

THE IMPACT OF AUTISM DIAGNOSIS ON THE FAMILY

BIANCA ANDREICA-SĂNDICĂ¹, SANDA PATCA², ALINA PANAETE³, SORIN ANDREICA⁴

^{1,2,3,4} Children Clinical Hospital, Cluj-Napoca, Children Psychiatry Clinic
^{2,4} University of Medicine and Pharmacy, Iuliu Hatieganu, Cluj-Napoca

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Abstract: Introduction: Having a child diagnosed with autism can be a challenge for any family. The study aims to identify the parental couples' emotions in order to start the process of parent involvement as a co-therapist to recover the child. Materials and methods: Twenty parents were included in the study, which have at least one child diagnosed with autism. We used a questionnaire composed of five parts which covered the following: Age of the child, the age at which the parent has seen the first signs of disease and the age at which the child was diagnosed with autism; Identifying the emotions (and their intensity) arising from knowing the diagnosis of autism; Placing the parent in one of five stages of the mourning process (denial, anger, bargaining, depression and acceptance); The description of the coping mechanisms used by parents with COPE questionnaire.; Specifying the parent type of locus of control and social desirability using the LOC scale. Results and discussion: The results allow us to make the following statements: Emotions identified by parents were: sadness, concern, pain, despair; The parents included in the study are in one of the stages: anger (10%), depression (10%) and acceptance (75%); The time elapsed from diagnosis to finding its acceptance is between one month and three years; The coping mechanisms used are: positive reinterpretation, acceptance, planning, the use of social support, active coping, religious coping; The locus of control belongs to a normal range of values and the social desirability was quantified in a range of increased values. Conclusions: The reaction to finding the diagnosis of autism varies from one family to another and may encounter a large variety: from disbelief, anger, guilt, helplessness, devastation, surprise, or even rejection of the child, to understanding and relief when finally the parents have an explanation for their child behaviors. Early intervention is important in the psychological sustaining of the parent, as parent involvement in the recovery of the child with autism has a determinant role in his development and in ensuring a high quality of life.

Cuvinte cheie:
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Rezumat: Introducere: A avea un copil diagnosticat cu autism poate fi o provocare pentru orice familie. Studiul de față își propune identificarea trăirilor părintelui și a cuplului parental pentru a demara procesul de implicare ca și coterapeut a părintelui în recuperarea copilului. Material și metodă de lucru: Au fost incluși în studiu 20 de părinți care au cel puțin un copil cu diagnosticul de autism. Am utilizat un chestionar compus din cinci părți care viza următoarele: Vârsta copilului, vârsta la care părintele a observat primele semne de boală și vârsta la care s-a pus diagnosticul de autism; Identificarea emoțiilor (și a intensității acestora) apărute la aflarea diagnosticului de autism; Plasarea părintelui într-una din cele cinci etape ale procesului de doliu (negare, mânie, negociere, depresie, acceptare); Descrierea mecanismelor de coping utilizate de către părinți cu ajutorul chestionarului COPE; Precizarea tipului locusului de control și dezirabilitatea socială a părintelui folosind scala LOC. Rezultate și discuții: Rezultatele ne permit să facem următoarele afirmații: Principalele emoții identificate de către părinți au fost: tristețe, îngrijorare, durere, disperare; Părinții incluși în studiu se află în etapele de: mânie (10%), depresie (10%), acceptare (75%); Intervalul de timp scurs de la aflarea diagnosticului până la acceptarea lui este între o lună și trei ani; Mecanismele de coping utilizate sunt: reinterpretare pozitivă, acceptare, planificare, folosirea suportului social, coping activ, coping religios; Locusul de control aparține unui interval normal de valori iar dezirabilitatea socială a fost cuantificată ca înscriindu-se într-un interval de valori crescute. Concluzii: Reacția la aflarea diagnosticului de autism variază de la o familie la alta, putând întâlni neîncredere, mânie, vină, neajutorare, devastare, uimire, sau chiar respingerea copilului, până la înțelegere și ușurare că, în sfârșit, părinții au explicație pentru comportamentul copilului lor. Este importantă intervenția precoce în susținerea psihologică a părintelui, deoarece atragerea părintelui în procesul de recuperare a copilului cu autism are rol determinant în evoluția acestuia și în asigurarea unei calități a vieții crescute.

INTRODUCTION

Autism is a disorder that is usually first diagnosed in early childhood. Autism is the fastest-growing developmental disability and it is estimated that 1% of the population may have a diagnosable autistic spectrum disorder (ASD) (1). Studies in Asia, Europe, and North America have identified individuals

with an ASD with an approximate prevalence of 0.6% to over 1%. A recent study in South Korea reported a prevalence of 2.6% (2).

Autism is a complex developmental syndrome, representing a heterogeneous group of individuals with similar symptoms and multiple etiologies. It is characterized by

¹Corresponding Author: Bianca Andreica, Ospătăriei street, Cluj-Napoca, Romania; e-mail: sbandreica@yahoo.com tel +40-0264428491
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qualitative impairments in social interactions, qualitative impairments in communication and speech, and repetitive, stereotyped, and reduced patterns of behaviour and interests.

