


## HEALTH BELIEFS OF PARENTS OF CHILDREN WITH TYPE 1 DIABETES

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**ABSTRACT** - The objective of the study was to describe the health beliefs of parents of carrying children with Type 1 Diabetes and to understand behaviors and attitudes that may influence treatment. We interviewed 13 people, 11 month to 10 years old children's parents with Type 1 Diabetes, using the "health beliefs" model. This model covers the: impact of the diagnosis, susceptibility, severity, benefits, barriers, self-efficacy and present expectations of the future. The parents experienced difficulties, fears and uncertainties in dealing with their children's diagnosis. In all stages of the disease, from diagnosis to the present time of interview, the parents disclose intense suffering from the pervasive feeling of imminent loss. We recommend that the parents receive support from a team of health professionals who have specific knowledge and are armed with the purpose of informing the family about the disease. This support should be aimed at minimizing the fears and uncertainties that can hinder the family's adhesion to the treatment. We expect that with this type of support, both the quality of life of the patients and their family will greatly improve.


*Key- words* - Type 1 Diabetes, Adhesion, Caregivers, Health Beliefs, Emotional Aspects.

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## CONVICÇÕES DE SAÚDE DE PAIS DE CRIANÇAS COM DIABETES TIPO 1

**RESUMO** - O objetivo do estudo foi descrever as convicções de saúde dos pais de crianças com diabetes tipo 1 e compreender comportamentos e atitudes que podem influenciar o tratamento. Entrevistamos 13 pessoas, pais das crianças de 11 meses até 10 anos com diabetes tipo 1, utilizando o modelo de "convicções de saúde". Este modelo abrange: impacto do diagnóstico, suscetibilidade, severidade, benefícios, barreiras, auto-eficácia e expectativas de futuro. Os pais experimentaram dificuldades, medos e incertezas em lidar com o diagnóstico de seus filhos. Em todas as fases da doença, desde o diagnóstico até o presente momento da entrevista, os pais revelam intenso sofrimento do sentimento generalizado de perda iminente. Recomendamos que os pais recebam apoio de uma equipe multidisciplinar com conhecimento específico e com o objetivo de informar a família sobre a doença. Este apoio deverá ter como objetivo minimizar os medos e incertezas que podem dificultar a adesão da família ao tratamento. Esperamos

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que com este tipo de apoio, tanto a qualidade de vida dos pacientes quanto de sua família melhorem muito.

*Palavras-chave* - Diabetes tipo 1, Adesão, Cuidadores, Convicções de saúde, Aspectos emocionais.

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Diabetes research on the consequences and complications of disease are extensive (Wright & Frier, 2008; Zerbini, Gabellini, Maestroni, & Maestroni, 2007). According to the high incidence of this syndrome and the high prevalence, more research is needed in this area so complex that it's necessary a work where we can count on the involvement of various skilled professionals. We see a need for studies that are focused on parents of children with Type 1 Diabetes. It is of fundamental importance for the treatment of children with Type 1 Diabetes, to understand how the parents live and how the disease developed. Also, there is a need to observe the psychological variables involved in the process.

The incidence of Type 1 Diabetes varies according to each country and state. In Chile the incidence is 1.6/100,000; in Colombia, 3.8/100, 000; in Paraguay, 8.3/100,000; in Peru, 0.4/100,000 in Uruguay, 8.3/100,000 and Venezuela, 0.1/100,000 (Karvonen, et. al., 2000). In Brazil, the incidence of Type 1 Diabetes are as follows: Paraná, 12.7/100,000 per year (Campos, Almeida, Iochida, & Franco, 1998), in São Paulo, 7.6/100,000 per year (Ferreira, et. al., 1993) and Rio Grande do Sul, 12/100,000 per year (Lisboa, Graebin, Butzke, & Rodrigues, 1998).

Diabetes is a chronic disease and one of the biggest challenges in the patient's adherence to treatment, is social support. The emotional support of family and friends is critical to the patient's adherence to treatment (Toljamo & Hentinen, 2001). It is important to involve the family in the practice of health care. Adaptation to Type 1 Diabetes, like any other chronic disease, depends on the mode of coping with the disease and the support of family and friends (Berg, Schindler, & Maharajh, 2008; Couch, et. al., 2008; Pereira, Berg-Cross, Almeida, & Machado, 2008).

