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Original article

STUDY REGARDING THE SOCIAL DIFFICULTIES FELT BY THE FAMILY OF THE CHILD WITH TYPE 1 DIABETES MELLITUS

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Abstract

Aim. This paper is made and published under the aegis of the National University of Physical Education and Sports as a partner of program co-funded by the European Union within the Operational Sectoral Program for Human Resources Development through the project for Pluri- and interdisciplinary in doctoral and post-doctoral program Project Code: POSDRU/159/1.5/S/141086, its main beneficiary being the Research Institute for Quality of Life, Romanian Academy. Our contribution to the development of this project is concretized in a research focused on the positive influence of a complex intervention strategy designed for the child with diabetes. The aim of this paper is to identify the difficulties encountered, at the social level, by the parents of the child with diabetes, whose responsibility involves not only the good management of this disease, but also the minor child's functional independence and social integration.

Methods. As research methods, we used: bibliographic study, observation, the survey method and statistics. The research took place between October and December 2014, within the UNEFS, in cooperation with the DiabNutriMed Clinic of Diabetes. The sample included 11 adults (aged 35 to 45 years), representatives of families taking care of children with diabetes. A questionnaire has been created, with a focus on: the child's functional independence, his/her social integration and the support granted by the system.

Results have highlighted that the difficulties encountered at the social level are related to the strict compliance with the diet and treatment, the social services and the population's level of information. The social impact felt by the parents amplifies the severity of the disease and makes it difficult to care for the child with diabetes.

Conclusion. The impact, at the social level, felt as a result of the interaction between persons with health problems and without health problems can be diminished by increasing the actions intended to inform and educate the population, which leads to an intensification of the empathy, emotional resonance and social cognition processes, reflected in the social cohesion.

Key words: juvenile diabetes, family, social integration.

Introduction

This research is part of a wider scientific approach within the POSDRU/159/1.5/S/141086 project, through which we aim to increase the efficiency of the interdisciplinary intervention on persons with diabetes.

If in our previous research we emphasized the role of physical exercise as a component element of the juvenile diabetes treatment and as a stimulating factor for the motor and psychomotor development of the child, this paper is an approach through which our interdisciplinary intervention goes further, at the level of social sphere.

The increased incidence of type 1 diabetes mellitus at small ages determines the specialists in different fields to be permanently concerned with both the treatment in itself and the social integration difficulties that might be encountered by the children and, implicitly, their families. The family can be considered a springboard for launching the child in a community, metaphorically speaking, and is an essential factor for the growth and

development of the individual, as an adapted member of the society he/she lives in. The family represents an environment propitious to learning the rational and affective behaviours, the cohabitation and cooperation requirements, as well as the ways of solving the different problems which arise during the interactions with the surrounding environment, the members of society or problems of the individual with himself/herself (Mitrache, Bejan, 2011). As a social instance, the family responds for and prepares the child to cope with the different needs involved by the socialization phenomenon, which Neculau (2005) divides in three main categories: need for communication, need for control and need for affection.

The specialists remind that, currently, there is a tendency to redistribute the socializing function of the family to other institutions with a formative role, such as the kindergarten, school, sports clubs etc., with which the child has an interaction extended over the duration of a day (Mitrache, Bejan, 2011). In the case of the child with diabetes,

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this phenomenon should not occur, because his/her medical care necessitates an increased interest of the parents, which does not suppose that they must become hyper-protective, but to keep the proportion with the severity of the disease and the risks to which the child is exposed. To properly manage the diabetes and to maintain it within the limits indicated by the attending physician, so that the complications can be avoided, the family should have a corresponding attitude, a positive, combative one, and should be involved in the entire process of diabetologic care, starting from the strict compliance with the treatment scheme, the meal and snack taking and up to directing the child towards the practice of motor activities. Besides these aspects, the parent must find the most appropriate answers when the child starts perceiving that he/she is different from the others and asks why other children are allowed to eat anything, anytime, without weighing the food, or why they are allowed sometimes to play more (Bogdan, 2011).

Cosmovici (1996) mentions that the family and friends connexions influence the emotional balance of the person, knowing different situations in which unhealthy relationships between family members are negatively reflected over the social behaviour of the child.

