

My Son has Diabetes... What's Next?

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Abstract

Introduction: This article presents the work developed by nurses from the Pediatrics Inpatient Service, with children and young people with Type 1 Diabetes Mellitus, inaugural episode and their families and focuses on parents' perception of the care process. It presents the results of a questionnaire applied to the parents of these children conducted in October 2016. It's an opinion study.

Objective: Evaluate the process of training parents to take care of their child with Type 1 Diabetes Mellitus, inaugural episode.

Materials and Methods: we elaborated a questionnaire centered on the process of training parents from theoretical assertions recently published in the literature. We use a Likert scale to measure each of the items in the survey. We sent the same internet to 32 parents of children and young people with Type 1 Diabetes Mellitus, admitted to our external consultation, whose inaugural episode of the disease was diagnosed in our Hospital and were hospitalized in the Pediatrics Service.

Conclusion: We obtained frankly positive evaluations of the care provided, focusing on informative/training aspects, training of skills and skills in parents and partnering parents/nurses in child/youth care and negotiating them.

Keywords: *Type 1 Diabetes Mellitus (DM1); International Diabetes Federation (IDF)*

Introduction

Type 1 Diabetes Mellitus (DM1) is a chronic disease characterized by insulin deficiency due to loss of pancreatic beta cells and with consequent hyperglycemia. According to the International Diabetes Federation (IDF) in 2017, there would be 425 million adults worldwide with Diabetes Mellitus. The most prevalent form in adults is Type 2 Diabetes Mellitus. In pediatric age type 1 Diabetes Mellitus is the most prevalent form [1].

In Portugal, according to data from the National Registry - DOCE, DM1 in children and young people in 2015 reached 3,327 individuals aged 0 - 19 years, which corresponds to 0.16% of the population of this age group [1].

The rate of appearance of new cases is maximum between 12 and 14 years, being equal in both sexes and higher in the winter months. In most cases (70 - 90%) DM1 is due to the loss of beta cells of the pancreas by the appearance of autoantibodies (autoimmune DM1 or type 1a); in the small number of cases that do not present these antibodies, the cause remains unknown (idiopathic DM1 or type 1b, with important genetic component). These antibodies may be present months or years before symptoms. Although DM1 is an autoimmune disease, it is based on a genetic predisposition. The overall incidence of Diabetes Mellitus type 1 has been increasing by a percentage of

about 3 - 4% per year, especially in younger children. This increase is probably due to environmental factors, still unknown mostly. On the contrary, breastfeeding seems to have a protective effect [1].

The criteria for the diagnosis of Diabetes Mellitus according to the protocol established by the International Society for Pediatric and Adolescent Diabetes (ISPAD) are:

- Classic symptoms of diabetes (polyuria, nycturia, enuresis, polydipsia, slimming)
- Serum glucose ≥ 200 mg/dl
- Fasting serum glucose (> 8 h) ≥ 126 mg/dl
- Serum glucose after Oral Glucose Tolerance Test (PTOG) ≥ 200 mg/dl (2h), using glucose load of 1.75 g/kg, up to a maximum value of 75g
- Hemoglobin A1c - 6.5%.

The PTOG is usually unnecessary, provided that one of the first criteria is present. Whenever hyperglycemia is observed, the child or young person should be oriented towards a specialized unity for the onset of appropriate therapy, since when the onset of insulin therapy is delayed, this may trigger metabolic imbalance, with consequent ketoacidosis [1].

Children and young people with Diabetes Mellitus type 1 are people with special health needs (NES). They require the support of multidisciplinary teams for the implementation of care programs that undergo self-control of the disease, surveillance, medical and nursing guidance, nutritional plan and psychosocial support [2-4].

The child/young with Diabetes Mellitus type 1 can have healthy growth and development and make their life "normal". These are strategic axes of care [5]:

1. Balanced feeding;
2. Control of glycemia and ketonemia levels;
3. insulin therapy;
4. Prevention of complications;
5. Physical activity;
6. Health surveillance.

In this article, we will explain the self-control of the disease, in the area of training parents to take care of their child with Diabetes Mellitus type I, inaugural episode, provided to them in the context of hospitalization. We present in summary format the nursing care promoters of the empowerment of the child/young/parents and the results of an opinion study conducted to parents of children and young people with Diabetes Mellitus type 1 who were hospitalized in the Pediatrics Service of the Santarem Hospital in the inaugural episode of the disease.

Training of parents of children and young people hospitalized with type I diabetes mellitus, inaugural episode

The Support Team for Children and Young People with DM1 of the District Hospital of Santarém and the Pediatric Nurses, have an active role in the care of children and young people with DM1 and their families who undergoes the diagnosis of the disease, reversal of episodes of decompensation (ketoacidosis and hypoglycemia) and education of the child, young and family that enables the self-management of the disease (surveillance and care), acting parents and nurses as resources when the child/young person, in the prevention of complications and promotion of well-being and quality of life.

