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Dear Guests...

Welcome to the 9th INTE, ITICAM & IDEC -2018.

International Conference on New Horizons (INTE), International Trends and Issues in Communication & Media Conference (ITICAM) and International Distance Education Conference (IDEC) are international academic conferences for academics, teachers and educators. They promote the development and dissemination of theoretical knowledge, conceptual research, and professional knowledge through conferences activities, the conference proceedings books and TOJET, TOJDEL and TOJNED Journals. Their focus is to create and disseminate knowledge about new developments in these academic fields.

INTE, ITICAM & IDEC conferences are now well-known international academic events and the number of paper submissions and attendees are increasing every year. This year our conferences have received more than 900 applications. The Conference Academic Advisory Board has accepted approximately 600 papers to be presented in Paris, France.

We would like to thank Prof. Dr. Mehmet Ali YALÇIN, Rector of Sakarya University and the President of the Association of Quality in Higher Education Prof. Dr. Muzaffer ELMAS, for their support of organizing these conferences.

We also would like to thank our distinguished guests, keynote speakers for their collaborations and contributions for the success of these conferences.

And finally, we would like to thank to all of our participants who have presented their academic works in INTE, ITICAM and IDEC- 2018, Paris, France.

Without their participation, INTE, ITICAM & IDEC-2018 would, of course, have been impossible.

We would like to sincerely thank all of you for coming, presenting, and joining in the academic activities.

We would also like to thank all of those who have contributed to the reviewing process of INTE, ITICAM & IDEC conference papers, which will be also published in TOJET, TOJNED, TOJDEL and TOJCAM.

Finally, we would like to wish you all a successful conference, pleasant stay in Paris, France.

Thank you

July 18, 2018 - Paris, France

Coordinators

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Parents' Experiences About Their Child's Type 1 Diabetes

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Abstract

Introduction: Type 1 Diabetes Mellitus is a chronic disease that is expanding and increasingly affects children and adolescents, resulting in changes in their lifestyle as well as in their families. **Objective:** To identify the experiences of parents regarding their child's Diabetes Mellitus. **Methods:** Qualitative, phenomenological study, having as participants 14 parents of children and adolescents who have diabetes and are followed up in consultations. We used the semi-structured interview and carried out content analysis. **Results:** Diabetes in children leads to a family restructuring and in particular to changes in diet and relationships with other children; represents a load of negative feelings and fears that lead to the demand for new parental skills and to the appreciation of health professionals and supports received. **Conclusions:** The results can help health professionals in the development of parental role, namely in accepting and adapting to the disease, in overcoming the difficulties and, above all, in improving the family's quality of life.

Introduction

The scientific and technological development has allowed the diagnosis of chronic diseases to be made increasingly early. Thus, an adequate therapeutic plan can be designed in order to control the evolution of the disease. Although early diagnosis does not prevent the onset of the disease, it contributes to a favourable outcome, preventing risks and complications (Gregory, Moore, & Simmons, 2013). Type 1 Diabetes Mellitus is a chronic, complex, and difficult to control disease that interferes with the quality of life of both the patients and their families. Correia (2011) points out that the unpredictability, characteristic of diabetes, generates a sense of discomfort and insecurity in parents when they are not close to their diabetic children. Over the past decades, it has been verified that the incidence of this disease is increasing in children and young people. In 2010, 18 new cases of Type 1 Diabetes were detected per 100,000 young people aged 0-14 years, nearly twice as high as in 2000 (similar to that observed in the 0-19 age group) (Boavida et al. 2012). This reality requires joint efforts on behalf of the health professionals, the child/adolescent and the family, with regard to the adaptation, treatment and metabolic control of this disease in order to minimize the complications that may result in the long term as well as to maintain the quality of life (Almino, Queiroz, & Jorge, 2009). Therefore, the need to involve the family as an integral part of the whole care process of the diabetic child and adolescent is evident (Alencar, & Alencar, 2009). In this sense, it seems relevant to identify the experiences of the parents regarding their child's Diabetes Mellitus. In fact, the family constitutes a system in which the behaviour of each individual is interdependent of the others (Correia, Franco, Demário, & Santos, 2012), and when exploring the parents' experiences of this phenomenon, we can obtain subsidies for the improvement of the health care provided by health professionals to the child/adolescent with diabetes as well as to their family (Sousa, 2012).