Familial dysfunctions, in the case of the child with diabetes, may be generated by both the treatment complexity and the modification of the personal lifestyle, as well as by the impact on the social plane, at the level of the group of friends, school group, community group etc., of the new life situations in which all the family members are together.

The anchoring of the adults who are in such a situation to the social environment they were part of before the onset of disease and the establishment of diagnosis depends on their capacity to care for the minor child, capacity to cope with new stressors, power to mobilize all the inner resources, but also on their capacity to continue exerting the social aptitudes. To the same extent, the community members' receptiveness to the different social condition of some individuals may restrict the inter human interactions of the families who take care of a child with health problems.

The management of this situation by the family is influenced by the quality and accessibility of the diabetologic care services, which must be analyzed similarly to any other medical care system based on the complex interaction of three factors: patient, provider and organizational system. The patient-related aspects derive from his/her financial possibilities, level of knowledge and information, opportunities to access the specialty literature, attitude towards the prevention and treatment of different diseases. At the same time, the providers of medical services are in close relationship with the national organizational system (Harris, Furler, Mercer, Willems, 2011).

It is considered that the main characteristics of health care services delivered to the population, depending on the national health system, are the following: availability, affordability, accommodation, appropriateness, acceptability. Taking as a benchmark these 5 A's commonly used in the specialty literature (Penchansky and Thomas, 1981), we present figure 1, which highlights the potential stressors that act simultaneously on the family who cares for a child with type 1 diabetes mellitus.

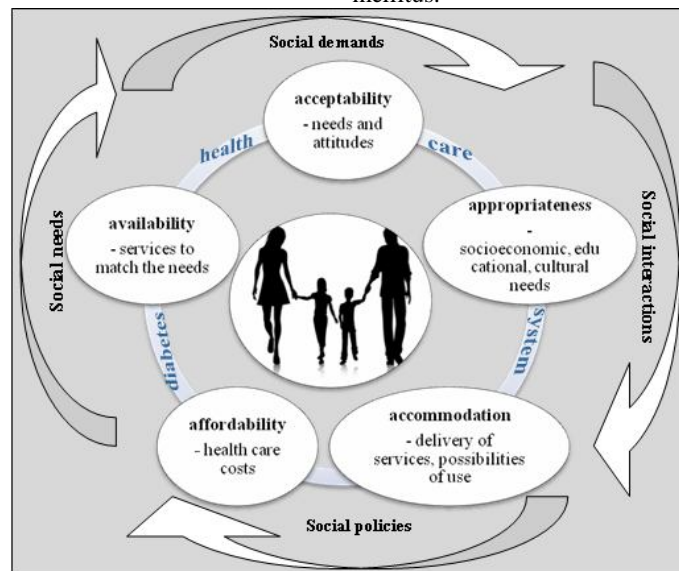


Fig. 1. The interplay between family, diabetes health care system and the social environment



In this context, we consider it opportune to bring up the concept of “social intelligence”, which is presented by Goleman (2007) as a wide-range phrase structured on two directions: social awareness and social ease of a person. Social awareness refers to observing and understanding the others’ inner state triggered by some difficult situations they have to face, at the social level. Social ease is subsequent to social awareness and is concretized in the development of inter human relationships corresponding to the needs of individuals who interrelate. Therefore, the empathy, emotional resonance, social cognition processes generate synchrony, preoccupation, influence and model the self-image. Within the family that includes a child with diabetes, there is a need for the manifestation of social intelligence in a bivalent sense, both from this one towards the members of social groups to which it wants to belong and conversely.

However, the specialty literature draws attention that generally, in today’s society, affective resonance, empathy, the concern for the others’ wellbeing and the initiative to create inter human relationships have diminished considerably, allowing free way to the acerbic struggle for accomplishing the personal needs and interests. We mention that one of the conditions favorable to the diminution of stressors which act, from the social point of view, on the family of the child with diabetes, consists in well informing and educating the members of society, so that they accept and integrate the persons in difficulty.