The family is fundamental in the treatment of the patient, as it directly influences the patient's acceptance of the disease. Family dynamics, cultural values and socioeconomic conditions are unique. Parents cannot ignore the changes in lifestyle caused by the diagnosis, because the injections of insulin, glucose monitoring, the pre-set time to eat, increased vigilance is essential to the welfare of the child. After diagnosis, the adjustments that the child has to make under the supervision of the parents cause intense emotions (Lowe, Gregory, & Lyne, 2005). Soon after diagnosis, the parents get involved in the training needs of specific treatment, assuming responsibility for the child and trying to recover the initial loss of control felt upon diagnosis (Boman, Viksten, Kogner, & Samuelsson, 2004).

The involvement of parents in encouraging the autonomy of the child is critical in the competence and care of diabetes. Patients need to learn the techniques necessary for self-care and take responsibility for their own healthcare (Hanna, Dimeglio, & Fortenberry, 2005). The aims of the study was to describe the health beliefs of parents of children with Type 1

Diabetes and understand the behavioral and psychological changes that may influence their conduct in relation to treatment.

## METHOD

### *Participants*

We interviewed 13 parents (10 mothers and 3 fathers) of children with Type 1 Diabetes. All subjects interviewed were married, aged between 26 and 52 years, with total number of children between 1 and 3, and with diagnosis ranging from 8 days to 2 years when the interviews were conducted. The subjects were selected for convenience in the field of endocrinology of two respected hospitals in the metropolitan region of São Paulo in Brazil.

### *Materials*

In the interviews conducted, we used a questionnaire to look into the health beliefs and the process experienced by parents of children with Type 1 Diabetes. The questions selected for interviews were presented not necessarily in the order relates. The evaluation of the interview was conducted based on the health belief model (Claydon & Efron, 1994; Harvey & Lawson, 2009; King, Porter, & Vertiz, 2008), with minor changes made to expand the interpretation of the interview and the content presented by the interviewees.

The health belief model considers five basic belief aspects that affect the patient's likelihood of adherence to treatment, namely: a) Susceptibility: beliefs about vulnerability to a disease or its consequences, b) Severity: beliefs about serious effects of consequences in life, c) Benefits: beliefs that health recommendations will be effective and will reduce any threat, d) Barriers: beliefs that recommendations should be carried out in spite of physical, psychological or financial barriers, e) Self Efficacy: belief that one is capable of carrying out the health recommendation. Beyond these five basic health beliefs established by the authors, we take the liberty of adding two more categories that are presented as important data for the interpretation of the interviews. These categories are the impact of the diagnosis which was placed before susceptibility, and later the expectations of the future presented by the parents.

### *Procedure*

This study was approved by the ethics committee. Participants were given an orientation before being asked to sign a consent form. No organic or psychological risk to any of the participant is foreseen, and confidentiality of information is ensured.

Data analysis- The qualitative method was used in the clinical research and analysis of results based on the health belief model that considers five basic belief aspects that affect the patient's likelihood of adherence to treatment (Claydon & Efron, 1994). The categories previously established in the health belief model are: Susceptibility; Severity; Benefits; Barriers and Self Efficacy. Beyond these five basic health beliefs established by the authors, we add two more categories: the impact of the diagnosis and the expectations of the future presented by the parents.

### RESULTS

In addition to the content categories previously established in the health belief model (Claydon & Efron, 1994), two categories were added: one related to the impact of diagnosis and the other related to parents' expectations of the future. Upon diagnosis, many parents recognized the severity of the disease although they were not too familiar with Type 1 Diabetes. Parents experienced fear, anguish and denial. In terms of susceptibility, there is a perception on the part of the parents that they have caused the disease in the child, despite doctors' suggestions that diabetes is known to have an organic cause. This type of thinking can cause feelings of guilt and helplessness.

In this study the parents reported having had no prior knowledge of the disease, even in one case where the grandmother was a carrier of Type 1 Diabetes. Thus, the subjects have come into contact with the child's susceptibility of the disease only at the time of diagnosis. The question of the susceptibility appears to result in the fact that the only think that if any member of your family can develop some kind of chronic disease is a worrying factor, especially being your child. This leads the person to come into contact with their vulnerability. So some parents tend to deny the possibility of becoming ill.

Severity describes how parents assess the seriousness of the illness of the child and how they face the effects and consequences of the disease accordingly. It's this severity that will help them understand the situation of susceptibility and vulnerability and assist in contact with the conflict to the possibility of developing strategies for coping with the situation. Recognizing the severity of illness of children makes the parents realize the need for a change in their routine so the treatment can be followed correctly.

