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Research Article

Parental Perceptions of the Diagnostic Process of Autism Spectrum Disorders in a Greek Sample

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Abstract

Diagnosis of Autism Spectrum Disorders (ASD) is complex and parents often experience mixed feelings during and after the diagnostic process. This study focused on Greek parent's perceptions and views of the diagnostic process relating to their child with ASD. One hundred and ninety three parents of children (N=193) completed a survey, which included information on various aspects of the diagnostic process, measures of satisfaction and perceptions of the post-diagnostic phase. Questionnaires were analyzed from a quantitative and qualitative point of view. Mothers (from the part of the family) and pediatricians (from the part of the professionals) were the first who recognized the early signs of ASD. The average age of diagnosis in the present sample was 4 years. A major finding is that parents whose children were diagnosed before or at 30 months of age held more positive and optimistic perceptions of the diagnostic process in comparison to the 'late diagnosis' group. In addition, the present study underlines the important role of various professionals during the assessment, although many parents do not feel satisfied from the diagnostic process. To conclude, the process of diagnosis remains a significant challenge for all those involved in this process. Implications for improvements in the diagnostic process of ASD are proposed.

Keywords: Autism spectrum disorder; Parental perceptions; Parental satisfaction of the diagnostic process; Diagnosis of ASD

Abbreviations

ASD: Autism Spectrum Disorders; PDD-NOS: Pervasive Developmental Disorders-not otherwise specified; KEDDY: Centre for Differential Diagnosis and Support (Greek abbreviation)

Introduction

Autism Spectrum Disorders (ASD) constitute a group of complex neurodevelopmental disorders characterized by impairments in communication, social interaction and restricted repetitive behaviors or interests. According to the Diagnostic and Statistical Manual-V (DSM-V, APA 2013) [1], Autism. They considered potential explanations, including different methodologies, recognition of associated behaviors and the development of specialist services. One part of the observed rise in autism disorders can be explained by the changes in diagnostic criteria and the growth of awareness of parents and professionals. However, the authors recognise that there may have been a true rise in the numbers of children with ASD, which is difficult to measure, without applying current diagnostic criteria to earlier studies [2].

The diagnosis of ASD

Early identification and diagnosis of ASD is a complex process which requires thorough investigations by different health professionals [3]. Diagnosis of ASD is made by recognizing patterns of behavior present in early life, requiring a detailed personal history that links together all the available information [4].Medical practitioners and psychologists generally conduct the diagnosis, although a multidisciplinary approach which includes assessment by a speech pathologist and occupational therapist has also been advocated as being beneficial in providing information that will assist with a diagnosis. Recently published national guidelines in each country aim to help clinicians in the diagnostic process [5].

The diagnostic process and its impact on parents

Receiving a clinical diagnosis of an ASD has an impact on the individual and the family. Assessment of ASD is a complex and ongoing process which involves a considerable amount of time. However, the benefits of an early and reliable diagnosis are many: the parents have access to reliable information about their child, the child has access to appropriate early interventions services [6,7]. Delays in receiving a diagnosis can lead to parental dissatisfaction and this can be a barrier in the implementation of effective support or intervention strategies [8]. Furthermore, parents who experience a long diagnostic delay may lose confidence in the healthcare professionals involved and are more likely to look for alternative treatments for their child which have poor empirical support [9,10]. Delays can also affect the quality of life for family members, the presence of behavior problems, care giving challenges, limited social life as well as increased risk of mental health problems for parents [11,12].

Although the symptoms of ASD can be present in a child as young as 12-18 months of age, the age of final diagnosis differs significantly between studies and countries. Howlin and Moore in a landmark large scale study in U.K found that children with ASD were diagnosed on average at 6 years old [13]. At the end of the 90's, the age of diagnosis fell gradually. The data obtained by Latif and Williams evidenced a decrease in the mean age at diagnosis for the

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ASD from 5.9 in the period 1994-1998 to 5.5 in the period 1999-2003 [14]. Mandell et al. evidenced that the average age at diagnosis was 3.1 years for children with autistic disorder, 3.9 years for PDD-NOS, and 7.2 years for Asperger syndrome [15].

The factors that usually hinder early diagnosis are: (a) the variability in the nature of ASD in children, (b) mild symptoms of autism (e.g Asperger syndrome) appear quite later in the child's life and are less observable, (c) the scarcity of assessment measures suitable for use with toddlers or preschool children, (d) long waiting lists for obtaining a diagnosis, (d) a lack of specialized training among professionals to recognize the subtle, early symptoms of ASD (e) comorbidity with other disorders complicating the diagnostic process (f) a shortage of specialized centers and (g) family's low income [6,16].