Against this background, it is imperative that the steps undertaken by the authorities towards supporting the families who take care of a child with an autoimmune disease become much more visible. We refer here to the necessity of increasing the human, material and informational resources, as well as to the diversification of services for juvenile diabetes (medical services, family counseling, psychological counseling, parental counseling, nutritional counseling, counselling about the practice of physical exercises etc.).

Thus, the purpose of this research is to identify the difficulties encountered, at the social level, by the parents of the child with diabetes, whose responsibility involves not only the good management of this disease, but also the minor child’s functional independence and social integration.

Methods

As **research methods**, we used: bibliographic study, observation, the survey method (Epuran, 2005) and mathematical and statistical processing methods.

Organization of the research

The research took place between October and December 2014, in Bucharest, within the UNEFS, in cooperation with the DiabNutriMed Clinic of Diabetes. The sample included 11 representatives of some families taking care of children with type 1 diabetes mellitus. The group was made up of adults aged 35 to 45 years, 9 mothers and 2 fathers, who participated on a weekly basis in the counseling activities provided within the project. Initially, they were subjected to a questionnaire-based survey. The questionnaire had 19 items grouped on three main directions of investigation: the child’s functional independence, his/her social integration and the support granted by the decision-makers. Respondents were asked to express their own perceptions related to different situational contexts in which their children with diabetes found themselves.

Results

Responses to the items of the questionnaire were statistically processed, but in the following lines we present only those parameters deemed to be relevant for this research.

Respondents belong to families counting between 3 and 5 members and supporting the care of the child with diabetes within the limits of an average monthly income exceeding 4501 lei in 57% of the cases, between 3501 and 4000 lei for 29% of the families, while 14% handle it with 2501-3000 lei for all the expenses. We make the specification that the children with diabetes from these families use, in a proportion of 70%, the DexCom Platinum continuous glucose monitoring system (CGMS), and 3 of them have an insulin pump, these devices requiring additional financial efforts.

With reference to the complex treatment of diabetes, based on the triad: insulin – diet – physical effort, it has been revealed that the families respect the intervention scheme proposed by the diabetologist, the children recording no extreme glycemic excursions in the past 6 months. It has been found that no child is medically exempt from physical education classes, all of them participating regularly in this formative motor activity within the mass education, and 71% of them are also engaged in leisure motor activities (basketball, swimming).

Recognition of the benefits brought by physical exercises to the development of the child with diabetes has highlighted an increased interest of the parents in getting the children involved in physical exercise programmes, without considering that their disease would be an impediment.

The most important benefits that have been reported are the following: harmonious physical development 33%, improved immune system 27%,

increased functional independence 13%, motor capacity development 13%, inter human relationships 7%, sense of belonging to a group 7%.

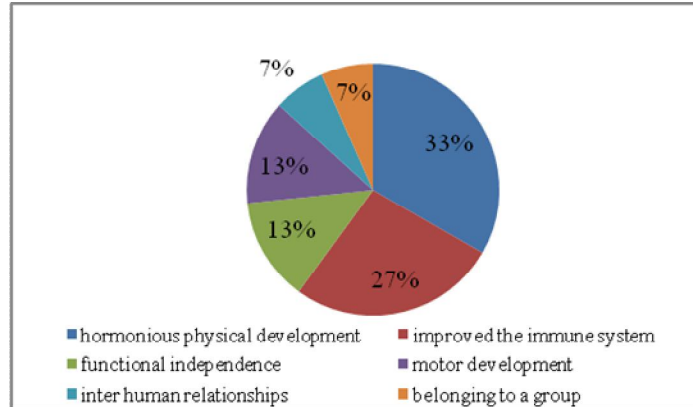


Figure 1. Graphical representation of the responses concerning the most important benefits of physical exercise practicing by the child with diabetes

Among the extracurricular activities which demonstrate the functional independence of children with diabetes, the surveyed parents have asserted that, in a proportion of 100%, the kids do not make friends only with individuals suffering from the same disease, but they feel at ease in any group of children with whom they interact. Analyzing the activities that the children are not allowed to perform without being monitored by their parents, it has resulted that, in a proportion of 100%, these ones do not spend the night at a friend's home and do not go to a trip or a camp in the absence of their own parents.

