36 - EDUCATION AND NUTRITIONAL QUALITY OF LIFE FOR PEOPLE WITH DOWN SYNDROME (DS)

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1. INTRODUCTION

Down syndrome (DS) is a trisomy of chromosome 21 originated in utero which was first described in 1866 by John Langdon. The identification of this anomaly can be checked soon after birth due to the manifestation of its major phenotypes, such as: flattened occiput, short, thick neck, single crease in the palm of the hand, impairment and mental retardation in length.

The patients with DS exhibit some pathologies such as congenital heart disease (40%); hypotonia (100%); impaired hearing (50 to 70%); vision (15 to 50%); changes in the cervical spine (1 to 10%); thyroid disorders (15%); neurological conditions (5 to 10%); premature aging and obesity (100 to 80%). (AMABIS, 1981).

As people with Down syndrome have a predisposition to develop obesity, nutritional risks compromise your lifestyle causing changes in the immune system, resulting in greater susceptibility to autoimmune diseases and recurrent infections, and metabolic characteristics, making them more vulnerable those related to nutritional status.

Regarding obesity, and Kerbauy Ades (2002) discuss that it is considered a chronic disease characterized by the accumulation of adipose tissue in the body. Also suggest that it may be considered a risk factor for other chronic diseases such as diabetes, cardiovascular diseases, hypertension, respiratory problems, damaging the quality of life of people with DS.

According to Fields et al. (2005), the characteristics related to obesity are related to the standard of food which has to be distinguished: from the choice of food by the process of chewing and swallowing. Accordingly, it becomes important to assess the quality of food so there is an appropriate intervention, this fact can improve the nutritional status of these individuals as these characteristics compromise adequate absorption of consumed, resulting from their slow metabolism nutrients. In this towards the choice and preparation of food are considered of paramount importance, since they have difficulty swallowing.

Besides these nutritional factors that compromise the quality of life of these people, lack of physical activity influences the performance of low metabolism impairing calorie burn, hence no weight reduction, these aspects also influence the hormonal disturbances such as changes in the gland thyroid, muscular hypotonia, constipation.

The laxity of the muscles involved in the swallowing process coupled with binge eating causes the DS patients do not have a sense of satiety compromising your nutritional status increases the risk of onset of obesity.

Given these diseases, it is necessary to make a related approach to nutrition education, for those with SD assist in improving the quality of life in relation to inappropriate feeding practices.

The objective of this paper is to show how the change in eating habits of patients with DS is directly related to improved quality of life, since many diseases like obesity that occurs in patients with DS, and that can be treated or prevented only with feeding.

2. THEORETICAL BACKGROUND

2.1 Down Syndrome

The SD can be classified in the following ways: Trisomy, Robertsonian translocation, mosaicism and duplication of a portion of chromosome 21. The simple trisomy, in which all cells have 47 chromosomes, is the most common form and accounts for about 90% of cases . Translocation, the extra chromosome pair 21 is attached to a chromosome of another pair. In mosaicism, what happens is an error in the distribution of chromosomes in the second or third cell division. In this case, both the egg and the sperm have a normal number of chromosomes, which may be usually divide, however, at a given time, one of the cells divide abnormally, resulting in a cell with 47 chromosomes and one with 45 chromosomes. In the duplication of a portion of chromosome 21, a region of chromosome 21 undergoes a doubling phenomenon. This would lead to an extra amount of genes of this chromosome can develop SD undetectable by karyotype (GONZÁLEZ, 2007).

From considerations of J. Langdon Down, other scholars have added new knowledge about the same. Fraser and Michell (1876), Ireland (1877), demystifying the terms "mongoloid idiocy" (similar to the people of Mongolia) of "cretinóide idiocy" which according to Saad (2003, p.5), "Such practices were consistent with the ideals classical culture and bodily perfection as political base of culture and classical Greek society. "So were people of different postulates of classical society standards, of Wilmarth (1890) and Telford Smith, in 1896, perfected a technique with thyroid hormone for the treatment of SD.

Only in 1932, a Dutchman called Waardenburg, who was an ophthalmologist noticed that the SD was caused by a chromosomal abnormality. In 1934, Adrian Bleyer believed that this abnormality could be a trisomy. In 1959, Dr. Jerome Lejeune, Patricia A. Jacobs and colleagues simultaneously discovered the existence of an extra chromosome.