Having a child diagnosed with autism can be a challenge for any family. Parenting patterns do not cause autism. However, high parental skill level in working with the child may improve prognosis (1).

THE AIM OF THE STUDY

The study aims to identify the parental couples' emotions in order to start the process of parent involvement as a co-therapist to recover the child.

MATERIAL AND METHOD

Twenty parents were included in the study, which have at least one child diagnosed with autism. We used a questionnaire composed of five parts which covered the following:

1. Age of the child, the age at which the parent has seen the first sign of disease and the age at which the child was diagnosed with autism.
2. Identifying the parent emotions (and their intensity) arising from knowing the diagnosis of autism.
3. Placing the parent in one of five stages of the mourning process (denial, anger, bargaining, depression and acceptance).
4. The description of coping mechanisms used by parents with COPE questionnaire.
5. Specifying the parent type of locus of control and social desirability using the Locus of control (LOC) scale.

In order to identify the parents' feelings as a result of learning the autism diagnosis, its evolution and its prognosis, we asked them to choose one or more of the feelings listed in the questionnaire, or to add another one (if it was not in the questionnaire). The quantitative description of what they felt was quantified through the intensity of the feeling: not at all, very little, some, much, very much.

The 5 stages of the grieving process (denial, anger, bargaining, depression and acceptance) were identified through questions pertaining to: the amount of time elapsed from learning about the autism diagnosis to present time; thoughts, feelings, behaviours which parents exhibit towards the autistic child.

The COPE scale contains 15 coping mechanisms, each with 4 items, making for a total of 60 items. Each item counts on a scale from 1 to 4 depending on the frequency of the expressed behaviour. Each coping mechanism can get a score from 4 minimum to 16 maximum. LOC refers to the perceived location of reinforcement sources for a person - that is, who or what is responsible to the things that happen to a person. LOC scale contains 50 items, 10 for social desirability and 40 for locus of control. Social desirability counts on a scale from 10 to 40, and locus of control from 40 to 160. This study was designed and conducted according to the guidelines provided in the Declaration of Helsinki.

RESULTS

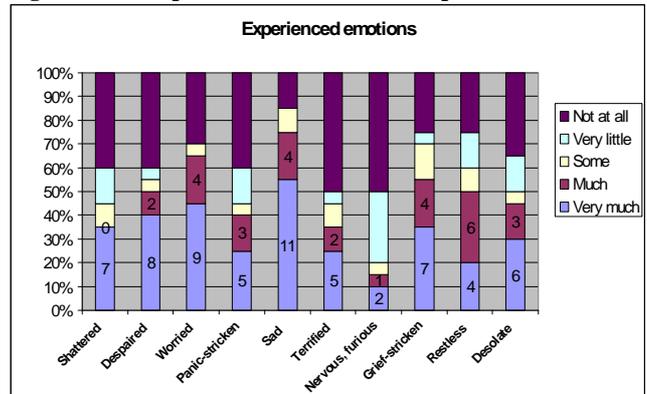
Analysing the data we found that the mean age of the child at the moment of evaluation was 6 years and 3 months, the mean age at which the parent has seen the first signs of disease was 2 years and 6 months and the mean age at which the child was diagnosed with autism was 4 years and 5 months.

Parents experience a range of emotions in response to learning that they have a child with autism (fig 1)

From this graphic, we can see that the parents felt the following when they were explained the autism diagnosis: shattered, despaired, worried, panic-stricken, sad, terrified,

nervous, furious, grief-stricken, restless, desolate, all belonging to the spectrum of sadness, anxiety and rage.

Figure no. 1. Experienced emotions of the parent



About 50% of the parents admitted to feeling sadness, worry was present in about 40% of the parents, and only three admitted to feeling fury.

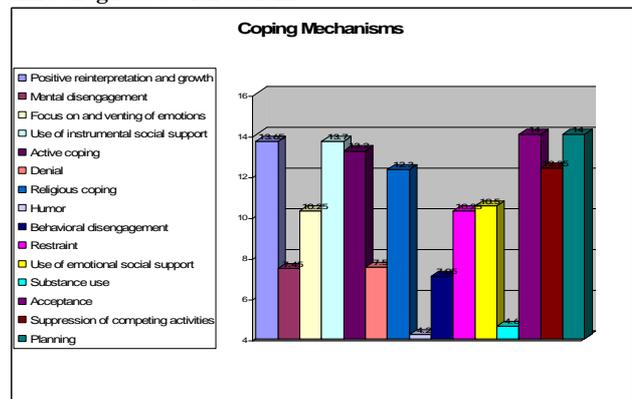
Parents go through a mourning process after a doctor tells them that their child has infantile autism, and that there is no cure (fig 2).