As regards the glucose measurement performed by the child using the blood drop, results have shown that 14% of the children do this permanently, 14% very often, 43% frequently and 29% occasionally (fig. 2). Beyond these percentage values, the parent intervenes to use the finger pricks.

Administration of the own insulin dose is achieved permanently in the case of 17% of the children, frequently for 33%, very often for 17%, occasionally for 17% and never for 16%. Beyond these values, the parent is responsible for the injectable treatment, until the child gets the habit to self-inject (fig. 3).

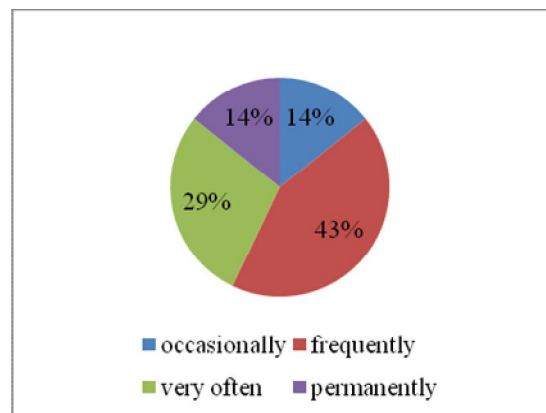


Figure 2. Graphical representation of the extent to which the children measure their glucose level using the blood drop

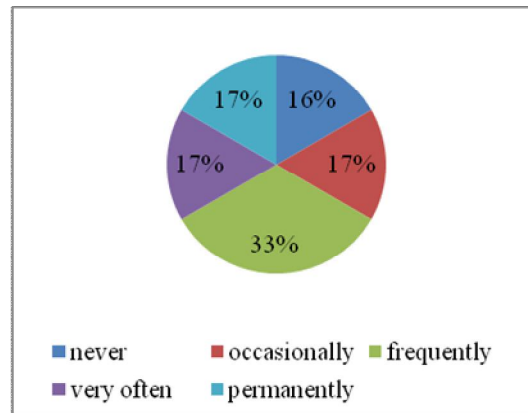


Figure 3. Graphical representation of the extent to which the children self-administer the insulin

The interviewed parents declare that the children are able to self-recognize the signs of hypoglycaemia and hyperglycemia, in different percentages, thus: occasionally 14%, frequently 29%, very often 29%, permanently 14% (fig. 4). Depending on the symptoms of hypoglycaemia they feel and identify, the children have a different

capacity to make their own choices of the most suitable food. 14% of the children do not manifest this capacity, 29% only occasionally, 29% frequently, 14% very often, 1% permanently (fig. 5).

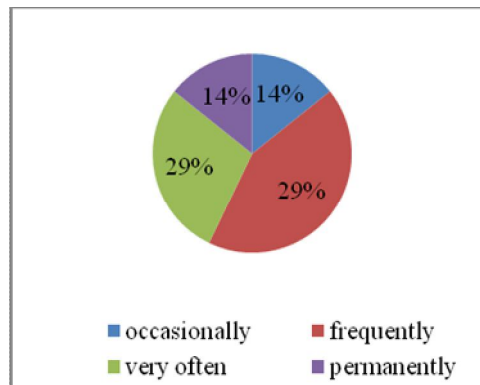


Fig.4. Graph for the responses regarding self- recognition of hyperglycemia and hypoglycemia

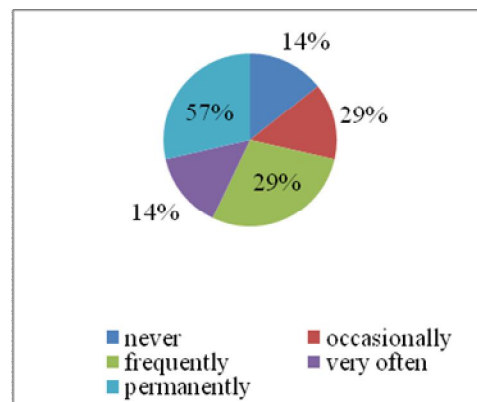


Fig. 5. Graph for the responses regarding the own choices of food suitable for hypoglycemia

Neither the parents nor the children hide the health problem they are confronted with, but the adults prefer to interact, in a proportion of 100%, with other families whose child has the same disease.