The phenotypic characteristics that stand out are: brachycephaly, very small fronto-occipital diameter, with upper slope palpebral fissures, epicanthal folds, flat nasal bridge and hypoplastic middle region of the face, the neck is short, and may have only one palmar crease, the tongue is protruding and hypotonic; There clinodactyly of the 5th finger of the hand and an increased Regarding the incidence of SD may be related to maternal age. According Santos et al (2006), the risk of a woman between 35 and 39 years having a child with Down syndrome is approximately 6.5 times larger than a between 20 and 24, the syndrome may vary from the expressions and intensity, and may not show physical manifestations.

According to the Organization of the Movement Down-OMD (2014), there still exists in the country specific statistics on the number of Brazilians with Down syndrome. An estimate can be raised based on the ratio of 1 for every 700 births, taking into account the entire Brazilian population. According to this account, or about 270 000 people in Brazil would have Down syndrome.

2.2 Nutrition and Down Syndrome

The process of proper nutrition for children with DS should happen immediately after birth through breast milk, as this is the best way to make child nutrition, being the most complete food in this stage of life to suck milk mother strengthen the muscles of the mouth.

The major difficulty in nurturing these children are related to muscular hypotonia, thus sucking and swallowing, early in

life, need stimulation to aid in muscle toning.

These incentives should be encouraged in children even when she starts feeding with solid food, and the food itself the vehicle for muscle toning, because the process of kneading the food rather than liquefies them, can avoid swallowing problems along the lives of these children.

Healthy eating habits should be introduced since childhood as well as prevent binge eating, a fact important for the onset of obesity, the relationship of eating enough to satisfy must be worked constantly since the difficulty of meeting the recurring little muscle tone can be a trigger factor for binge eating aggravating the nutritional aspects and triggering obesity impaired quality of life.

Little is known about the specific nutritional needs facing people with SD, as well as the parameters used to assess nutritional status of this group by health professionals. What is found in the literature are studies that present data on growth and development curve weight and height. Therefore, do not settle the basic dietary guidelines, that is, recommendations for optimal intake of macro and micronutrients targeting the growth and development expected in order to avoid greater involvement of clinical conditions. (COHEN, 1999; SANTOS et al, 2006).

To Cotran et al (2005) due to the predisposition to obesity of patients with SD, stems from genetic and exogenous factors such as hypotonia of the muscles involved in digestion does not provide a feeling of fullness after a meal, which makes they eat compulsively, in addition to decreased basal metabolic rate, thereby reducing the burning of genetic material derived from feeding occurs, beyond the practices of insufficient physical activity increases the risk of sedentary life, harming their health.

According to Ellis et al (2008) point out that studies show the prevalence of overweight and obesity in children with Down syndrome, resulting from decreased basal metabolic rate, hence they have greater difficulty losing weight, needing nutritional guidance so that there is a development normal.

Diabetes mellitus type 1 is apparently more common condition among patients with this syndrome than in the general population, with an estimated prevalence of 1.4 to 10.6% (ANWAR et al, 1998).

The increased survival of patients with SD is directly related to the new treatment technologies, primarily for the treatment of congenital heart disease, which are the biggest cause of premature death of these individuals.

Various pathologies resulting from SD appear arising from improper eating habits increase the risk of complications. If there is treatment with health care and food and food-restricted diet for some groups (carbohydrates, proteins and lipids), these conditions tend to reduce or control symptoms but with nutritional intervention these early events in tend not appear.

3. FINAL THOUGHTS

Research on the nutrition of patients with DS are still scarce, which makes the analysis more precise about how proper nutrition can help improve the quality of life of patients with SD. But genetic factors such as impaired muscle hypotonia in common SD hindering the process of chewing, especially in children with Down syndrome, resulting in an inefficient nutrition, besides compulsive food intake due to the lack of common satiety in SD being precursor of obesity and disease chronic non-communicable.

However, when doing related to adequate food for SD bibliographic, can relate that healthy eating habits should be present dede these people infancy because the spur is correct intake, nutrition becomes relevant, since some pathologies arising from the syndrome can be prevented or controlled with proper nutrition including obesity. Nutritional Education for SD is a fundamental tool for there ability to understand and learn how proper nutrition can be extremely important in improving their quality of life with DS.

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EDUCATION AND NUTRITIONAL QUALITY OF LIFE FOR PEOPLE WITH DOWN SYNDROME (DS)

ABSTRACT

The Down Syndrome (DS) is a genetic disorder with specific phenotypic characteristics, these characteristics along with their sufferers have low basal metabolism which is related to the onset of obesity and chronic diseases such as diabetes, heart disease, dyslipidemia. The objective of this paper is to show through the literature review, such as changing eating habits of

patients with SD is directly related to improved quality of life, since obesity and these chronic non-communicable diseases that affect can be treated or prevented with feeding. Theoretical foundation for the scientific articles, theses and dissertations on those with SD and Nutrition Education as aspect of improving quality of life were used. Before these appointments, it is necessary that healthy eating habits are present from childhood for people with Down syndrome, because while encouraging proper intake of food, nutrition becomes important in improving the quality of life of these people.

