procedure and applications that can last more than one year. On the International market there are modern wireless insulin pump that offers a better comfort for the patient and a better insulin dosage. In Romania, there are so few specialists in paediatric diabetes and modern medical technologies that can educate the primary and secondary care-givers for the right use of the wireless insulin pump and that can help relieve the families for the burden of this chronic disease.

In our case study, the family benefits from the powerful involvement of the physician who monitors the glycaemia oscillations 24h/24h.

The diet represents a challenge both for parent and child. The mother, who is the primary care-giver has the responsibility in weighing the amount of food and calculating the values of carbohydrates. The mother feels the pressure from the child who wants to eat certain foods in the wrong moments. The child is focused more on the wants than on the needs. From this dynamic the relationship between parent and child needs to find a balance, the parent offers and restricts in the same time so that the child do not feel only frustration.

The physical activity is important in the diabetes therapy; the parent is willing to involve the child in different sports, such as swimming, martial arts and dance. The child does not prove a real interest in exercising and finds different reasons for not participating.

- The second direction of the interview is related to the social issues. From this point of view the mother claims that the Romanian State doesn't have a support network system of care for the families with children with type 1 diabetes. Each family needs to create a network for themselves and looks for the support in different directions: medical and social. This family finds resources inside the Support for Diabetes Association where they join a group of parents and children motivated to fight the system and raise their quality of life through balanced diabetes. This group has initiatives and organizes events as workshops, info-sessions, parties, camps and trips for T1DM children.

On the other hand, in this case study the school is an understanding environment, supporting the therapy strategy. The medical staff changes their schedule so that they can take care of the girl's medical needs, and intervene in case of emergency. The primary teacher sets her limits in taking care of the girl, but she has a positive attitude towards her problem so the rest of the children and their parents do the same. The school mates learn the sounds of her insulin pump and when the level is too low they offer her different snacks, so she feels a little bit spoiled, and special in the same time, enjoying a lot of attention. From the interview dialogue results other situations where children need to change schools because of the lack of the school community support. The mother is aware of these situations and appreciates the attitude towards her daughter.

- Related to the emotional issues, the most difficult time is considered to be the moment of the beginning of the diet/ regime, when the child started to feel the restrictions and the frustrations in getting what she wants. The parent has to say no, and this refusal makes the mom feel very bad and guilty not providing the small pleasures of her child. As a response to the diet limits, the child starts to ask for the food that she doesn't normally consume, like juice, for example.

The child is allowed to participate to her friends parties and the mother feels joy for all the social interactions the girl has, on the other hand she feels worried about the child's desire to drink lots of juice and eat sweets, despite the glycaemia values. She feels that she cannot handle properly the situation. The mother encourages her to take part in different social events.

For the mother it is a difficult moment when she understands the fear of the paternal grandparents that used to take care of the girl over the weekends. Before the diagnosis, she used to spend the weekends over their house; after the diagnosis the grandparents feel a lot of fear and confusion and they refuse to let the girl to stay overnight. So the relationship with their niece starts to change, and for the mother it is emotional hard to witness the *rejection*, in a certain way.

The parent, the interviewee, blocks her emotions about the period of the diagnosis; and her effort is overcome by all the challenges related to the new life regime, the management of the crisis, and by the building of a supportive network for the child at school. The successful social integration is so important and the mother emphasizes the success as an expression of joy for her daughter's functional autonomy. So, in the interview we find out more about the successful actions and less about emotional challenges.

As a symptom of burn out, the mom says that she is less sensitive about the physical discomfort that other people claim at work. She doesn't make a secret about her daughter's health problem and she tries in a harsh way to keep the issues separated: work from personal life. On the other hand she doesn't trust that the people can truly empathize with her. We can understand an emotional disconnection from the group support. She thinks that only the parents living a similar life experience can truly understand her. Even so she keeps in contact with the old friends and the girl passes time with the family friends.

The girl depends on the mother and on her therapeutic supervision and advices. This situation is new for them and creates a change in their mother-daughter relationship. They spend a lot of time together going to the movies, visiting museums and going to the shopping. This tight relationship offers and generates a state of security for both of them but in the same time reinforces the emotional dependency.

The mother is over anxious about the younger son's health and she gets so scared when the child asks for water so that she decides to do some special blood exams for diabetes. The exams are meant to calm her down, more than to clarify a health uncertainty of her boy. The need for the control is so high and the medical exams of the younger son have an emotional meaning for the mother and the role to decrease her anxiety as she starts losing control over the holiday family time. She looks for a medical certainty, and the fear creates strong projections over the baby boy. So she acts trying to control the reality of everyday life; ideally she would like a treatment for the disease that she could better control the effects.

- The needs claimed by the parent are linked to the lack of information about the paediatric diabetes, the telemedicine devices and the

developmental problems during the life span and the changes brought by the puberty and adolescence.

Often the parents feel anxious about the effects of the life span development linked to the diabetes but they prefer to postpone the search for information, future solutions and predictions. Living day by day with the present challenges limits their perspective and future certainty. Right now they rely on modern medicine devices, but their future heads to artificial pancreas.

6. Discussions

There are few key elements that influence dramatically the children's development and their behaviour such as: balanced family life, the life principles adopted by the family, communication and team-work among the family members, emotional approach of the children, the amount of time spent with the children [14].

Our case study reveals a good practice example regarding the responsibility of the treatment from the family, the communication between mother and daughter, the guidance of the T1DM child towards functional autonomy and social integration. It is remarkable that the family doesn't hide the child diagnosis and do not isolate in group of people taking care of children with health related problems.