Respondents said that they were sporadically in social situations in which the other parents showed

an attitude of rejection or isolation, respectively to a small extent 29% and not at all 71% (fig. 6).

On the other hand, their children were rarely in different social contexts in which they encountered attitudes of reticence, rejection or chicaning manifested by the other children (fig. 7).

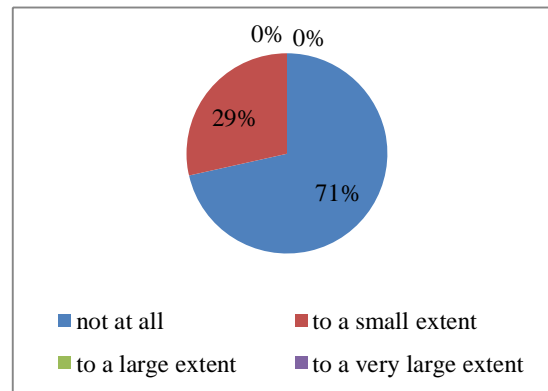


Fig. 6. Percentage to which the parents encountered attitudes of rejection or isolation manifested by the others

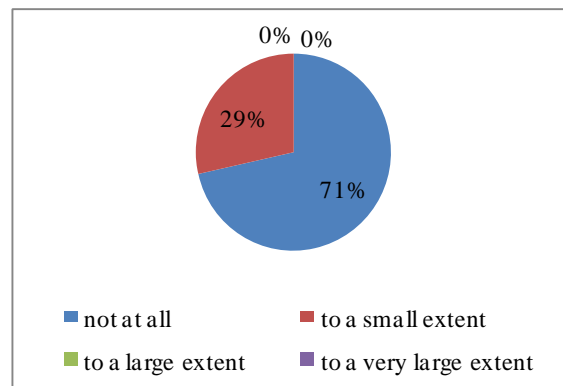


Fig. 7. Percentage to which the children encountered attitudes of rejection or chicaning manifested by the others

Among the factors that exert a great pressure on the parent who takes care of the child with diabetes, the following have been mentioned: the danger of a severe hypoglycemia, their permanent state of alert related to the glucose values, their own psychic resources, the military lifestyle derived from the strict compliance with the treatment, the society's lack of interest in the persons from this category.

The parents declare that they have felt to a very large extent (57%) the need for having more sources of information about the care of the child with diabetes (fig. 8) and that they have encountered numerous shortages in the system which delivers social and health services (fig. 9).

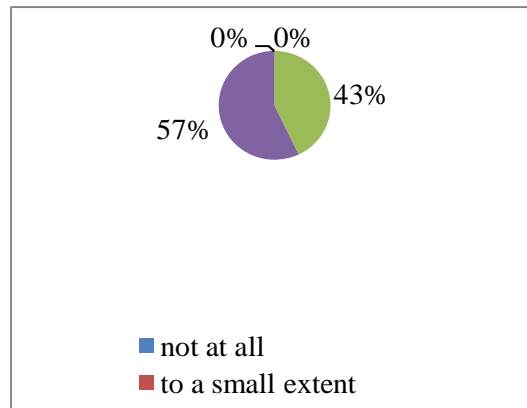


Fig. Graph for the responses regarding the difficulties encountered because of the insufficient sources of information made available to the parents

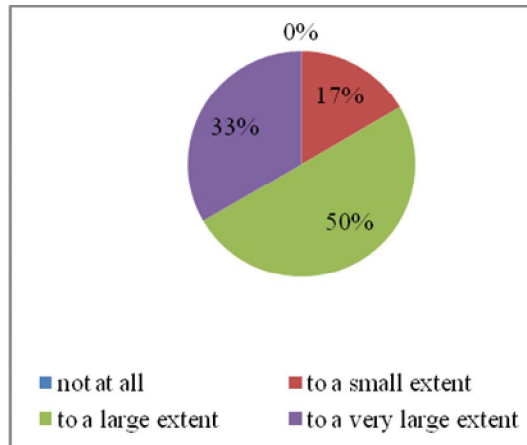


Fig. Graph for the responses regarding the difficulties encountered when working with the medical system

The increased costs of both the treatment and diet are considered by the parents as one of the difficulties they have to face when taking care of the child with diabetes. 43% of them sustain this fact to a large extent, while 57%, to a very large extent.