KEYWORDS: Down Syndrome. Nutrition Education. Quality of life.

ÉDUCATION ET LA QUALITÉ NUTRITIONNELLE DE VIE POUR LES PERSONNES ATTEINTES DU SYNDROME DE DOWN (DS)

RÉSUMÉ

Le syndrome de Down (DS) est une maladie génétique ayant des caractéristiques phénotypiques spécifiques, ces caractéristiques ainsi que leurs patients ont un faible métabolisme de base qui est liée à l'apparition de l'obésité et des maladies chroniques telles que le diabète, les maladies cardiaques, dyslipidémie. L'objectif de cet article est de montrer à travers la revue de la littérature, telles que la modification des habitudes alimentaires des patients atteints de SD est directement liée à l'amélioration de la qualité de vie, puisque l'obésité et ces maladies chroniques non transmissibles qui affectent peuvent être traitées ou prévenues avec l'alimentation. Fondement théorique pour les articles scientifiques, thèses et mémoires sur ceux avec SD et éducation à la nutrition comme aspect de l'amélioration de la qualité de vie ont été utilisés. Avant ces nominations, il est nécessaire que de saines habitudes alimentaires sont présents dès l'enfance pour les personnes atteintes du syndrome de Down, parce que tout en encourageant la consommation adéquate de la nourriture, la nutrition devient important dans l'amélioration de la qualité de vie de ces personnes.

MOTS-CLÉS: le syndrome de Down. Éducation nutritionnelle. Qualité de vie.

EDUCACIÓN Y CALIDAD NUTRICIONAL DE LA VIDA DE LAS PERSONAS CON SÍNDROME DE DOWN (SD)

RESUMEN

El síndrome de Down (SD) es un trastorno genético con características fenotípicas específicas, estas características junto con sus pacientes tienen baja el metabolismo basal que está relacionado con la aparición de la obesidad y las enfermedades crónicas tales como diabetes, enfermedades del corazón, dislipidemia. El objetivo de este trabajo es mostrar a través de la revisión de la literatura, como el cambio de los hábitos alimenticios de los pacientes con SD está directamente relacionado con la mejora de la calidad de vida, ya que la obesidad y estas enfermedades crónicas no transmisibles que afectan pueden ser tratadas o prevenidas con la alimentación. Se utilizaron fundamento teórico para los artículos científicos, tesis y disertaciones sobre las personas con SD y Educación Nutricional como aspecto de la mejora de la calidad de vida. Antes de estas citas, es necesario que los hábitos saludables de alimentación están presentes desde la infancia para las personas con síndrome de Down, ya que mientras alentando el consumo adecuado de los alimentos, la nutrición se vuelve importante en la mejora de la calidad de vida de estas personas.

PALABRAS CLAVE: Síndrome de Down. Educación Nutricional. Calidad de vida.

EDUCAÇÃO NUTRICIONAL E QUALIDADE DE VIDA PARA PORTADORES DE SINDROME DE DOWN (SD)

RESUMO

A Sindrome de Down (SD) é uma anomalia genética, com características fenotípicas específicas, juntamente com estas características os seus portadores apresentam um metabolismo basal baixo o qual está relacionado com o aparecimento da obesidade e das doenças crônicas não transmissíveis como: diabetes, cardiopatias, dislipidemias. O objetivo deste trabalho é apontar através da revisão da literatura, como a mudança de hábitos alimentares dos portadores de SD está diretamente relacionada à melhora da qualidade de vida, visto que a obesidade e estas doenças crônicas não transmissíveis que os acometem podem ser tratadas ou prevenidas com a alimentação. Para a fundamentação teórica foram utilizados artigos científicos publicados, dissertações e teses, sobre os portadores de SD e a Educação Nutricional como aspecto da melhora da qualidade de vida. Diante destes apontamentos, faz-se necessário que os hábitos alimentares saudáveis estejam presentes desde a infância das pessoas com SD, pois ao incentivar uma ingestão correta dos alimentos, a nutrição torna-se relevante na melhora da qualidade de vida destas pessoas.

PALAVRAS-CHAVE: Síndrome de Down. Educação Nutricional. Qualidade de vida.