According to Mansell and Morris the diagnostic process involves at least four stages: pre-diagnosis, diagnosis, post-diagnosis and a final stage of acceptance and adaptation [15]. During the period prior to diagnosis, parents are confused with the behavior of their child, they try to explain it and they often feel stressed and worried. Evidence suggests that parents experience frustrating delays before they finally receive an appropriate diagnosis [17,18]. The time of diagnosis elicits mixed emotions for parents ranging from relief, shock, or disbelief to understanding. Most parents find the realization that their child has an ASD upset as they begin to feel the consequences for their lives. The post-diagnosis period is full of concern, hope, disappointment and search for information and support. Acceptance and adaptation is the final stage. Parents can now understand better their child's behavior and stop blaming themselves for the condition. On the other side, the diagnosis implies that the child will never be completely 'normal', and creates worry about the future.

Parental perceptions of the diagnostic process

There is an increasing literature on parental perceptions about the diagnosis of ASD. Smith et al.'s pioneer research described the difficulties which parents and children face on the path to the care in autism in a period of over two decades [18]. Findings show that there has been a progress for the younger group of children in earlier referral and final diagnosis in comparison to the older group of children, but not a corresponding progress in the advice given by the professionals to parents.

Howlin and Moore [17], expanded on the Smith et al.'s study [18], collecting data with over 1200 participants falling in the age range of 2-49 years all over the UK. The average age at which the diagnosis was received was 6 years, which the authors reported as being earlier than before, but still late. Satisfaction with the diagnostic process was found to be dependent on the length of time parents had to wait, the geographical area where diagnosis was received, the child's age at diagnosis, the child's current age, delay between first seeking help and confirmation of diagnosis. Howlin and Asgharian [13] analyzing in depth the experiences of 700 parents from the previous study, found that parents of children given a diagnosis of Asperger syndrome had experienced significantly longer delays and greater frustration in obtaining a diagnosis than those with a child with autism. This may happen because children with Asperger syndrome present milder characteristics of autism which remain unnoticed for much more time.

A recent study by Siklos and Kerns [16] on the geographical region of British Columbia, Canada, examined the diagnostic experience of 56 parents of children with ASD. The results indicated that on average, children were being diagnosed at about 5 years of age, while parents experienced significant difficulties obtaining a diagnosis. Parents were particularly dissatisfied by the initial way the diagnosis was disclosed, and parents stated that their reactions followed the stages of the 'grief cycle' (e.g., shock, grief, anger, helplessness, and guilt) [19]. In addition, not only were these parents dissatisfied with the initial diagnosis, but they expressed frustration because of the long waiting lists for the services and interventions their children needed after the ASD diagnosis. A more recent study by Saggu [20] in the area of BC, Canada, underlines that the only factor that mattered regarding parental satisfaction of an ASD assessment was the time they had to wait.

Another study in Canada has been conducted by Barrie [21] including 29 parents of children with ASD. The earlier the parents are concerned about their child, the younger the children received diagnosis. Parents also reported that their persistence was a major factor in obtaining diagnoses. They also described feelings of relief and gratitude when they received the diagnosis.

A French study by Chamak et al. [22] enabled the comparison of the practices of the professionals now and in the past in relation to the autism diagnostic procedure. According to the authors, currently the diagnosis is obtained much earlier than the previous decades, around the age of 3 years old ±1 year. The mean delays between first consultation and diagnosis were significantly reduced. Regarding the way the diagnosis was announced, 63% of the parents of children with autism and 93% of the parents of adults with autism were dissatisfied. Being given the diagnosis with a large amount of information and help, contributes to decrease the degree of stress that parents experience when facing the disclosure of their child's diagnosis. The latter is also reported by Osborne and Reed [23] who investigated parent's perceptions of communication with professionals during the diagnosis of autism. Goin-Kochel et al. [24] conducted a large scale web-based study in five countries to determine parental level of satisfaction with the diagnostic process of ASD. Higher levels of parental education and income were associated with earlier diagnosis and greater satisfaction with the diagnostic process. Parents were more satisfied with the diagnostic process when they saw fewer professionals to get the diagnosis and when the children received the diagnoses at younger ages. However, 40 percent of the sample reported that they were not satisfied with the diagnostic process.