Methodology

In our clinical practice we have seen an increasing number of children and young people with type 1 diabetes. Inevitably, we have also noticed the difficulties, anxiety, fears and exhaustion of parents in dealing with this situation.

In order to identify the parents' experiences with their child's Diabetes Mellitus, we developed this study based on the following research questions: What are the feelings experienced by parents after the diagnosis of Type 1 Diabetes Mellitus has been made to their child? What experiences struck the parents during the process of acceptance and adaptation to diabetes? To what extent did the intervention of the health professionals influence the adaptation of the child/adolescent and his/her family to diabetes?

We conducted a qualitative, exploratory-descriptive, phenomenological study using the semi-structured interview. The target audience was the parents of children/adolescents with Diabetes Mellitus type 1 who are followed in the Paediatrics External Consultation of a Hospital Centre in the North of Portugal. We used a non-probabilistic sample of 14 parents (10 mothers and 4 fathers). The inclusion criteria were parents of a child or adolescent with Type 1 Diabetes Mellitus, 4 years of age or over, and in whom the diagnosis of the disease had been carried out more than 6 months ago. The study had been authorized by the Hospital Centre and obtained a favourable opinion from the Ethics Committee. The interviews were carried out by the researcher in a private consultation office and, prior to each interview, parents were informed of the objectives, benefits and nature of the research, and the

confidentiality and anonymity of the data was ensured. We obtained a written informed consent from each parent to guarantee eligibility to participate in the study.

A coding grid was drawn up for each interview, with the interview number, time and duration. An audio recorder was used and later the interviews were transcribed into a word document. We performed the content analysis by coding the data (Amado, 2000; Bardin 2009; Streubert, & Carpenter, 2002). That is, the relevant characteristics of the message content were transformed into units so as to allow their description and precise analysis. A careful reading of each interview was carried out, followed by a re-reading in the attempt to eliminate irrelevant information for the study and to better understand the material analysed in order to construct the categories. For each interview a code was assigned (M1 to M10 for mothers and P1 to P4 for fathers).

Findings

Our sample is composed of 14 participants, 10 mothers and 4 fathers. We found that 57.1% are between 31 and 40 years old. All parents are employed and 50% of the mothers, too. The majority of the participants (57.1%) has a level of schooling below secondary level, 28.6% completed the secondary level and 14.3% have a degree in higher education.

Regarding marital status, 78.6% of the participants are married and 21.4% live in a non-marital partnership. Half of the sample has 2 children, 35.8% have 1 child and 7.1% have 3 children and the same percentage has more than 3 children.

To what concerns children/adolescents with diabetes, 8 of them (57.1%) are boys and 6 (42.9%) are girls. The majority is between 6 and 10 years old (57.2%) and only 21.4% are between 11 and 15 years old. In the majority of the children, diabetes was diagnosed before the age of 5 (57.2%).

Regarding the elapsed time since the diagnosis was made, we verified that it had been performed more than 4 years ago in 42.9% of the children, between 2 and 4 years in 21.4% of the children, and between 6 months and 2 years in 35.7% of the children/adolescents.

On the following pages we present the content analysis of the interviews. Taking into account the process inherent in qualitative studies, the categories that are represented in the following tables with their indicators arose.

Impact Of Diabetes On The Family

It was verified that the diagnosis of diabetes ascends within the family, changing its dynamics. The parents' discourse reveals the existence of the impact of diabetes on the family (Table 1), giving rise to the need for a restructuring of the family life. We have verified the existence of seventeen enumeration units in this indicator. The parents report this fact as follows: "(...) *there were some repercussions, we had to change some habits (...)*" (M3), or even more significantly "*I had ... to stop working. P had to be pricked and I had no help (...)*" (M6).

In the implications on the parents' personal life, we witnessed the difficulties experienced and felt because of diabetes, both in terms of accepting it and in the repercussions that it entails. Examples of this are expressions such as "(...) *at first, I did not want to believe it (...)* but then I accepted it, I had no choice (...). *I tried to adapt to hospitals, to insulin (...)*" or even "(...) *sleep, forget it! I do not think I have slept a single night*" (M3).