The families that have T1DM children face frequently tensions, conflicts, communication issues, and difficulties in assuming crucial roles in dealing with problematic medical situations [5].

The interviewee has a pretty good situation at home and at work. The family manages well their everyday challenges, tensions, and has good economic, social and emotional resources for taking care of the child with T1DM.

Regardless of the source of care, all providers caring for children with diabetes should understand the normal stages of childhood and adolescent development and how they affect diabetes management. Every child newly diagnosed with type 1 diabetes should be evaluated by a diabetes team (consisting of a paediatric endocrinologist, a nurse educator, a diet educator, and a mental health professional) qualified to provide up to date paediatric specific education and support [10].

The children and the parents need a good support from a professional team and this network should be build by the State Health System for every T1DM patient and for every family, no matter where are

they from. The network should provide educational tools regarding insulin therapy, diet, physical activity, psychological counselling and social support.

7. Conclusions

The parent of a T1DM child deals with an emotional charge as a consequence of the implications of the chronic disease fearing the unknown and the uncertainty of the limits of the specialists, telemedicine devices or drugs in therapy or crisis.

The parents rely on the telemedicine devices for the hyperglycaemia and hypoglycaemia values that can put in danger the child. The use of these tools brings a sense of comfort for the entire family during all children's activities, especially when the parent is away.

The feeling of guilt is replaced when the parent gets used to the new life regime and child's responses to the therapy, by the fear of not being a good parent. He is the one that chooses for the child's best interest the educational demarches, social environment and extra-curricular activities.

We underline the need of counselling for the primary and secondary care-givers that have to sustain and to handle the management of paediatric diabetes while they have their own emotional charge that can influence their behaviour and decision process regarding the child's activities.

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References

- [1] Alvarez-Guisasola F, Yin D. D., Nocea G., Qiu Y. Mavros P. Association of hypoglycemic symptoms with patients' rating of their health-related quality of life state: A cross sectional study. *Health Qual Life Outcomes*. 2010 (8). p. 86
- [2] Desrocher M & Rovet J. Neurocognitive correlates of type 1 diabetes mellitus in childhood. *Neuropsychol Dev Cogn Sect Child Neuropsychol*. 2004(10)-pp. 36-52
- [3] Diane K. Wherrett, Chiang, J. L., Delamater, A. M., DiMeglio, L. A., Gitelman, S. E., Gottlieb, P. A., Herold, K. C., Lovell, D. J., Orchard, T. J., Ryan, C. M., Schatz D. A., Wandler D.S., Greenbaum C. J. Defining Pathways

- for Development of Disease-Modifying Therapies in Children With Type 1 Diabetes: A Consensus Report In *Diabetes Care*. 2015. 38(10). pp. 1975-1985
- [4] ***. Early Prevention of Diabetes Complications in People with Hyperglycaemia in Europe” project (ePREDICE) Available at: <http://www.epredice.eu/en/the-project>, Accessed on 3 November 2017
- [5] Eckshtain D., Ellis D. A., Kolmodin K., & Naar-King S. The effects of parental depression and parenting practices on depressive symptoms and metabolic control in urban youth with insulin dependent diabetes. *Journal of Pediatric Psychology*. 2010(35). pp. 426–435
- [6] Golu M. Fundamentele psihologiei. Vol. I. București: Ed. Fundatiei, Romania de maine. 2007. pp. 656-657
- [7] Kakleas K., Kandyla B., Karayianni C., Karavanaki K. Psychosocial problems in adolescents with type 1 diabetes mellitus. In *Diabetes Metab*. 2009. 35(5). pp. 339-350
- [8] Sandu A., Necula R., Frunza A., Unguru E., Damian S. A qualitative inquiry in the social construction of chronic illness. Case study on diabetes mellitus. Doctors’ perspectives. *Archiv Euromedica*. 2017. 7(2). pp. 18-23
- [9] Secrest A. M., Becker D. J., Kelsey S. F., Laporte R. E., & Orchard T. J. Characterizing sudden death and dead-in-bed syndrome in Type 1 diabetes: analysis from two childhood-onset Type 1 diabetes registries. *Diabet Med*. 2011. 28(3). pp. 293-300
- [10] Silverstein J., Lingersmith G. K., Copelad, K., Plotnick L., Aufman, F. K., Laffel L., Deeb, L., Grey, M., Anderson, B., Holzmeister, L.A., & Clark, N. Care of Children and Adolescents With Type 1 Diabetes. A statement of the American Diabetes Association. In *DIABETES CARE*. 2005. 28(1)
- [11] Stahl A., Straßburger K., Lange K., Bächle C., Holl R. W., & Gianì G., Rosenbauer J. Health-Related Quality of Life Among German Youths With Early-Onset and Long-Duration Type 1 Diabetes. In *Diabetes Care*. 2012. 35(8). pp. 1736-1742
- [12] Vehik K. & Dabelea D. The changing epidemiology of type 1 diabetes: why is it going through the roof? *Diabetes Metab Res Rev*. 2011 (27). pp. 3–13
- [13] WHO. 2017. Available at: <http://www.euro.who.int/en/health-topics/noncommunicable-diseases/diabetes/data-and-statistics> Accessed on: 3 November 2017
- [14] Zus B. Afectivitatea la varsta scolara mica. 2014. Retrieved at: <https://www.monitorulsv.ro/Meseria-de-parinte/2014-01-14/Afectivitatea-la-varsta-scolara-mica> , Accessed on May 13, 2016