Gaitonde [25] surveyed 126 parents of children with ASD in the United States. He found that the diagnosis of autism is becoming more systematic and is being received at much younger ages. In this study no link between current stress of parents and satisfaction of services was found. Parents living in rural areas did not differ significantly from those living in urban areas. However, parents of children with other diagnoses (Asperger's and PDD-NOS) reported being more satisfied with speech therapy and special education at school than the parents of children with autistic disorder. Gaitonde [25] underlines that although the analyses did not yield significant correlates of stress, it was clear that parents were experiencing stress. This stress may be exacerbated by the fact that professionals do not spend time discussing parent's emotional reactions and coping strategies.

Generally, since autism is a spectrum disorder, it may be difficult to pinpoint the stress stemming from the unique challenges faced by parents in different countries and various public health systems. In reviewing the relevant literature, parents seem to express more satisfaction from the diagnostic process when the following issues are addressed: Firstly, there are no long waiting lists to obtain a diagnosis. Secondly, the manner in which the professionals disclose the information differs significantly. Professionals who were sensitive, knowledgeable and supportive are highly preferred. Thirdly, the amount of information given was an important factor in high satisfaction ratings. Parents were more satisfied with a significant amount of information than less, and if they had the opportunity to ask questions throughout the session [26].

ASD in Greece: The issue of assessment and diagnosis

Autism prevalence is an issue that requires further study in Greece, as no studies have been conducted using globally standardized methods and diagnostic tools. According to Autism-Asperger Hellas [27], a non-govermental organization which tries to raise public awareness of ASD, the number of children and adults with ASD is assumed to be proportional to the population of the country. The Centre of Educational Research [28] reported an increasing number of children with autism from 2004 to 2006 in the public school population which was estimated to be around 1%. However, there is no other data to cross check the results.

Diagnosis still remains a complex experience for parents and children in Greece. It is provided by government funded (public) and private organizations. Important steps have been made by changes in legislation and the establishment of multi-disciplinary teams for the diagnosis of autism and other special needs in each perfecture of Greece (Government Gazette of the Hellenic Republic) [29]. However, early intervention is mainly provided by private centres. According to Ververi et al. study [30] in a clinical, laboratory population, the mean age of diagnosis was 43.7 months in a sample of 222 children aged 1.5-9 years from Northern Greece. Significantly earlier diagnoses were obtained in children with comorbid disorder (eg. epilepsy, hearing problems, genetic/metabolic disorders etc). This study underlines the importance of early identification of children with ASD in Greece through the appliance of screening and surveillance programs.

Parents play an important role in defending the rights of the autistic children in Greece and raising public awareness. Kalyva [31] explored the relationship between parents of ASD children and mental health professionals after an intervention with a partnership protocol. She found that after the intervention, parents expressed significantly more positive attitudes towards mental health professionals. The information that parents receive from mental health professionals was more important to them than sympathy or psychological support.

In a study by Kourkoutas et al. [32] exploring the impact of autism on parents, 24 parents were interviewed to express the problems they experience everyday when dealing with a child with autism. Most parents clearly described being overwhelmed by negative feeling immediately after the diagnosis. The following reactions are described by them: shock, distress, denial of the truth, helplessness, depression even shame towards the rest of the family. A significant finding was the low quality of the services provided to children and the intense feelings of disappointment that parents experience in their relationships with professionals. Because of the small number of parents in the former study, we decided to explore parent's perceptions and attitudes towards the diagnosis of autism in a larger sample of parents all over Greece.

The main research questions of the present study are:

(a) How do parents perceive the diagnostic process?

(b) Which are their levels of satisfaction from the diagnostic process?

(c) Which are their feelings and thoughts after the diagnosis?

(d) How do 'early diagnosis' versus 'later diagnosis' impact on parent's perceptions and feelings?

Method

Sample

Parents were recruited from three local associations of parents with children with ASD from different parts of Greece. The researcher invited the associations to inform their members about the purpose and the nature of the study, and explained that their replies would be anonymous and confidential. It is indicated that parents could contact her to obtain the attached file with the questionnaire or to fill it in directly on the Internet. In addition, 75 questionnaires were sent to the autistic associations by post for parents who prefer to answer and return the questionnaire by post. Because of the double data collection methods, information on the total number of the parents approached is missing. As a result, we put a time limit for the data collection which was the period of four months. During this period any parent can access the questionnaire via internet or through their local associations of autism. The sample of the research was comprised of one hundred and ninety three parents of children with ASD (N=193). The basic demographic characteristics of the sample are presented in Table 1.