In topic-related to benefits, it was assessed the benefits that people with diabetes and their parents may have by following the treatment properly, in which the recommendations of health will be effective and reduce the threats. The benefit of treatment is to help parents in trying to follow the treatment properly. This helps prevent complications demonstrated by the severity and cause some calm and relief when they realize the benefits they can get on following medical recommendations.

Most parents in this study experienced anxiety, fear of making mistakes and an excessive need for control. Treatment was seen as a savior to prevent future complications due to poor control of diabetes. Even realizing that it is a disease that causes a multitude of feelings and changes in family routine, parents realize that following the treatment will benefit the health of the child. Parents cannot ignore the changes in lifestyle caused by the diagnosis, because the injections of insulin, glucose monitoring, pre-set the times for food, increased vigilance is essential to the welfare of the child.

Parents and people with diabetes know the ways to prevent the onset of chronic complications due to poor control of diabetes may avoid situations that cause damage or sequel, sometimes irreversible that put the carrier at risk. Due to these conditions, the control of diabetes causes changes in behavior and lifestyle to carry out its essential care. Mastering the knowledge on the disease prevents or reduces the occurrence of complications.

There is a difference of perception among parents regarding the barriers to treatment, namely: physical, psychological and financial. Was observed in this study that in some cases

the father leaves the whole responsibility upon the mother. It is perceived how necessary the father's involvement in this process is, because the mother has to accept that responsibility, thus reinforcing a climate of exclusion of the father in relation to decision making on the future of the child.

The self efficacy aspect is aimed at verifying the belief that the person is able to follow the recommendations of treatment to prevent diabetes complications. In this aspect, we try to evaluate the effectiveness of the parents in the treatment of their children. Self efficacy demonstrates whether the required treatment is being performed adequately by the people involved. This includes the patients themselves and their family, because if treatment is followed properly it generates, as already seen, benefits for patients, which demonstrate that the effectiveness is good, producing effects and assisting in the perception of improvement that the treatment is providing for both.

Regarding future expectations, the parents equated the onset of diabetes with a shorter lifespan. Also, chronic complications of the disease are foreseen by the parents. The parents expressed their desire for their child to have a life that is not just free from diabetic complications but free from the disease itself. The content analysis of interviews revealed the dynamic that parents experience during the process of the disease. They experience difficulties, fears and insecurities, the illness of the child, the more intensified by the fact of being a chronic disease.

It was remarkable that at whatever stage of the disease, the parents appeared to remain at the stage of initial diagnosis and news of their child's predicament. It is apparent that they require professional support from a multidisciplinary team who will help them deal with issues and information related to diabetes and treatment. Feelings provoked by the onset of the disease must be processed since the emotional state of the parents has a decisive influence on the ability of parents to accept the situation and their capacity to help their children maintain the treatment. The team must include a psychologist who has the specific knowledge and tools to analyze and understand the psychological variables involved in the situation. Parents and children alike can be given proper avenues to deal with their fears and insecurity. Placate those bad feelings can generate improvement in treatment and a better quality of life of the family in general.

In most cases, the diagnosis of the disease was delayed because medical service was sought only after the later onset of symptoms. Early symptoms were not recognized since most parents had no knowledge about the disease and its symptoms.

Faced with the diagnosis of the disease, many parents experienced denial while others were able to overcome the moments of crisis. Regardless of the choice made by each to support the new situation, the entire sample passed through the moment of impact. Even the ones that at first denied the situation in order to avoid suffering, later, the contact with reality led them to experience the impact of the disease. This movement of parents to "accept" or "deny" the situation was seen from their reports. These are thoughts and behaviors that demonstrate that they supposed that their children had diabetes.

Knowledge of the constant nature of the treatment triggered in the parents anxieties due to the fear of making mistakes. There is a felt need for control so that the treatment can be accomplished successfully, avoiding any organic complications. The greater responsibility of

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treatment was shown to fall on the mothers, although fathers showed interest and participation in the care and education of their child.

Government support in the material supplies (medicines, syringes, tapes, and other devices) decreases the financial barriers in the treatment of the disease. Another important factor was observed in relation to the difficulty that parents have to put limits on children. They tend to adopt extreme measures. It allows "everything" and yet not allows "nothing." This fact seems to be linked to not understanding the treatment and the consequences of non-adherence. The diet is presented, usually as a major problem not only at home, but mainly on social events.