The Hospitalization Unit in particular focuses on diabetic education. We highlight the education of inaugural diabetics, with nurses playing a dynamic, active and complementary role in the multidisciplinary team. To this end, it has an Clinical Guidance Standard of nursing care to the child/young/family with Type I Diabetes Mellitus, inaugural episode [5], which is a conceptual guide, advisor to the actions of nurses, based on the following flowchart.

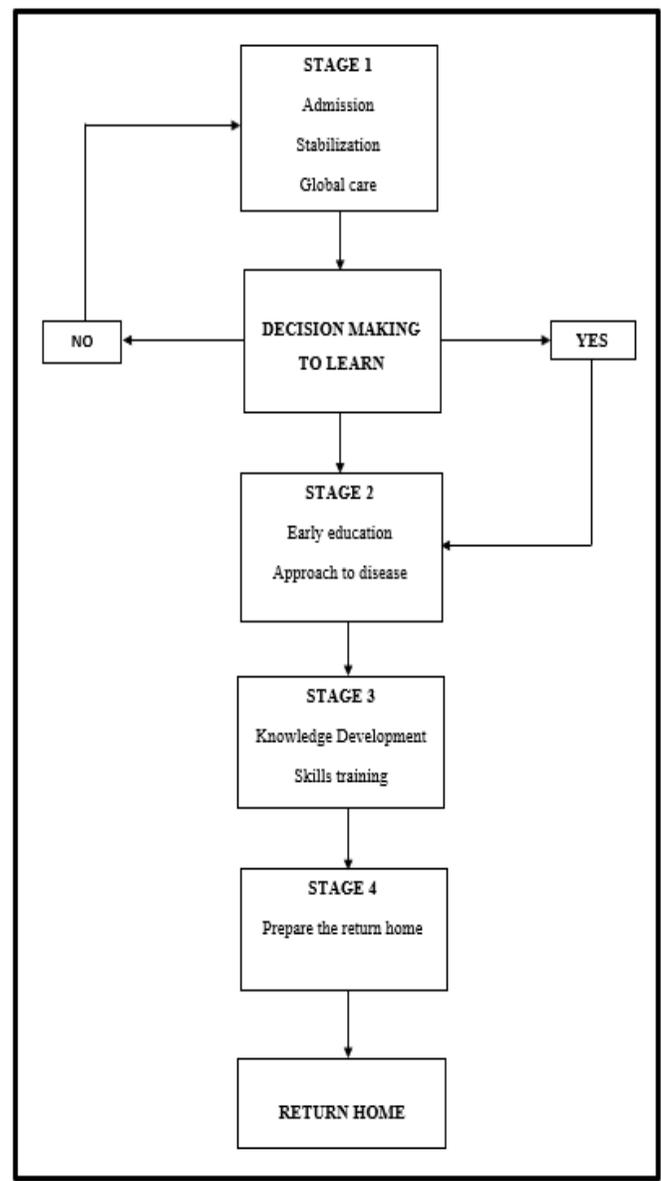
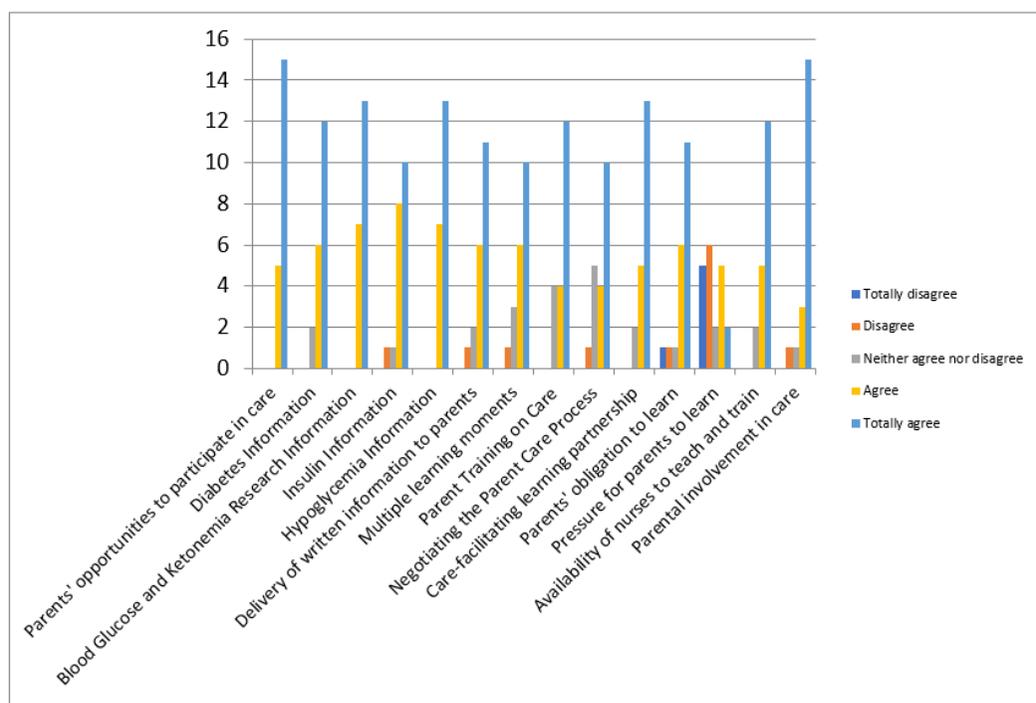


Figure 1: Flowchart of the child and young child care process with Type 1 Diabetes Mellitus and their families.