In addition to the personal implications, the onset of diabetes in the family also affects the social life of the parents. The speech of the parents reflects this constraint especially with regard to their children's school and to them being a part of society when they state, "(...) *I wanted to take my child out of the nursery. I was afraid that they were not prepared to administer insulin and also because of the food (...)*" (M10), and also "*When we are sometimes socializing (...) and he/she wants to eat and we cannot allow it (...) people start to stare (...)*" (P1), or in the expressions "(...) *people are sometimes a bit uneducated in this aspect (...) I feel like using foul language!*" (P2).

Table 1 – Impact of diabetes on the family

Category	Indicators	Recording unit
Impact of diabetes on the family	Restructuring of family life	17
	Implications in personal life	12
	Implications in social life	8

Parents' Feelings/Emotions

The diagnosis of diabetes represents a milestone in the life of parents with a huge negative burden that provoked several feelings in the participants of this study (Table 2). The most expressed feeling by parents was fear/insecurity. "(...) *one is always afraid (...)* always afraid that something will happen (...)" (M3). As a consequence of fear, insecurity also arises "(...) *even when I was told "now you do not need to see it in the middle of the night", I would still see it, that is how it is..."*" (M3), or as participant M9 describes it "(...) *not showing my insecurity was very complicated (...)*".

The second feeling most referred to by parents was concern. The fact that the child has diabetes represents, for most parents, an increased responsibility (M1, M5, M6, M7, M8, M9) with a need for control, as M3 states: "*It is always that anxiety about whether or not everything is okay... it is that concern (...)*". P2 and M10 also stress this idea when they say "*I am always more worried, I have to always be on top of him (...)*".

We verified that sadness/anguish is also within the feelings that are the most visible by the participants in the study. Many times this sadness is manifested by crying: "*I got tired of crying in this hospital ... it was complicated!*" (M6, M4, M8, M9). In some of the parents, this feeling lingers and accompanies them on a day-to-day basis, as verbalized by P2 "*It took a toll on me and still does.*"

Revolt/frustration was also reported by the parents. Participant M4 testifies this revolt when she says "*(...) why did it have to happen to our daughter? Why her?*". Also, father P1 stresses this feeling when he says "*(...) I felt destroyed ... and revolted (...)* I was outraged".

Feelings like guilt and denial also emerged in the analysis of the data. Initially, the non-acceptance of that reality "*(...) I did not believe it...*" (M2) and later the feeling of guilt when confronted with the diagnosis of diabetes "*(...) I am almost positive that I did not wash my hands well when I made her soup, or I did something wrong when she was a baby (...)*" (M4). Sometimes blame perpetuates, as expressed by P2 "*We always feel guilty (...)*".

Table 2 – Parents' Feelings/Emotions

Category	Indicators	Recording unit
Parents' Feelings/Emotions	Fear/insecurity	12
	Concern	11
	Sadness/anguish	10
	Revolt/Frustration	8
	Guilt	4
	Denial/shock	4
	Disorientation	3

Changes in Family Life

The diagnosis of diabetes forced some changes in the family life of the study participants (Table 3). The change in eating habits was the most mentioned indicator: "*We learned how to eat better, to eat at certain times of the day.*" (M5).

We also found that after the diagnosis had been made, the parents felt the need to monitor and supervise their child more. This fact can be verified through various expressions made by the parents: "*(...) to be more on top of her (...)* the need to have to watch over her" (M1, P2, M8). However, this need is closely related to the concern with the child's clinical situation, as can be seen in the following excerpts: "*(...) stressful day and night (...)* we never let J. sleep alone at night (...)" (M9); "*I always carry my mobile phone (...)* then she calls me (...) to say (...) how she is doing" (M10).