As far as the children with ASD are concerned their basic characteristics are summarized here: 150 children of the sample are boys (77.7%) and 41 are girls (21.2%). For 2 cases the sex was not recorded (2%). The mean age of the children was 113 months (9,5 years old). 143 children have a diagnosis of autism or autistic spectrum disorder (74.1%), 27 children have a diagnosis of Asperger syndrome (14.0%), 2 children have Rett syndrome (1.0%), 7 children have Developmental Disorder-not otherwise specified (3.6%) and 11 children receive other diagnosis (5.7%) For 3 cases the diagnosis is not recorded. As far as the educational placement of the children is concerned, they attend all available types of school in Greece: daily care center (14.5%), public special school (28.5%), private special school (4.1%), mainstream public school with support (25,9%), mainstream private school with support (3,6%), mainstream school without support (13,5%), other (7.8%).

Research instrument

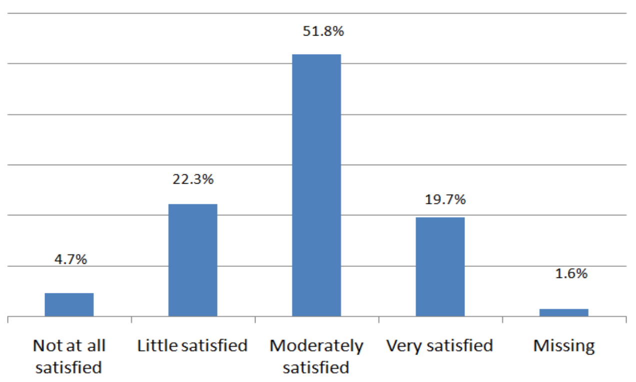
A questionnaire was developed to survey parent's experience of the assessment and the diagnostic process. It was a mixture of questions generated from a review of the work of Baker [7] and Gaitonde [25]. The questionnaire provided information about the age at which parents first became concerned about their child's development, the age at which help was first sought, the professional(s) seen, the

Table 1: Demographic characteristics of the sample (parents).

Demographic variables		Percent (%)
Sex of the parents		
male	39	20,2
female	152	78,8
Missing	2	1,0
Total	193	100,0
Age		
18-30	4	2,1
31-40	93	48,2
41-50	75	38,9
51-60	19	9,8
Missing	2	1,0
Total	193	100,0
Nationality		
Greek	185	95,9
Other	5	2,6
Missing	3	1,6
Total	193	100,0
Educational level		
Elementary school graduate	4	2,1
High school graduate	54	28,0
College/ University graduate	113	58,5
Postgraduate studies	20	10,4
Missing	2	1,0
Total	193	100,0
One-child family		
yes	49	25,4
no	143	74,1
Missing	1	,5
Total	193	100,0

number of visits to specialists, the final diagnosis obtained, satisfaction with the diagnostic process and the types of therapies proposed after diagnosis. Several questions were answered according to a 5-point Likert scale (eg. strongly disagree, disagree, neutral, agree, strongly agree or not at all satisfied, little satisfied, moderately satisfied, satisfied, very satisfied). There were also multiple choice questions. An open-ended question was added at the end of the questionnaire to elicit participant's personal comments.

For the reliability analysis the following assumptions were made: demographic variables and questions with multiple answers were not been included in the analysis. As a result, nineteen items (questions) were used in the analysis. The Cronbach α for the nineteen items were 0,696 which is satisfactory for a research in social sciences [33]. Missing data ranges from 2.1% up to 3.6 % in most Likert type questions while the open-ended questions were answered only by 45 parents out of 193 parents (23.3%).



Graph 1: Parental satisfaction from the diagnostic process of ASD.

Results

Descriptive statistics

The first result concerns the variable of age at different points of the child's life. Families, on average, first became concerned about their child approximately at 27 months of age (=2years and 3 months) and they waited about 8 months before consulting a professional for an initial evaluation which was obtained on average at 35 months = 2 years and 11 months). On average, the final diagnosis was obtained at 49 months=4years and 1 month) (S.D 26 months, range from 12 to 161 months). Pearson r correlations were conducted between the three variables (age at initial concern, age at first referral and age of final diagnosis). There were significant correlations between age at initial concern with the other two variables (age at first referral [r=.884, p=.000], age of final diagnosis [r=.535, p=.000]). Significant correlations were also observed between age at first referral and age of final diagnosis (r=.549, p=.000).