Figure no. 2. Mourning processes



According to this graphic, 75% of the parents (referring to the assessed parent) are in the acceptance stage, 10% in the depression stage, 10% in the anger stage and 5% in the negation stage. Parents identified as being in the depression or anger phase were recommended to seek psychological counselling. These stages do not necessarily come in the order noted above, nor are all steps experienced by all patients, though it is stated that a person will always experience at least two.

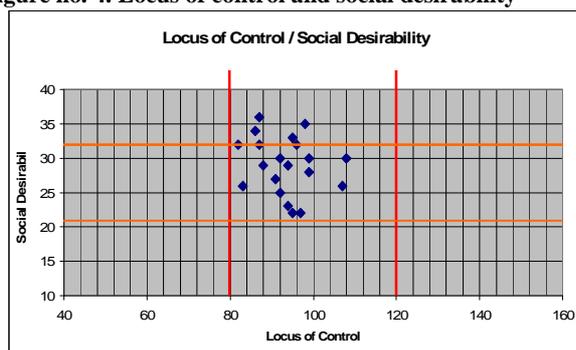
Figure no. 3. Coping strategies used by parents having a child diagnosed with autism



Parents of autistic children and adults cope with issues ranging from guilt and frustration to financial issues, isolation,

and sheer loneliness. In our study we found 6 coping mechanisms relevant to parents raising a child with autism: planning, acceptance, positive reinterpretation and growth, active coping, use of instrumental social support, and religious coping (fig 3). The graphic that shows locus of control and social desirability (fig 4) presents: a) locus of control situated in the 80-120 interval – which allows us to assert that it belongs to a normal interval; b) social desirability is at the upper limit, or it exceeds 30. Social desirability represents the tendency of the respondents to replay in a manner that will be viewed favourably by others.

Figure no. 4. Locus of control and social desirability



DISCUSSIONS

Diagnosis of autism requires careful history taking, focusing on the developmental story, presence of core behaviors, and observation of the child in several settings.

In our study we found that the mean age at which the child was diagnosed with autism was 4 years and 5 months. Mandell and Novak show that the average age of diagnosis was 3.1 years for children with autistic disorder, 3.9 years for pervasive developmental disorder not otherwise specified, and 7.2 years for Asperger's disorder. The average age of diagnosis increased 0.2 years for each year of age. Rural children received a diagnosis 0.4 years later than urban children (3). The average age of diagnosis for autism disorders in the United States has remained at 3 to 4 years of age, and even later for children living in socio-economically depressed and rural communities (4). Learning that a child has a chronic illness or disability can be devastating for many parents, especially those without an extended support system. Parents often feel alone, isolated, and their emotions may fluctuate between the reliefs of finally knowing what is wrong, to the despair that the child suffers from a disability with no known cure. Following diagnosis, confusion, guilt, anger, depression, and resentment may occur. Faced with a lifetime of challenges, family members may become depressed or even suicidal. Kübler-Ross originally applied the stages of mourning process to people suffering from terminal illness, later to any form of catastrophic personal loss (job, income, freedom) (5). Often, people will experience several stages in a "roller coaster" effect—switching between two or more stages, returning to one or more several times before working through it. None of the parents evaluated in our study were identified to be in the denial stage because it wasn't for the first time that they have heard about the diagnosis of autism.

The COPE Inventory was developed to assess a broad range of coping responses, several of which had an explicit basis in theory. The inventory includes some responses that are expected to be dysfunctional, as well as some that are expected to be functional. There is some evidence that mother's and father's coping mechanisms differ. Among the parents interviewed in our study, 18 were mothers. A study published by

Hastings (6) shows that parents of children with autism use the following coping mechanisms: active coping, problem-focused coping, positive coping, religious coping, denial. Active coping was related to more stress and health problems in parents.

Mothers reported more stress than fathers. Mothers used problem focused coping strategies more frequently than fathers, but no difference was found for emotions focused coping strategies (6). Locus of control refers to the extent to which individuals believe that they can control events that affect them. Individuals with a high internal locus of control believe that events result primarily from their own behavior and actions. Those with a high external locus of control believe that powerful others, fate, or chance primarily determine events. Locus of control is similar to other control-related constructs, such as attributions, learned helplessness, and self-efficacy. Research shows that whereas high externality scores are associated with high depression scores, internality is associated with more positive adjustment to a physical disability (7).

Seeing the high levels of social desirability we consider the normal interval of locus of control to be as a result of trying to cover the real situation of the families with a child with autism.

CONCLUSIONS

The reaction to finding the diagnosis of autism varies from a parent to another and may encounter sadness, worry, grief-stricken.

75% of the parents are in the acceptance stage of the mourning process.

The time elapsed from autism diagnosis to finding its acceptance is 2 years and 3 months.

The coping strategies frequently used by parents are acceptance, planning, positive reinterpretation, social support; religious coping and less used are drug use and humor.

The practitioner who works with families with a child with autism need to be aware of coping mechanisms used by parents in order to help them to prevent the onset of mental health disease.

Working with families is an important part of the evaluation and intervention in autism, and the parent has a determinant role in the child development and assuring a high quality of life for his child.

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