The verbalisation of the participants regarding the limitations of going out is also noticeable. "*We ... basically stopped going out, to restaurants*" (P1, P2); M9 says "*(...) we stopped doing some less important things, like going out, trips to the beach*". This limitation is justified by P3 when stating that "*The disturbance had to do with him going to the house of his grandparents, uncles, because people do not want to be held responsible for such care.*" Some parents also voiced the need for some changes related to diabetes, for instance: "*What changed was having to measure the amounts and give him insulin according to the amount*" (P3), and also "*(...) in the morning, there is always that precaution to get up early (...)* and not enjoy what we are doing (...)" (M10) and M6 points out "*I just had to stop working. P. had to be pricked and I had no help.*"

Table 3 – Changes in Family Life

Category	Indicators	Recording Unit
Changes in Family Life	Change in eating habits	14
	Higher monitoring and supervision of son/daughter	13
	Limitations of going out	8
	Changes related with diabetes	7
	Limitations in shopping	3

Changes in family dietary

We can see in this category (Table 4), that the most mentioned change was related to the type of dietary. The parents stated that they had to reformulate the dietary according to the type of food and quantities, as M2 states "*(...) I removed the sweets but added more vegetables!*" and also M4 "*(...) we are much more careful with what we eat (...)*". Faced with the care inherent in diabetes, meal times also changed. Thus, M10 and P4 convey "*(...) we started having schedules to eat*", and M2 as well "*(...) the schedules to eat changed, because she did not have any schedules (...) she ate whenever she wanted.*" We also noticed that some participants stated that they only had to make some adjustments, such as M3 when referring "*(...) we already had everything more or less set, fixed meal times, except for supper (...) now everybody has supper (...)*", or even M6 "*The only thing he changed was that he would not eat at night (...)*".

One of the mothers said "*(...) during meals, we would all eat together and now I have to cook food separately (...)*" (M7), and M8 says that "*(...) I sometimes make two types of soup ... but the rest of the food is the same for everyone.*"

They mentioned some difficulties in eating habits, mainly introducing vegetables in the dietary. One of the mothers (M8) reports that "*He would not eat a bit of cabbage or lettuce.*" Regarding the ingestion of certain food items or sweets by their children, M4 refers "*(...) we sometimes have to be strict. And sometimes she eats without us noticing (...)*".

Table 4 – Changes in Family Dietary

Category	Indicators	Recording Unit
Changes in Family Dietary	Type of dietary	12
	Meal Times	11
	Family dietary	9
	Difficulties felt by parents	9

Parenting children with diabetes

Some indicators that reflect the readjustment of family life emerged (Table 5). In this context, the development of parental competences has become crucial to allow the readjustment of the parental role. The parents' commitment to acquiring these new skills is noticeable throughout the speeches, especially when M7 and M9 refer, "*(...) I did not understand, nor did I know what it was, diabetes (...) after that I got used to it (...)*". Still, M9 adds "*I have read absolutely everything on it (...) I try to do everything that is within my reach.*" Also, P2 says that "*(...) the first time I administered it, (referring to insulin) I had to bend down because I thought I would not be able to get back up*" P2.

Another one of the indicators refers to the difficulties in accepting diabetes. These are related to the parents' emotions as shown by P1 "*... there comes sadness from the bottom of the chest ... but it stays inside ... we try not to demonstrate it (...)*", or M2 that says: "*It was a bit hard (...) because I was just a child (...)*". In some cases this difficulty may be associated with parental perception as expressed by M10. "*As much as they say that she can live a normal life, she has to live a different life from everyone else,*" and P2 says "*He is more limited, he cannot play as much as he used to (...)*".

Some positive aspects of the acceptance of diabetes, such as the fact that the child or adolescent has accepted his/her clinical condition, were perceived "*(...) he had enough strength for himself and for me*" (P2). Another mother says "*(...) but only because she reacted very well, she was not a girl who cried because she had to be pricked (...) I think we all adjusted well (...)*" (M3).

Some difficulties in the relationship are essentially related to the behaviour of the children, as we can see from the following excerpts: "*(...) we are still going through a phase ... everything is out of control ... we do not live well ... but we are living (...)*" (P1). Also, M2 refers "*(...) she will cry alone and not tell anyone anything (...)*".

