BRIEF REPORT

Quality of life in siblings of autistic patients

Qualidade de vida em irmãos de autistas

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Original version accepted in English

Abstract

Objective: *To evaluate the Quality of Life (QoL) among siblings of autistic patients.* ***Methods:*** *Casuistic: siblings of autistic patients (n = 31) and, as a control group, siblings of patients with speech disorder (n = 30). Inclusion criteria: age between 7 and 11 years old; absence of current mental disorder; regular attendance to school. Exclusion criteria: antecedents of clinical or psychiatric diseases; disabilities (visual, auditive or motor); antecedents of cognitive and/or intelligence disabilities. Instruments included a questionnaire which evaluated the quality of life in a subjective way.* ***Results:*** *it was observed worse QoL among siblings of autistic patients (p = 0.000).* ***Conclusions:*** *The hypothesis that the quality of life was compromised in children (aged 7 to 11) by the presence of an autistic sibling was confirmed, and was worse than that of siblings of children with speech disorders.*

Keywords: *Autistic disorder; Quality of life; Sibling relations; Questionnaires*

Resumo

Objetivo: *Avaliou-se a Qualidade de Vida (QV) em irmãos de autistas.* ***Métodos:*** *casuística: irmãos de autistas (n = 31) e irmãos de crianças com problemas de fala (n = 30), como controles. Critérios de inclusão: idade entre 7 e 11 anos; ausência de transtorno mental atual; freqüentar escola regular. Critérios de exclusão: antecedentes de doenças clínicas ou psiquiátricas; deficiências visual, auditiva ou motora; deficiências cognitivas e/ou de inteligência. Utilizou-se questionário que avalia a qualidade de vida de forma subjetiva.* ***Resultados****: houve prejuízo na qualidade de vida de irmãos de autistas, em relação ao grupo controle (p = 0,000).* ***Conclusões:*** *Confirmou-se a hipótese de que a QV estaria comprometida, em crianças de 7 a 11 anos, pela presença de um irmão(ã) com autismo e seria pior do que a de irmãos de crianças com problemas de fala.*

Descritores: *Transtorno autístico; Qualidade de vida; Relações fraternas; Questionários*

Study performed at the Child and Adolescent Psychiatric Service (SEPIA) of the Institute of Psychiatry of the Medical School of the University of São Paulo (FMUSP), São Paulo, Brazil.

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Introduction

There are often found in the clinical practice parents of autistic children who are concerned about the possibility of their children being at risk of developing problems due to their social and communication impairment or to their behavior.[1] The parents have also doubts if their home would be worse for the 'normal' children, as they dedicate more time and energy with the mentally disturbed child.[2]

With the increasing awareness about the significant impact of a sibling on the development of the other and the potential stress and confusion of roles that siblings may experience when there is a child with mental impairment or chronic disease in the family, it is increasingly important that the needs of these siblings be considered and met.[3]

In order to assess the impact of the presence of a sibling with Child Autism (CA) on a child's life, this study has evaluated the Quality of Life (QoL) among siblings of autistic children.

According to the World Health Organization,[4] the QoL can be defined as the perception of a subject regarding his/her position in life, in the context of his/her culture and values and with regard to his/her objectives, expectations and standards. The QoL may also be 'colored' by factors such as physical health, psychological state, level of independence, social relationships, environmental factors and the subject's personal beliefs.

When the QoL is focused on childhood and adolescence the assessment should not be limited to the child's social, physical and emotional functioning, as it is important to take into account alterations stemming from the development in this period of life.[5] The perception about what is QoL for a child seems to be different than that of an adult.[6] Probably in this phase of life the environment and the economic conditions are more important than the subject's physical and mental conditions, as the child is born and develops in these circumstances, which influence his/her perception of QoL.[7]

A good instrument to assess the Qol on childhood should be built under the child's point of view, covering a wide spectrum of his/her centers of interest and domains of life. The *Autoquestionnaire Qualité de Vie Enfant Imagé* - AUQEI - *Qualidade de Vida em Crianças de 4 a 12 Anos*[8] (Quality of life of children aged 4 to 12 years) - is an instrument which gathers these qualities and takes into account the level of development, dependence, the particularities of application of a questionnaire in a child and is easily applicable.[9] Up to now, the AUQEI is the only instrument in our milieu to assess the Qol in childhood.

The control group in this study was siblings of children with Specific Speech Articulation Disorder (SSAD), due to the interest in the influence of communication in the QoL.

The objective of this study was to assess the QoL among children whose siblings have diagnosis of CA and compare it to that of siblings of SSAD subjects. The main hypothesis is that the QoL would be more impaired among children, due to the presence of a sibling with CA, than among SSAD subjects.

Methods

It was used a questionnaire to assess the QoL among children with CA and, as a control group, siblings of SSAD children.

