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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 show a 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 perceived. In this sense it is important to assess the quality of life of these adolescents and to identify the factors that influence that perception.

3. Research Questions

The research questions raised in this research are: What is the Quality of Life perceived by youth / adolescent siblings of people with autism spectrum; which factors most affects this perception?

4. Purpose of the Study

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.

5. Research Methods

It is a non-experimental, descriptive and correlational study that used a quantitative methodology. The sample is non probabilistic for convenience and consists of 68 adolescents, siblings of people with autism enrolled in APPDA (Portuguese Association for Developmental Disorders and Autism) from the city of Viseu, Portugal, were the data was collected between March and September, 2013.

The dependent variable is the quality of life of adolescents and the independent variables are the socio-demographic and circumstantial.

Procedures

The data were processed using the Statistical Package for the Social Sciences (SPSS) version 17.0 for Windows with descriptive measures and the parametric and non-parametric tests, to interpret the results.

The study was approved by the Superior School of Health of Viseu's Ethics Committee. Permission to use the scales was granted by the authors and data collection was authorized by those responsible for the institutions involved.

6. Findings

We can see that the participants of our study are in number 68, 40 female and 28 male. The age of the total sample varies between a minimum value of 7 and a maximum of 20 years, corresponding to an average age of 14.29 years, standard deviation of 3.92.

When considering schooling, we verified that the group with the highest percentage representation (35.3%) is attending the 3rd cycle following those who are in secondary education (23.5%). In third position we have with equal percentage (17.6%) those attending the 1st cycle and University (23.5%), and finally we just 5.9% which is attending the 2nd cycle of schooling.

The whole sample lives with their parents, 90.9% has brothers, 35.7% has sisters, 29.1% refers to integrate grandmothers into their household.

The quality of life (dimensions and total) of adolescents was evaluated with a scale which includes 52 items and can range from 52 to 260 points. In our study we found values ranging between 138 (Min) and 232 (Max) with a corresponding average of 175.52 points (67.50) and a standard deviation of 31.2 (M = 67.51; Sd = 12, 0).

Overall we found (cf. Table 1) that the highest values are positioned in the dimensions, provocation, economic issues and general humour state; lower values are those corresponding to free time, friends and school environment.

Table 1. Descriptive statistics of the dimensions scale of Kidscreen

<i>Dimensions</i>	<i>Min</i>	<i>Max</i>	<i>Mean</i>	<i>Sd</i>	<i>Mean*</i>	<i>Sd*</i>
<i>Health</i>	13	22	16,00	2,4	64,00	9,6
<i>Feelings</i>	17	27	20,53	3,2	68,43	10,8
<i>Humour</i>	18	35	26,00	5,2	74,28	14,9
<i>Self Perception</i>	10	25	17,29	3,7	69,17	15,0
<i>Free Time</i>	6	24	13,47	5,1	53,88	20,4
<i>Family / environment</i>	14	30	19,70	4,2	65,68	14,1
<i>Economic issues</i>	6	15	11,82	2,2	78,82	15,1
<i>Friends</i>	10	29	18,35	6,0	61,17	20,0
<i>School environment</i>	15	25	19,18	3,3	63,92	11,1
<i>Provocation</i>	9	15	13,18	2,1	87,84	14,6
<i>QOL TOTAL</i>	138	232	175,52	31,2	67,51	12,0

*Average on a scale from 0 to 100

7. Conclusions

Thus, and by way of summary, we conclude that:

QOL of siblings of children / adolescents with autism is very satisfactory (M = 67.51) for the majority, finding the highest values linked to the dimensions, provocation, economic issues and general humour state. The most affected aspects are free time, friends and school environment;

We also found that overall QOL is higher in boys between 7 and 12 years, attending the 1st and 2nd cycles, whose knowledge was given by other elements than parents and in those who do not feel harmed;

The majority (64.7%) of participants had situational awareness of autism by parents, having been concern the dominant feeling. The prevalent reactions were surprise, revolt / rejection, sadness and shock;

Most clearly assumes that this condition affected their life as opposed to 17.4% (all elements males) who denies this interference;

The increased implications that are more referred are "the need to frequently monitor him", the "have to help him in all" and having "to understand him." The girls express more implications in personal life than boys;

About the feelings and the attention that the family dispenses their brother answers are vague and conflicting, but are distributed by the expressions "I feel very bad", "I think it's an injustice", "I understand the situation" and "there are no differences";

The implications brought their lives, are essentially "feeling little attention from parents", the "feel that it's an injustice", "that the priorities are all for him" and finally the "not leaving the house, on account of possible shame". The analysis by gender shows that girls express more personal implications in life than boys.

The evidence from this study confirm the multiplicity of factors involved in QOL, still it invites us to reflect on new strategies that allow obtaining a better understanding that facilitates the establishment of training and information intervention programs aimed at promoting the quality of life of these subjects.

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