In continuity, we present the “look” of parents on the training process given to them.

Parental perception of the training process



Graph 1: Parental perception about the training process.

All parents reported that they were given the opportunity to participate in care from the moment the diagnosis was made, valuing the importance of partnership care if they started as early as possible. The involvement/participation of parents in child care aims at their full training [2,3,6].

Most parents (90%) agreed that the nurses informed about Diabetes, transmitting the concept to him in an enlightening way, to be provided with information that helped them empower themselves and make informed decisions about the health/illness process of their children [2,3].

All parents agreed that nurses reported on the research of glycemia and ketonemia, which is one of the first aspects addressed, in accordance with the Good Practice Standard for Nursing Care for Children and Youth with Type Diabetes Mellitus, inaugural episode [5].

The parents valued the sensitivity and attention of nurses to work clinical aspects [6] and accept the knowledge, skills and experience of nurses in providing good care to the child [6,7].

Most parents (90%) agree that nurses reported on insulins, dose calculation to be administered and how to administer. For people with Type 1 Diabetes Mellitus, insulin to be administered takes into account preprandial glycemia values and subcutaneous insulin administration is effective, reducing morbidity and costs [4].

All parents agree that nurses reported on hypoglycemia, being a fundamental aspect in the education of children/young/parents, because it is a complication of the disease. It is necessary to know how to act quickly and should deserve special attention from health professionals. Effective education of these attenuates the incidence of severe hypoglycemia [4].

Most parents (85%) agree that nurses complemented learning with written information. Communication is an indispensable tool in the context of care, considering the great contribution of the written material in the context of health education and the role of these resources to promote health, prevent diseases, develop skills and favor the autonomy of the person [8].

80% of parents agree that nurses provided several learning moments. The various work experiences with nurses are positive, they are facilitators of the integration of knowledge and capacity development in parents [2,3]. Diabetic and family education is the key to successful disease management [9].

80% Of parents agree that nurses trained their parents in care: in the handling of equipment, in the technique of glycemia and ketonemia research and insulin administration. In the training process, it is essential to train parents in care, acquiring a set of skills that allow them to take their child home and maintain the provision of care at home [2,3]. The handling of glycemia and ketonemia monitoring equipment and technique, as well as insulin, are starting points in this process [9].

Most parents (70%) mentioned that nurses negotiated the start of learning and their involvement in care. We value the fact that the negotiation on the beginning of learning was an aspect considered by nurses, as opposed to the results of recent research studies in the area of the care partnership that concluded that this aspect is not always the result of a negotiation process, but rather an obligation felt by parents [2,3,10-12]. Regarding the involvement in care, these results are in agreement with recent studies [2,3,13].

90% Of parents considered that work in parent/nurse partnership facilitates the learning process of parents. The various experiences of working with nurses are valued as learning moments [3]. Parents establish strong partnership relationships when professionals are very present in the day-to-day lives of families and with willingness to help [3].

85% of parents felt obliged to learn, so they could go home with their child. In agreement with the data from the literature that report that the parents made the decision to learn, because they felt their obligation [3,10-12].

Most parents did not feel pressure to learn how to take care of their child, thus verifying that nurses gave decision-making power to parents about their involvement in the learning process, without impositions, being a shared process, leading to joint decision-making [2,3].

Most parents (89.5%) agreed that nurses were available to teach and train parents in care. The availability of nurses is an essential attribute for work in partnership and in supporting the training of parents [3].

90% of parents agreed that being involved in care helped deal with their child's health situation, having the opportunity to learn how to deal with the complexity of children's health/disease condition, meeting their needs and those of their families [6].

Conclusion

Worldwide, the number of new cases of children and young people with Type 1 Diabetes Mellitus gradually increases every year. In the population that uses our Hospital we also found the emergence of new cases annually, to those who seek to offer quality health responses, which prevent complications and promote well-being and quality of life.

When parents come across a diabetic child, nurses are a fundamental resource in their training process to take care of their child.

We seek to continuously improve the scientificity, rigor and art of our care in this population of children and young people with special health needs. To achieve this goal, we went looking for the perception of parents about the process of caring for their child, obtained after the diagnosis of the disease.

Of the results, it was concluded that by “the look of the parents”, these, they had the opportunity to participate in care from the moment when the diagnosis of the disease was made, the nurses informed about what diabetes is, about the research of glycemia and ketonemia, insulins and hypoglycemia. They delivered written information (leaflets), provided several learning moments, trained parents in care, negotiated the start of care and the involvement of their parents, established partnerships with parents in the provision of care, in short, were always available to the child/young and parents.

The parents felt the obligation to learn to take their child home but did not feel pressured to learn. They found that involvement in care facilitated their role as parents.

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