Table 5 – Parenting children with diabetes

Category	Indicators	Recording Unit
Parenting children with diabetes	Development of parental competences	19
	Difficulty in accepting diabetes	6
	Favourable aspects for binding and accepting diabetes	7
	Difficulties in binding	5

Experiences with other children

In this category, the participants of the study mentioned behaviours and feelings related to the experiences of their children with other children (Table 6). We find that jealousy is felt among siblings of children or adolescents with diabetes, as P4 says. *"He was sometimes jealous, that I would pay more attention to her (...)"*.

On the other hand, some parents highlight the understanding and mutual help between siblings. M5 states that *"His brother very understands (...) if he wants something, he is careful enough so that the other does not see it."* M8 stresses this feeling by saying *"Her sister is very responsible (...) she helps out."*

However, some parents have expressed some difficulties in dealing with this situation given its peculiar characteristics. P4 says *"(...) it may not seem like it, but they are two children and sometimes I think that we are giving more affection to his sister than to him ... but we are not ..."* P2 reinforces this difficulty by referring *"One can and the other cannot; I think it's unfair (...) sometimes we try to avoid going out with them together just to avoid requests ..."*.

Table 6 – Experiences with other children

Category	Indicators	Recording Unit
Experiences with other children	Jealousy	5
	Understanding and mutual help	4
	Difficulties felt by parents	5

Fears experienced by parents

After the diagnosis of diabetes, the participants expressed some fears and anxieties regarding the future of their child (Table 7), namely fear of other pathologies appearing *"(...) there is always that fear that something else will happen with her health (...)"* (M4). Hypoglycaemia is also a cause for concern, and M5 points out *"(...) I am afraid because of his hypoglycaemia ..."*

Adolescence represents an important milestone in life, full of challenges, where autonomy is increasing and personality is created. Hence, this symbolizes one of the parents' yearnings about the future, as seen in the following excerpts: *"(...) when she goes to university, when she starts to go out at night and we can no longer say "do not eat that", "do not drink that", "do not do that", (...)"* (M4).

Vascular complications are a concern for some parents as witnessed in the expression: *"(...) losing a leg, (changes) of the eye sight (...) not being able to lead a normal life"* (M8).

Table 7 – Fears experienced by parents

Category	Indicators	Recording Unit
Fears experienced by parents	Diagnosis of other pathologies	5
	Hypoglycaemia	4
	Adolescence	4
	Vascular Complications	2
	Fear of making mistakes	1

Opinion on the health professionals and supports received

All of the parents expressed satisfaction considering the care of excellence provided. *"It's an excellent team (...). For both her and me, it helped a lot (...)"*(M2). Other parents also expressed their satisfaction: *"It was very good (...) our needs were fulfilled"* (P1, M9, P4).

Essentially, the study participants felt the support of the health professionals. Some examples of this are the expressions of M6 and M8 *"(...) the nurses, the doctor, in general"* and M9 *"(...) I liked it very much (...) and here in the consultation, we receive a lot of support"*. In addition to this support, the parents also mentioned the support of their child with diabetes *"(...) he had enough strength for himself and for me..."* (P2), and the support of other relatives as M5 states *"From my sister-in-law, from my other child (...) my sister-in-law (...) stays with him (...) if she didn't take care of him, I don't know how I would manage..."*.

Table 8 – Opinion on the health professionals and supports received

Category	Indicators	Recording Unit
Opinion on the health professionals	Satisfaction	14
	Support from health professionals	13
Supports received	Support of the child with diabetes	2
	Support from other family members	2
	Other supports	2

Discussion

The participants reported the difficulties felt when diabetes was diagnosed, as well as the need to restructure their family life, to establish new parental roles, and to take on the implications inherent in both their personal and social life.

