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The impact of the diagnosis of autism in parents of children

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Abstract

The impact of the diagnosis in parents causes the cycle of family life will change profoundly, with serious disturbances in the reorganization and adjustments to this new reality. The objectives of the study aim to evaluate the quality of life of children / adolescent siblings of people with autism; to know the perception / opinion of the brothers on the impact that autism has had on family and check what kind of association between sociodemographic variables and of opinion on the impact of autism on the family and the QOL of participants. This is a study of the quantitative, non-experimental, descriptive correlational where 96 parents with autistic children participated kind. Data were collected through a questionnaire and a scale to assess the impact of the diagnosis of autism. The data show that on average the impact of the diagnosis of autism in parents showed moderate. Parents, mostly not yet managed to overcome the initial shock and showa great concern for the future of their children. The adjustments and changes made to the social level are dimensions where parents have lower difficulties. The data show that the impact of the diagnosis of autism in parents participating in the study was quite variable, depending on different variables, reinforcing the importance of continuity of studies on this topic in order to mitigate this impact.

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Keywords: Autism, parents, impact of diagnosis.

1. Introduction

Infantile autism is a mental disorder which falls within the pervasive developmental disorders. It is characterized by severe and pervasive qualitative impairment in several areas of development, such as reciprocal social interaction skills, communication skills or presence of behaviours, stereotyped interests and activities, this loss represents a marked deviation from the development or mental age of the individual (APA, 1995).

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The family is a primary social group, which plays determinative roles in the formation and development of the individual and in the affective, cognitive and psychological domain. However, the whole family cycle changes when a child is born with a disability, having to rearrange, add new expectations and making new realities emerge.

To Martins et al. (2006), the sibling interactions are essential and important components of socialization, as they allow the development of instrumental and affective skills of relationship. What is learned in relationships with siblings can influence and enhance the cognitive, affective and social interaction skills, as well as enable the development of a positive self-image; and frequent positive interactions between siblings provide an important source of emotional support while infrequent and negative interactions can affect the psychological adaptation process.

The quality of life of adolescents is described as a construct that encompasses components of well-being and emotional, mental, social and physical behavioural functions, as perceived by themselves and by others (Gaspar et al., 2006).

There are multiple factors that affect the behaviour of adolescents in their lifestyle and may be positive for health promotion, as well as damaging and negative triggering situations which are not favourable to their quality of life. Factors such as physical activity, family, school, friends, socioeconomic status, perception of oneself and free time are determinants to be evaluated as teenagers understand the quality of health-related life (Gaspar et al., 2006).

Ferreira et al. (2009) reported that siblings of children with chronic illnesses, such as autism, must deal with a range of emotions, with the isolation from family and familiar with various changes in day-to-day and therefore need to be accompanied and assisted going through that experience. Dinis (2005) says also that the need for these brothers to deal with the stigma of having a chronic sick in the family is a constant factor in their daily lives.

Generally, it is assumed that siblings of children with disability or chronic illness are more susceptible to psychological maladjustment than siblings of healthy children. However, despite believing that siblings of these individuals are at increased risk for a variety of problems, some research indicates that cohabitation is not necessarily a harmful experience (Hewitt, 2006; Feinberg, 2000). There are even authors who advocate a positive influence.

Stoneman et al. (1988) stated that older siblings, particularly sisters of children with delayed cognitive development, assumed more responsibility for care of the affected brother, than brothers of healthy children. For this first group, this increased responsibility has generated conflicts between siblings, diminished opportunities for contact with other children and decreased leisure activities.

In fact, siblings of children with disabilities and chronic illnesses can experience numerous experiences related to this peculiar situation, as less parental attention, changing roles, structure and family activities, identification with the disabled child, feelings of guilt or shame, as well as negative reactions from people outside the family. The difficulties may be even more pronounced in small families, in which the task of care of a disabled child cannot be divided easily and there are no other siblings to compensate for the lack of parental attention. Furthermore, the increase of stress in the parents can generate concomitant or residual adverse effects in those siblings (Oliveira 2009).

Studies conducted by Bagenholm and Gillberg (2006) and Pereira (2009) showed that siblings of autistic tend to be more concerned about the future, felt more alone and had more problems in relationships with other children.

Given the framework, and based on an ecological approach to the psychological and social development of children and adolescents, siblings of people with autism, the relevance of the study of their quality of life seems to us of an unquestionable importance and so we opted for studying this subject.

2. Problem Statement

The few studies carried out on the quality of life of adolescent siblings of autistic persons show that this (QOL) can be highly influenced negatively by the disease situation, however there are many factors to affect the way this is perceptioned. In this sense it is important to assess the quality of life of these adolescents and to identify the factors that influence that perception.