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Early Detection Programs for Type 1 Diabetes: Addressing the Emotional Impact on Families

Early diagnosis programs for type 1 diabetes, aimed at identifying individuals at risk and those in presymptomatic stages of the disease, have been expanding globally in recent years. This is due to their potential to reduce rates of diabetic ketoacidosis (DKA)—a potentially life-threatening but preventable complication—as an initial presentation of the disease, decrease hospitalizations, and facilitate access to both clinical trials and

treatments that may alter the disease's progression. In this regard, the identification and monitoring of individuals at risk or in early stages of type 1 diabetes mellitus have been shown to lower DKA rates at the time of diagnosis of stage 3 (symptomatic stage) from 25%–62% down to 4%–6%. Additionally, reducing DKA at diagnosis may have a long-term impact by lowering HbA1c levels and decreasing the risk of complications.

Screening programs can be based on genetic testing (analyzing genetic regions associated with risk) or the analysis of autoantibodies. Genetic testing helps identify individuals at higher risk, but it does not diagnose the disease. However, detecting two or more diabetes-related autoantibodies allows for the diagnosis of type 1 diabetes before symptoms of insulin deficiency appear.

Screening programs based on pancreatic autoimmunity can target specific populations (first-degree relatives of individuals with type 1 diabetes or those identified as high risk through genetic screening) or the general population. These programs are considered the most useful, as 90% of individuals who develop the disease have no family history.

Regardless of the approach, receiving the diagnosis of a chronic illness such as type 1 diabetes has a significant psychological impact on both the individual and their family. While early-stage diagnosis allows more time for diabetes education and emotional adjustment, it also introduces uncertainty about disease progression.

The impact of receiving a positive pancreatic autoimmunity result involves cognitive, emotional, and behavioral aspects. Most studies have focused on parents, showing that anxiety and worry are the most common reactions. Although these feelings tend to subside over time, some individuals may be particularly vulnerable to prolonged anxiety or depression.

For this reason, major scientific societies, including the International Society for Pediatric and Adolescent Diabetes (ISPAD), the American Diabetes Association (ADA), and Breakthrough T1D, recommend in their guidelines the systematic assessment of the psychological impact of a presymptomatic type 1 diabetes diagnosis and the provision of continuous psychological support for patients and their families. These organizations emphasize the importance of regularly evaluating stress, anxiety, depression, and quality of life, as well as early intervention to address emotional challenges associated with managing a chronic illness. They also advocate for integrating psychologists and social workers into multidisciplinary

care teams to ensure a holistic approach to diabetes care.

PSYCHOLOGICAL IMPACT ON PARENTS

Most literature on the psychological impact of screening and predicting type 1 diabetes focuses on the parents' emotional reactions when they learn that their child is at risk or receives a presymptomatic diagnosis. Most parents report concern or distress upon receiving this information, as it brings uncertainty about the future diagnosis and fear of complications.

A diagnosis of type 1 diabetes in children affects both the patient and their family, leading to increased stress, anxiety, and depression. Studies show that:

A total of 35% of parents of children with type 1 diabetes report high levels of stress at diagnosis, and in 19% of cases, this stress persists for 1-4 years. A total of 59% of parents experience severe anxiety at diagnosis, and more than 20% develop symptoms of depression.

However, families diagnosed through autoantibody screening programs report less anxiety, fewer difficulties, and better quality of life than those diagnosed after hyperglycemia symptoms appear. Preventive Behaviors

Once parents have been informed about their child's risk of type 1 diabetes, they often adopt preventive behaviors. The most comprehensive study to date observed a significant increase in blood glucose monitoring and awareness of diabetes symptoms. These behaviors include dietary changes, regular physical activity, and ongoing health monitoring

ANXIETY AND WORRY

While worry and anxiety are common responses to early diabetes diagnosis, they typically diminish over time. However, some groups may be especially vulnerable to high levels of anxiety or depression, particularly such as parents of children with positive autoantibodies and families with a direct relative with type 1 diabetes. Uncertainty about the future can heighten these feelings, emphasizing the need for adequate psychological support.

RECEIVING A DIAGNOSIS OF A CHRONIC DISEASE LIKE TYPE 1 DIABETES MELLITUS HAS A SIGNIFICANT PSYCHOLOGICAL IMPACT ON BOTH THE INDIVIDUAL AND THEIR FAMILY



FOLLO-UP BEHAVIORS AND LIFESTYLE CHANGES

Many families adopt increased vigilance behaviors and lifestyle changes, such as paying more attention to diet, exercise, and continuously seeking information about the disease.

Here are some recommendations for managing anxiety in the best possible way:

- **Follow health care professionals' advice:** Complete all necessary tests and follow-ups, and consult with medical professionals about any doubts or concerns.
- **Take things one step at a time:** Focus on the next step rather than anticipating the future, paying attention to relevant symptoms.
- **Treat your child regardless of the situation:** Maintain normalcy and avoid letting the medical condition dominate all family interactions.
- **Seek support from diabetes organizations:** Connect with people in similar situations to share experiences and receive emotional support.
- **Avoid information overload:** Learn only what is necessary about the condition at each stage to prevent feeling overwhelmed.
- **Manage fear and anxiety:** Recognize these feelings as normal and find strategies to cope with them, such as writing down concerns and discussing them with the health care team. **D**

CONCLUSIONS

The diagnosis of type 1 diabetes has a significant psychological impact on both the patient and their family, potentially leading to increased levels of stress, anxiety, and depressive symptoms. Screening programs for early diagnosis offer several advantages, including a reduction in diabetic ketoacidosis, decreased hospitalizations, access to clinical trials and immunomodulatory treatments, and the opportunity for early diabetes education. From a psychological perspective, early diagnosis allows for more time to adapt and emotionally prepare for the condition. Ensuring access to professional psychological and emotional support, along with adequate information, is essential for families participating in screening programs. These measures contribute to a better quality of life, more effective disease management, and a reduction in the long-term negative impact on mental health and family well-being.

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