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

A RESTRICTED GLÚTEN AND CASEIN DIET FOR THE TREATMENT OF AUTISM: WHAT ARE PARENTS LOOKING FOR? – DIET AND AUTISM

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Abstract
This study aims to understand parents perceptions of the importance of restricted glutén and casein diet for the treatment of autism. The study sample consisted of mothers and teachers of five children / adolescents with autism. All the mothers reported some improvement in the children due to the diet, while teachers attributed any improvement to their own work or family support. Only one of the mothers related the search for a diet as treatment to a specific explanatory model for the disease. For mothers, the difficulties of their children leads to a sense of frustration and impotence facing autism. It remains, however, hope, revealed by the search for therapeutic options, which is expressed by the demand of the diet. Teachers highlighted the potential of these children and their positive development with the pedagogical work. Both mothers and teachers highlighted their lack of knowledge regarding the cause of autism. Diet appears as one more form of treatment in the quest of mothers searching for improvement in their autistic children, despite lacking a connection to a specific explanatory model about the disease for the vast majority of mothers.

Keywords: Perceptions; Parents; Autism; Treatment; Diet.
INTRODUCTION

Autism spectrum disorder (ASD) have no defined etiology and are characterized by abnormalities in sociability, language and behavior.\textsuperscript{(1)} There is no defined etiology and no pharmacological treatment directed to the key symptoms of ASD. Studies show that over 75% of children’s family with ASD choose treatments outside the official medical system, based on their perceptions of safety and previous experiences with adverse effects on pharmacological therapies suggested by biomedicine.\textsuperscript{(2)} Based on the theory that exogenous peptides (glutemorphin and caseomorphin) play a role in the pathogenesis of ASD interfering with neurotransmissions in the central nervous system (CNS), the restricted gluten and casein diet has attracted interest. Some authors defend that children diet GF / CF improved attention, communication, social interaction and motor skills.\textsuperscript{(3,4)} Other studies, however, showed no significant improvement of symptoms in children with ASD on this diet.\textsuperscript{(3)}

OBJECTIVES

To evaluate parents perceptions of the importance of this treatment for the children and determinate the motivation of their mothers for choosing it and know how they perceive the effects of this diet.

METHODS

The study sample was composed of children already diagnosed as having Autistic Disorder according to the DSM-IV (2000) enrolled in school specializes in treating children with ASD for at least six months and during treatment with diet GF / CF for at least three months. Mothers and teachers of five autistic children were interviewed with a semi-structured interview in order to understand the perceptions of parents and teachers about the child’s illness, the effects of diet GF / CF and why they have chosen this treatment.\textsuperscript{(5,6)} The Aberrant Behavior Checklist was used to evaluate the severity of symptoms of children according to the assessment of family members and teachers.\textsuperscript{(7)} The interviews were transcribed and analyzed on two levels (analysis based on questions and analysis based on narrative evidence).\textsuperscript{(8)}

RESULTS

The study sample consisted of mothers and teachers of five children / adolescents with autism. The children were between five and eight years, there was still a young man of 20 years, all male. The age of onset ranged between nine months and two years
and the diagnosis was made between two and a half years and seven years old. All children were followed at specialized school for at least two years and made some other therapeutic approach: Regular School, Medicines, Phonoaudiology, Occupational Therapy, Ludotherapy and Sports. The length of treatment with diet ranged from nine months to three years. The results of the ABC scale were arbitrarily considered mild when the score was less than or equal to 49 points and severe when greater than 49 points. It was considered that three children had mild symptoms by the evaluation of teachers and parents; one had severe symptoms by the evaluation of both mother and teacher; another, mild symptoms by the evaluation of mother and severe by the evaluation of teacher. There were differences between the views of the mothers and teachers, alternating between predominantly positive and negative aspects. All the mothers reported some improvement in the children due to the diet, while teachers attributed any improvement to their own work or family support. Everybody mentioned their ignorance of the cause of autism, though some of the mothers are beginning to try to find organic explanations for the symptoms. Only one of the mothers related the search for a diet as treatment to a specific explanatory model for the disease. In the first level of analysis, positive perceptions about children predominated in the speech of mothers, whereas negative perceptions are more often evidenced by the teachers. Children, who were seen more negatively, present agitation and aggression, which interferes in social child’s and parents’ life, as well as the possibility of teachers’ performances. Different from direct answers to the questions of the interviewer, the second level analysis reveals that for mothers, the difficulties of their children leads to a sense of frustration and impotence facing autism. It remains, however, hope, revealed by the search for therapeutic options, which is expressed by the demand of the diet. For teachers, the comparison between the two levels of analysis shows opposite trends from mothers: in the first level of analysis predominates perception of the limitations and difficulties of children, while in the second level analysis appears highlighted the potential of these children and their positive development with the pedagogical work. However, this teachers’ speech, about the children’s improvement, is not related to the use of the diet. Thus, the discourse on hope for the improvement of children seems to be related to their own work and their expectations for this dedication.

**DISCUSSION**

Both mothers and teachers highlighted their lack of knowledge regarding the cause of autism. The few incipient attempts of mothers’ explanations of this disorder are focused on organic or biological causes, while the teachers point out the flaws in
the parents’ education as possible causal factors: “too much love” and “lack of limits”. The search of a particular treatment is generally a reflection of the underlying cause of illness or problem. People seek significances (experience, cause) for different signs (illness) and according to their experiences, seek treatments that can somehow remedy their greatest difficulties in facing this reality. Thus, treatment of the cause can lead to symptom resolution and healing. The narrative of only one mother fits this comprehensive model. She suggests early use of antibiotics as a possible cause of autism in her son, since this use would had interfered with the immune system. The effect of diet in improving the immune system, preventing inflammatory and allergic processes, according to mothers, can act in the child overall improvement. Most mothers, however, reported a pilgrimage hopeful among the various therapeutic options, reflecting powerlessness in relation to the disease, which is also noticed in the discourse of teachers. How treatment sought proved ineffective, it may also reflect the absence of an explanatory model for the disease. The posture of powerlessness against the disease manifestations, even more pronounced in the speech of the teachers, reinforces that they do not have a clear idea about the causes and possible treatments for these children.

CONCLUSION

Diet appears as one more form of treatment in the quest of mothers searching for improvement in their autistic children, despite lacking a connection to a specific explanatory model about the disease for the vast majority of mothers.

REFERENCES


