

RESEARCH GROUP: INTERDISCIPLINARY LABORATORY FOR RESEARCH IN AUTISM (LABIRINTO)

PERCEPTIONS, MEANINGS AND PRACTICES OF MOTHERS OF CHILDREN DIAGNOSED WITH AUTISM

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Abstract

This was a qualitative study in which semistructured interviews were used to collect data. The mothers of autistic children with milder symptoms tend to be more optimistic and emphasize the positive aspects of their children, whereas mothers of children with more severe symptoms talked of the particularly disabling symptoms of their child. With respect to the cause of the problem, the mothers' reference to organic reasons is a recurrent feature of the interviews. No explanatory model of autism other than that derived from biomedical knowledge was provided in this study. The limitations imposed by autistic children on the lives of their mothers were part of all the narratives, most particularly those of the mothers of children with more severe symptoms. Social support and the identification of a network with which to share experiences and the suffering of their children appear to minimize the effects of isolation in these mothers.

Keywords: Perceptions; Parents; Autism; Social support.

INTRODUCTION

This article is based on the realization that numerous health belief systems are present in society, leading to different conceptions in terms of the etiology, patho-

physiology, severity and treatment of disease.⁽¹⁾ These belief systems are triggered by different cultural views of the world, providing each individual with meaning and defining their collective experience. On the other hand, such a cultural framework is determined by where people are located in the world, how they perceive life events and how they behave.⁽²⁾

The objective of this paper is to understand parents' perceptions of symptoms experienced by their children, seeking to identify the relationship between parental perception of the disease, the severity of the children's symptoms and the therapeutic options selected.

METHODS

This was a qualitative study in which semistructured interviews were used to collect data. These interviews were recorded and then transcribed. The data analysis was performed on two levels.⁽³⁾ The first level addressed the content of the interviews with respect to the information obtained by direct answers to the questions, while the second level of analysis evaluated relevant content that did not relate directly to the investigator's questions. The Autism Behavior Checklist (ABC) was used to assess the severity of symptoms in the autistic children.⁽⁴⁾ The children had been previously diagnosed with an autistic disorder in accordance with the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR).⁽⁵⁾

RESULTS

The study sample consisted of nine mothers of autistic children and a great-aunt who was the legal guardian of one of the children. At the first level of analysis, most parents were found to emphasize positive aspects in their child. Many also referred to behavioral disorders or a developmental delay, while others failed to mention any problem at all. The severity of the child's symptoms appears to affect the different perceptions of mothers regarding their autistic child. Mothers who reported milder symptoms tended to emphasize their child's more positive aspects and were generally more hopeful about the future than mothers of children with more severe symptoms. About parents perceptions of the cause of autism, most believed that autism has an organic origin usually associated with difficulties during childbirth. In which refers to treatment, these parents considered the best treatment to be specialized schools or regular schools if they had been adapted to include autistic children. Monitoring of the child by a multidisciplinary team involving physicians, a psychiatrist, general practitioner, psychologist, physiotherapist, speech therapist and occupational therapist is

also considered important. Parents expect their child to acquire greater independence through treatment. They also expect his/her speech and socialization to improve. At the second level of analysis, a recurrent theme in all the interviews concerned the overwhelming need for the mother to dedicate herself to her autistic child and the requirement for major changes in parents' lives in order to deal with an autistic child.

DISCUSSION AND CONCLUSION

The mothers of autistic children with milder symptoms tend to be more optimistic and emphasize the positive aspects of their children, whereas mothers of children with more severe symptoms talked of the particularly disabling symptoms of their child. With respect to the cause of the problem, the mothers' reference to organic reasons is a recurrent feature of the interviews, irrespective of education level. A study conducted in China also showed that the organic aspects, particularly those referring to genetic and prenatal conditions,⁽⁶⁾ are the cause of autism most commonly mentioned by mothers. Parents look for ways to make sense of the problems they face and the belief in an organic disease can contribute towards alleviating feelings of guilt, particularly given that many authors have historically blamed a mother's lack of affection as a cause of autism.⁽⁷⁾ No explanatory model of autism other than that derived from biomedical knowledge was provided in this study. Most of the mothers believe that its origin is organic, but are unable to produce any explanatory model. For treatment families seek professional assistance and educational programs to deal with the stress of having an autistic child, but it did not seem to be related to a previous explanatory model of the disorder. The emphasis given in the present study to treatment in specialized schools is probably due to the fact that all the children included in the study were enrolled at a specialized school, since this was where the study was conducted. It was noted that while the children were in class, their mothers would gather in the schoolyard to wait for them. There they had the opportunity to socialize, sharing their doubts and anxieties and exchanging ideas on how to deal with their child's problems. Therefore, the school does not only provide treatment for the children, but also offers a means of socialization for the caregivers. The most recurrent theme in all the interviews was the extent of the mother's dedication to her autistic child and the fact that mothers had to make major changes to their lives to be able to cope with this child. These results are in agreement with a study conducted with Australian mothers, who reported that an autistic child in the family prevented them from working outside the home environment.⁽⁸⁾ The limitations imposed by autistic children on the lives of their mothers were part of all the narratives, most particularly those of the mothers of chil-

dren with more severe symptoms. The life course of these mothers is changed because of the constraints brought about by the birth of an autistic child. Social support and the identification of a network with which to share experiences and the suffering of their children appear to minimize the effects of isolation in these mothers.

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