



The role of the nurse in the care of children with down syndrome

O papel do enfermeiro nos cuidados de crianças com síndrome de down

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INTRODUCTION

Down syndrome is a genetic condition caused by trisomy 21 and which leads to inadequate chromosomal distribution during the meiosis phase. Down syndrome is not a disease.

It consists of a natural genetic occurrence that happens for unknown reasons, in pregnancy, during the division of the cells of the embryo. It is a chromosomal alteration, when children are born endowed with three chromosomes (trisomy) 21, and not two as usual. This genetic alteration affects the development of the individual, determining some peculiar physical and cognitive characteristics.

Faced with the positive diagnosis for down syndrome, family members, especially parents, receive a very large impact and have different reactions, often without knowing what to do, how to proceed, become disoriented, and develop various feelings such as fears, anguish, uncertainty, shame, insecurity, among others.

In this sense, the role of the nursing professional is to guide this family, with a humanized approach, passing on to it the care inherent to the patient, and the knowledge about the syndrome.

The nursing professional for being in charge of the care the family has in its attributions, especially the care, and in the families that receive this diagnosis its role is of paramount importance to the clarification and welcoming of these parents.

In addition, nursing care directed to patients with Down syndrome should be humanized, where through this care the nurse can also guide family members not to see it as a disease, but to demonstrate that this child can lead a normal life, with some limitations only.

In this sense, the study will seek to demonstrate the true role of the nursing professional in the care of patients with the syndrome, as well as family members.

For this understanding, the following question was developed: Given the difficulties faced by nursing professionals, inherent to the care of patients with down syndrome and their families, is this professional really qualified?

To answer the problem, the study is divided into three moments in order to clarify the main specific objectives that consist of a first moment to contextualize what is the Down syndrome, and its characteristics,



in a second moment, the study brought the understanding of the role of the nursing professional in relation to the care of patients with Down Syndrome and their families, And finally, the third and last chapter seeks to demonstrate the importance of nursing professional training in the care of patients with Down syndrome.

The present theme is extremely important not only to the innovations of nursing in general, but also to society as a whole, in view of the exponential increase of children diagnosed with Down Syndrome, who lack treatments aimed at improving static and dynamic balance, since the syndrome affects beyond the cognitive system, the motor coordination of these individuals. Many family members and parents when receiving a positive diagnosis for the syndrome need a humanized follow-up that has the function of clarifying their doubts about this pathology. In this sense, the nursing professional, for being at the forefront of the care treatment, has a significant role in the approach of this family.

Thus, the research will be of great relevance, in order to clarify the importance of this professional not only in relation to the specific care of patients with Down Syndrome (DS) but also, as should be their treatment in relation to the family members who receive the diagnosis.

Therefore, the research will contribute significantly, especially to nursing professionals, in order to demonstrate the importance of this professional in the care provided to these families, as well as to clarify whether these professionals are in fact prepared to care for both patients and family members.

Regarding the methodological procedures of the present study, methods of content exploration were used, seeking information in books and scientific articles in order to better clarify the subject. Addressing the opinion of authors, in order to understand the problem of the study in question.

To this end, the methodology used will be made through a bibliographic survey based on studies in scientific articles and theses developed from 2012 to 2022 published in the Digital Library of Theses and Dissertations (BDTD), Capes, Scielo.

The study focused on references with a time cut from 2012 to 2022, however some previous references were necessary for scientific basis.

The following descriptors were used: Nursing, Care, Down Syndrome. The selection of articles occurred initially by reading the titles and abstracts, followed by reading in full only the selected articles, where the most relevant information for the present study was highlighted. Only articles whose full texts can be accessed were used.

GOAL

To develop a discussion about the work of nursing professionals in the face of the positive diagnosis of a child with Down syndrome.



METHODOLOGY

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DEVELOPMENT

Nursing, seen as a social practice, attends to people as its object of work and provides care inherent to the disciplinary knowledge of the field so that their attitudes emphasize the epidemiological profiles of the community and focus on the health needs to respond later, following the epidemiological model, which in turn focuses on the collective as a whole (MIRANDA, et al, 2014)

According to Silva (2019) the biggest problem that families face when they receive the diagnosis of a child with Down syndrome is the lack of information about the syndrome and how to deal with this new reality that is to come, which is something unknown, often the treatment of a child with Down syndrome requires circumventing the syndrome and this scares families, which in turn suffer from a lack of information.

In this sense, nursing care requires sensitivity in dealing with families, clarifying doubts about how to provide for the child, always remembering that all this is new in family life and this generates anxiety and concern about the best way to welcome the child (SILVA, 2019)

Araujo (2019) explains that taking care of the health of a child with Down syndrome is not an easy task for nursing professionals, and initially this professional should focus on supporting and informing the family and diagnosing the pathologies associated with the syndrome.

From 2 years to 10 years, they should be guided in the maintenance of a healthy lifestyle, development of physical activities, autonomy for self-care, education, structural monitoring, specialized care for emotional/psychiatric disorders, laboratory tests of thyroid hormone (TSH, T4L, T3) (SILVA, 2019)

The nurse's role is to guide the family about the syndrome and how to deal with the child with down, which surprises the diagnosis and the family often has no reaction and does not know how to deal with this new reality. Nursing has a great role in this moment, because it deals directly with the family and its



insecurities that the news brings to their reality. That is why it is important to explain that this child can also grow and realize their dreams, making the family aware of the importance of encouraging the child and helping him to be as dependent as possible is the role of the nursing professional (SILVA, 2019)

In this sense, good care should be developed that provides maintenance of the family structure, control of parental anxiety and general and specific orientations. The approach should be systematic and the planning of interventions should focus on the care provided throughout life, from the newborn to adulthood. (SAINTS, 2014)

FINAL CONSIDERATIONS

Down syndrome (DS) is a chronic condition caused by a chromosomal abnormality that occurs on average from 1 in 700 to 800 live births, with the most common health problems being congenital heart disease, respiratory, vision, hearing, hypothyroidism, and emotional and emotional problems. growth disorders. Most children with DS are moderately mentally retarded and progress through the normal stages of development, but at a slower pace.

The syndrome is characterized by a chromosomal abnormality in which individuals have 47 chromosomes in their karyotype, the development of an abnormality resulting in chromosome 21. The diagnosis of this abnormality is usually made at birth or soon after based on physical characteristics. Individuals affected by this syndrome have marked mental retardation, as well as delay in the development of motor and intellectual functions.

The conclusions point to the valorization of nursing work and show its importance in the team in the face of the person with Down syndrome. The results also show that caregivers need to be open and prepared for this care not always assumed, both for the child and for the family, which is also seen as an active participant in the development of this child.

There is a need for greater training of professionals in this area to emphasize the importance of its implementation and the benefits for the patient and his family, as well as the satisfaction of the nurse when receiving the reward for their commitment.

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