It is also a concern of parents when the carrier has autonomy and is not over the constant control of their parents. What concerns, significantly, are the possible complications arising from organic disease, as there are several reports of cases where these organic complications reached the extreme, thus scaring the expectations of the future and imagine that parents expect to their children with diabetes.

Hoping for a cure of the disease is ever present. Parents hope for a cure to be developed soonest to avoid the physical and mental pain, and the suffering of the child and the entire family. Besides the possibility of complications that may occur regardless of a good control or not.

### DISCUSSION

The onset of diabetes, as triggered by stressful events, has appeared in the present study as well as in other studies. Predictors of self-immune attack of the pancreas reveal certain characteristics in the lives of parents (stressful life, serious difficulties, foreign parent, and low socioeconomic) that are associated with self-immunity against beta cells of children. These factors present a high risk of becoming diabetic (Sepa, Wahlberg, Vaarala, Frodi, & Luddvigsson, 2005).

Corroborating the data, of the question that if any member of your family can develop some kind of chronic disease is a worrying factor, especially being your child, a study showed that mothers who have cases of diabetes in the family, when passing through a genetic mapping, in which appears the possibility of their child developing diabetes in future, they are more concerned than the mothers who have the same opportunities, but have no cases of diabetes in the family (Lernmark, et. al., 2004).

Parents of children with Type 1 Diabetes, after the diagnosis, start the training of the specific needs of treatment, as an attempt to master all the parts needed for a good control in order to assume responsibility for the child (Boman, et. al., 2004). Although not easy, after diagnosis, parents have to adapt to necessary changes and help the child to adapt to the new situation, thus causing the production of intense emotions of the situation (Lowe, et. al., 2005).

This study showed that some parents who fear nocturnal hypoglycemia, not only sleep beside their child, but also wake up during the night to check whether the child is breathing. Authors report that parents experience such post-traumatic stress disorder in the period of six

weeks and six to twelve months after the diagnosis of diabetes. All mothers of children who had episodes of severe hypoglycemia had post-traumatic stress disorder.

The attitude of overprotection is found to develop in all parents, which can impair adherence to treatment by people with diabetes. It is important that parents help their child's quest for autonomy. Essential to the competence and care of diabetes, is the child's learning the techniques necessary for self-care and consciousness and responsibility of care of diabetes. Similar findings were reported that parents of adolescent patients have a less active role in supporting and encouraging the individualization and autonomy of their children than healthy adolescent's parents. (Seiffge-Krenke, 2002).

The role of the fathers as partners is also critical in treatment. Mothers have been observed to exhibit hostility to the child. Some authors observed that there may be a link between parental hostility and poor glycemic control. The lack of partner support leaves the mother as sole provider of the care and support needed by the child (Worrall-Davies, Owens, Holland, & Haigh, 2002). When the stress level becomes too high, the mothers exhibit hostile behavior. Sole provider of In the present study, only three (Karvonen, et. al., 2000) fathers were able to participate. The mother is more involved in caring for the child and the treatment of disease. This is a factor to be considered for the success of the treatment. When the mother does not feel overburdened and she knows that she can count on the support of the partner, the family relationships improve and treatment becomes successful.

Health professionals recommend an education program in diabetes that involve interventions which combine cognitive and affective components (Barceló, Robles, White, Jadue, & Vega, 2001).

In this study, we investigated the health beliefs of parents of children with Type 1 Diabetes, considering the basic beliefs on: impact, susceptibility, severity, benefits, barriers, self efficacy and expectations for the future. From this study it was observed that parents live all the steps proposed in this model of health beliefs. From the moment they are faced with the diagnosis of the disease, which causes great impact, up to the expectations of the future in relation to the carrier and the disease itself. Although the parents live all beliefs, we could see that this sequence is just an attempt to didactically structure the presentation of the results, but in practice it is not necessarily in that order. Nor is it just when parents are faced with the expectations of the future. Thus, the barriers may "appear" before the severity, and this may arise before susceptibility. This demonstrates the need to have attention to each case.

One of the limitations of this study is based on small number of parents interviewed. The other limitation is the fact that mostly parents interviewed are low-income population, which may demonstrate a different way of life and health beliefs. Further studies can focus on the psychological aspect of treatment, the adherence/non adherence to treatment and the role/influence of a multidisciplinary team/support to the parents. We also suggest programs of health promotion and prevention and treatment of diseases, which may lead to information about Type 1 Diabetes, focusing on the symptoms until the treatment in question and its consequences considering a good and a bad control.

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