Delayed speech (75,8%), difficulties in social communication (56,8%) and obsession, as well as repetitive movements (45,8%) are the most common first signs noticed by parents. All three categories constitute the basic characteristics of ASD [1,34]. A member of the couple was the first who noticed the first signs of autism in the 75.2% of the cases while the first referral for assessment was made by the pediatrician (44.6%), the nursery teacher (15.5%), a relative/friend (8.3%) and the parent itself (31.6%)

Most families received the first assessment from a public hospital (39,9%), a family doctor (30,1%), a psycho-educational public centre (19,7%), a multidisciplinary team (KEDDY) (5,2%) or other institution (5,2%). 77,2% of families reported that the professional who made the first assessment was located in Athens (the capital of Greece), 11,9% in Salonica, 9,2% in another big city while 1,2% in a small town. When parents were asked if they were satisfied from the first assessment, 46,1% were satisfied while 52,3% were not. In addition, half of the parents (49,7 %) saw two or three professionals before obtaining a final diagnosis of ASD, 13% of parents saw four of five professionals and 9,8% saw more than five professionals.

The next results focus on final diagnosis' issues. Most families received the final diagnosis by institutions in a similar order to the first assessment (public hospital, psycho-educational centre, family doctor, KEDDY or other institution). As far as the satisfaction from

Table 2: First thoughts after the diagnosis.

	Responses		Percent of Cases
	N	Percent	
My child will overcome his/her difficulties	132	30,8%	69,8%
My child will live a normal life	160	37,4%	84,7%
What will my family think?	9	2,1%	4,8%
What will my friends think?	10	2,3%	5,3%f
What treatments my child need?	117	27,3%	61,9%
Total	428	100,0%	226,5%

Table 3: First feelings after the diagnosis.

	Responses		Percent of Cases
	N	Percent	
I was confused	91	21,1%	48,4%
I didn't know what to do	58	13,4%	30,9%
I felt shocked	93	21,5%	49,5%
I felt anger	41	9,5%	21,8%
I thought 'why me'	73	16,9%	38,8%
I felt relieved	39	9,0%	20,7%
I thought the diagnosis was wrong	37	8,6%	19,7%
Total	432	100,0%	229,8%

Parents can give more than one answer (% of cases).

the diagnostic process is concerned, parents seemed to be moderately or little satisfied (Graph 1). As far as the information or advice given after the diagnosis of their child, most parents found them insufficient and incomplete (around 78% of parents declare not at all, little or moderately satisfied).

An interesting result is that most of the parents asked for help immediately after the diagnosis. 68,9% of parents seek help one week after the diagnosis, 19,2% in one month, 3,6% in 2-3 months, 2,1% in 4-6 months, 1,6% in 6 months up to 1 year and 2% after 1 year.

Parents thoughts and feelings after the diagnosis were mixed. Table 2 shows parent's first thoughts after they get the diagnosis of their child while Table 3 shows their feelings after the diagnosis.

In addition, the diagnosis seems to have a positive impact for many parents. 50,8% of parents agreed and 19,7% strongly agreed with the statement that the diagnosis help them to take decisions about the needs of their child. 50,8% of parents agreed and 30,1% strongly agreed that after the diagnosis, they understand better the behavior of their ASD child. As far as the siblings are concerned, only 26,4% of parents agreed and 8,8% strongly agreed with the statement that the diagnosis helps the sibling understand better the child with ASD. The diagnosis helped parents to stop blaming themselves in around 40% of cases, while the remaining 60% of parents continued to blame themselves after their child received a diagnosis.

Inferential statistics

Inferential statistics were used to check the effect of certain demographic variables on parent's perceptions and feelings. As far as the sex of the parent is concerned, mothers were the first who noticed child's difficulties in comparison to the fathers [χ^2 (1)=18,861, p=0.000]. The sex of the child was found to be associated with pediatrician as the first person who noticed child's difficulties [χ^2 (1)=4,059, p=0.04]. This means that pediatricians observed more often difficulties in boys rather than in girls. Severity of autism was found to be associated with a feeling of relief to get the diagnosis [χ^2 (2)=7,564, p=0.023]. More specifically, 28.1% of the parents with children with mild autism are relieved when they get the diagnosis, in comparison with 16.2% and 10.8% of parents with children with medium and severe autism respectively.