As measures proposed for diminishing the above-mentioned difficulties, the parents who responded to our questionnaire agreed to the ideas of intensifying the campaigns spread through the media, approaching this topic within the civic educational lessons, educational classes or health education lessons, attracting sponsors, printing informative materials accessible to the broad public and distributing them for free, founding non profit organizations which support the persons in difficulty, accessing the European funds.

Discussions

Even if most subjects use the computerized continuous glucose monitoring systems, one does not give up the blood drop and finger pricks to check the glycemic value and calibrate the electronic devices. Many specialists reveal the fact that the CGMS is a well tolerated device, having the advantage of indicating the glucose trends for hyperglycemias or hypoglycemias (Jeha, Karaviti, Anderson, O'Brian Smith, Donaldson, McGirk, Haymond, 2004).

Percentages recorded to identify the child's functional independence in relation to the medication treatment are relevant only if they are directly connected to the age of the children. It is said that only after the age of 10 the insulin administration by the parent is proposed to be transferred, as an action, to the child, by considering that until this stage the habit of taking an injectable treatment has been gradually formed. Referring to the food that is ingested



independently, as intervention measures in case of hypoglycemia, but also depending on the age, the children may choose the most appropriate products to increase their glucose level or those ones they prefer as sweets, due to their taste. There are known several studies demonstrating that parents interested in well-controlling the diabetes, encourage the members of their families to behave independently (Anderson, Miller, Auslander, Santiago, 1981).

Even if the interviewed parents asserted that they had found themselves to a small extent in social contexts where they were faced to attitudes of rejection or isolation, their previous responses had revealed a preference towards the interaction with families in which it was a child with health problems. Maybe the families participating in this survey have a social comfort created throughout the time, they choosing carefully the social group they want to be part of, as a measure for the child's protection and self-protection.

Referring to the medical services for children with diabetes, several studies underline the fact that the families taking care of children with diabetes recognize their needs for more information about, but also for emotional support (Lawton, Rankin, Elliott, Heller, Rogers, Zoysa, Amiel, 2014). The participants of our project have access to the private care system, being treated by a diabetologist to whom they may appeal at any time of the day or night and who monitors permanently their glucose level through a computerized system. The quality of these services is directly reflected in the evolution of disease and the control of functional parameters, which protects the children from complications and extreme glucose values, but also from the costs involved by the compliance with the treatment scheme and the utilization of modern technology.

Conclusions

Managing the juvenile diabetes supposes a change in the lifestyle of the entire family and the cultivation of a social intelligence which helps the child feel less the difficulties generated by the interaction with non-empathic persons and the necessity to cooperate with the providers of medical services in the national health system.

Acquisition of the functional independence by the child with diabetes depends on the family's concern with well managing the diabetes and fulfilling the needs of the child, as an active member of the community to which he/she belongs (school group, sports group, group of friends etc.). The most important aspects of functional independence are considered to be the following: glucose measurement, insulin administration,

recognition of the signs of hypoglycemia and hyperglycemia, knowledge of the energetic value of food and practice of the physical exercises. We think that the habit of choosing the sweets for intervening in case of hypoglycaemia must be formed in the family, so that the healthiest of them are among the child's preferences.

There is a need to diversify the medical and social services, in the sense of creating some juvenile diabetologic care teams, within which the family occupies a central place. Thus, the family members should manifest an open attitude towards a possible cooperation with a counselor, a nutritionist, a specialist in motor activities.

The impact, at the social level, felt as a result of the interaction between persons with health problems and without health problems can be diminished by increasing the actions intended to inform and educate the population, which leads to an intensification of the empathy, emotional resonance and social cognition processes, reflected in the social cohesion.

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