Uncomfortable feelings such as a sadness, anguish, revolt, guilt and essentially fear, are present in the speeches of the participants in this study. The studies of Martins, Ataíde, Silva, & Frota (2013) also make it possible to perceive the suffering of the parents before their child's diabetes and the feeling of impotence before this diagnosis. Pilger, & Abreu (2007), point out that these feelings can be understood as a process through which parents face their child's illness and try to find a solution and to adapt to this new reality. At this stage, the role of the multidisciplinary team with the child or adolescent and their family is of the utmost importance, with the aim of providing them with the care needed to help them in this moment of change. In the study, the need that parents feel to supervise their child with diabetes is visible. This situation brings suffering and they feel a need for a greater dedication and vigilance. Some parents had to leave their professional activity in order to be entirely available to care of their child since they had no other support. This need was also verified in other studies. Leal, Fialho, Dias, Nascimento, & Arruda (2012) report that the difficulties experienced can comprise several dimensions and that the treatment of the disease requires special care and attention on behalf of the family.

Another change verbalised concerns social life. As in the study by Corrêa et al. (2012), when faced with diabetes, parents experience their social life with some limitations. At times, they stop going to places or participating in events and festivities, so that the child is not in contact with food that he/she should not consume. Martins et al. (2013) stress that even after adapting to the disease, families continue to avoid going out to social gatherings, which can lead to the family's social isolation.

The change in eating habits is perceived by the study participants as one of the main alterations, both with regard to the type of dietary as well as the need to establish meal times. Its restructuring implies changes that, in most cases, extend to the whole family. We also found that many parents see these changes as beneficial to the family's health, as food becomes healthier and there are meal times to follow.

With regard to the development of parental competencies, parents feel compromised in their parental role when faced with the difficulties inherent in diabetes. These adversities require developing skills and competences to become capable and to feel confident in caring for the child. The role of health professionals with the family is fundamental so as to contribute positively to the definition of the new parental roles, which is corroborated by Corrêa et al. (2012) and Martins et al. (2013).

We see an ambivalence of feelings in the relationship with other children. Parents perceive feelings of jealousy on behalf of the siblings, but also report understanding and mutual help. Sometimes they find it difficult to make decisions in relation to a healthy child and another child with a disease that implies certain limitations, mainly at the dietary level.

The analysis of the interviews shows the parents' yearning regarding the consequences and the risks of diabetes. The concomitant appearance of other pathologies and hypoglycaemia are the parents' most feared complications. We verified unanimity in parents' satisfaction with the care provided by health professionals. They mentioned the favourable contribution of the multidisciplinary team, especially the nursing team, in acquiring knowledge and skills on how to deal with diabetes. The interviewees said they felt the support, essentially from the health professionals, but did not rule out the pertinent support they felt from other family members, too.

Conclusions

The diagnosis of diabetes has repercussions in families with an enormous impact at a behavioural, personal and social level. The family faces a new reality and experience, new feelings and concerns, and the involvement of all its family members is necessary for the reorganization of the family dynamics.

Bearing in mind the starting points, we carried out a qualitative research in 10 mothers and 4 fathers to identify the feelings experienced with their children diagnosed with Type 1 Diabetes Mellitus, and to understand the most challenging experiences in the process of acceptance/adaptation in the caring for the child with diabetes.

Given the complexity of diabetes, parents' anguish, fear, and disorientation are understood after the diagnosis and throughout the process of acceptance and control of diabetes. In this sense, we sought to understand the extent to which the intervention of health professionals in the adaptation of the child and the family in this process of transition to diabetes was important.

From the feelings mentioned above, parents feel the need for greater vigilance and supervision of their children by dedicating much more attention and time to them. Given the characteristics of diabetes, the family needs to change eating habits, essentially with regard to the type of food and the meal times. Some of the respondents avoid participating in festivities or events so that the child does not have to be in contact with food that they cannot eat. When there are other children involved, parents face a daily challenge regarding decision-making in relation to a healthy child and another one with diabetes.

Some parents feel their parental role is compromised and seek to develop skills and abilities to become capable and confident to care for their child. Some parents feel disoriented, sad and sometimes guilty. Thus, they become very vulnerable, so the support provided to them is extremely important for parents to gain strength and to be able to care for their child.

All the interviewees mentioned the support of the health professionals as a valuable aid in the acceptance of diabetes, in the acquisition of skills and competences, and in the redefinition of the parental role.

With this study, we are better able to understand the experiences of the parents in relation to the child/adolescent with diabetes. In light of this data, health professionals will better understand the difficulties experienced by parents and thus foster good practices and improve the quality of life of the child and his/her family.

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