Samples were obtained at the Child and Adolescent Psychiatric Service of the Psychiatric Institute of the Medical School of the University of São Paulo and completed at the Lapa Mental Health Municipal Ambulatory and at the ambulatory of Child and Adolescence Psychiatry and Psychology of the Hospital of the Municipal Public Servants of São Paulo.

The proposal for this study was submitted to the Ethical Committee for the Analysis of Research Projects (CAPPesq) of the Clinical Hospital of the Medical School of the University of São Paulo (HC-FMUSP) and was approved in August 8, 2001 (Research Protocol 319/01). It was also submitted and approved by the two other services in which these samples were completed.

Casuistic

Siblings of subjects diagnosed with CA (F84.0, ICD 10) and, as control group, siblings of subjects diagnosed with SSAD (F80.0, ICD 10)[10] were selected.

Data collection was performed between October 2001 and March 2003. Seventy-three interviews were scheduled and sixty-eight were effectively accomplished. Seven subjects were excluded according to the following criteria:

1) Inclusion criteria: age between 7 and 11 years, regardless of gender, color or race; score below 14 in the QMPI - Child Psychiatric Morbidity Questionnaire (for children aged 5 to 14 years);[11] regular attendance to school.

2) Exclusion criteria: diagnosis of medical chronic diseases, severe chronic impairment (visual, auditive or motor) or psychiatric diseases; diagnosis of cognitive and/ or intelligence alterations.

The age range chosen was from 7 to 11 years, in order that children had the same level of cognitive development, that of concrete operations.[12]

Therefore, two samples were obtained: SIBLINGS-CA with 31 subjects, siblings of subjects with diagnosis of CA; and SIBLINGS- SSAD with 30 subjects, siblings of individuals with diagnosis of SSAD.

Table 1 shows the samples' characteristics.

Table 1 – Demographic Data [Means (Standard Deviation)] and results of the AUQEI: comparison between SIBLINGS-CA and SIBLINGS-SSAD

	SIBLINGS -CA Mean (sd) or n(%)	SIBLINGS - SSAD Mean (sd) or n(%)	Total	p
Age	9.5 (1.7)	9.1 (1.4)	–	0.365
Mean number of siblings	1.9 (1.7)	1.7 (0.8)	–	–
Gender				0.452
female	17 (53.1)	15 (46.9)	32	
male	14 (48.3)	15 (51.7)	29	
AUQEI	49.3 (5.6)	57.7 (4.5)	–	0.000

Instruments

In order to assess the QoL it was used the AUQEI,[8] which consists of 26 questions applied to the own child and assesses his/her satisfaction in different life circumstances, by means of 4 factors (autonomy, leisure, functions and family), being supported by images, aided by 4 faces expressing different emotional states. For each question the child should answer if he/she is very unhappy, unhappy, happy or very happy and the answers are given scores from zero to three.

In this study questions number 14 (How do you feel when you are in hospital?) and number 20 (How do you feel when you take your medicines?) were excluded, as they are not related to the population of subjects studied.

Results

Both samples were statistically similar regarding the variables age (Student t-test, p = 0.365), gender (Chi-Squared test, p = 0.452) and mean number of siblings (Table 1).

For the results of the AUQEI, after performing the Student t-test, it was obtained p = 0.000, indicating difference between the AUQEI means of both samples: SIBLINGS-CA with mean (SD) 49.3 (5.6) and SIBLINGS- SSAD with 57.7 (4.5) (Table 1).

Discussion

Subjectively, according to the opinion of the own siblings of autistic children, obtained through the AUQEI, the QoL was impaired. The scores of the sample of siblings of autistic subjects were significantly lower than those of the control group.

AUQEI has shown to be a goof questionnaire to assess the QoL in childhood, being easily applicable and understood by the children. This questionnaire has taken into account the children's point of view, their development and the several aspects of dependence in their lives (such as physical and psychical ones), which were considered as the most important factors to assess the QoL in childhood in this study.

We have not found similar global data to compare the same type of population (siblings of autistics children), regarding the overall Qol. Only one study mentions the QoL among siblings of children with chronic disease (in this case, cancer) and these siblings reported low QoL levels.[13]

Subjects with SSAD, besides speech problems, may have problems with sociability and behavior, expressed differently and with lower intensity than in the CA. Due to this, the comparison with a control group of siblings of SSAD children was of especial interest, as it made us suppose that the deficits found are more related to the autistic syndrome as a whole and not to the specific deficits of CA. The understanding of this factor (or factors) may the subject for further studies.

Conclusion

The hypothesis of this study, that the QoL is impaired among children aged 7 to 11 years due to the presence of a sibling with CA and is worse than that of siblings of children with SSAD, was confirmed.

Therefore, it becomes crystal clear the need of attention and help to the siblings of autistic children. Further studies should focus on the understanding of the factors which may contribute for the better adaptation of these siblings, for the role of the family in this context and for the development of preventive interventions for this population.

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