Another set of analysis was performed based on the time of ASD diagnosis. Children with ASD were divided into two groups: a) an early diagnosis group: parents with children diagnosed with ASD at or before 30 months of age and b) a later diagnosis group: parents with children diagnosed with ASD later than 30 months of age. Chi square analysis revealed that there is a significant association between the group of diagnosis (early or later) and the following variables: parent's first concern about child's behavioral problems [χ^2 (1)=5,787, p=0.016], parent's first concern about lack of symbolic play [χ^2 (1)=5,137, p=0.023], parent himself or herself noticed first the problem [χ^2 (1)=5,203, p=0.023], nursery teacher first noticed the problem [χ^2 (1)=13,854 , p=0.000], denial of the problem [χ^2 (1)=5,934 , p=0.015],, talk first to the paediatrician [χ^2 (1)=7,174, p=0.007], early intervention program, [χ^2 (1)=5,641, p= 0.018] and special education program [χ^2 (1)=11, 569, p= 0.001]. To sum up, the time of diagnosis has an influence on parental perceptions, emotions and decisions. In other words, the earlier there were concerns about children's development, the earlier the children were referred for evaluation and the earlier the intervention started.

Analysis of parent's responses to the open-ended question

Parent's answers to the open-ended question 'Note something that you think important as far as the diagnostic process is concerned' were transcribed verbatim and analyzed through thematic analysis [35]. Two researchers read the transcripts and determined the themes. Five main themes were identified: a) positive aspects of the diagnosis, b) negative aspects of the diagnosis, c) instinct and intuition d) advice to other parents and e) factors which do not facilitate diagnosis. Below are selected quotations of the participants for each theme.

a) Positive aspects of the diagnosis

'I think that the diagnosis was short and effective because we were in Athens and all the specialists were well informed about autism'.

'The first diagnosis was correct and it has never been questioned later on. However, the diagnosis was confirmed 4 years later when my child showed his real profile and strengths. Searching various sources of information through articles and books, contacting foreign institutions helped me to decide about the therapeutic interventions for my child. In addition, I was better prepared to observe the changes in the behavior of my child and discuss with specialists and teachers how to support him in each developmental stage'.

'Parents should not be afraid to seek for a diagnosis whatever symptoms they see to their child. In addition, fear and shame have no place in their life. The earlier the diagnosis is made, the better the development and course of life for the child'.

b) Negative aspects of the diagnosis

'Unfortunately 10 years ago before when we looked for a diagnosis, we suffered a lot. Today for us who live in small cities there are no clinicians and educators to train our child with autism. Diagnosis is important but it has no value when treatment is unavailable'.

'The pediatrician told us about our child with no sensitivity. She told us that we had to visit a child psychiatrist for further consultation. When we went to a public hospital, they didn't tell us the whole truth which was unacceptable because we didn't help our child early and many times we came into conflict with the therapists and with each other as parents'.

'I felt alone. Doctors, psychologists and psychiatrists disagree with each other about the diagnosis. The first specialist spoke us about autism, the second said no, and we asked for a third opinion to come to a diagnosis. At the end, I was searching the internet to find information and see what to do'.

c) Instinct and intuition

The diagnosis came at 5 years old but I knew that something was different from the age of 2. We did many treatments but the most important is to understand the world of your child and conversely to help him understand your world. Therapists follow specific steps in their work to come to a diagnosis but the basic therapist is the parent.

After watching a film about autism on TV, when my son was 1 year old, I suspected that my child was in the autistic spectrum. I was not surprised when I got the diagnosis. Today, after 12 years I can say that I am proud and lucky because I have this little angel in my family.

d) Advice to other parents

'When my son was 1 year old I saw a movie about autism in TV and I understood that my son is autistic. As a result I did not feel shocked when the diagnosis came. After 12 years I can say with certainty that autism is a different way of thinking and living. Early diagnosis is the most important thing. Parents should not afraid to talk with specialists about their child and they should not be ashamed of him. I thank God who opened my eyes early enough and now I enjoy and share my life with my little angel'.

'Parents should not be afraid of asking for help. The sooner they accept autism, the better they help their child'.

'The diagnosis broadened my horizons. I expanded my knowledge about autism and I was able to support other parents with ASD children'.

e) Factors which do not facilitate diagnosis

'It is really sad that parents have to discover alone 'everything about autism'. There is no guidance for early screening of autism. If you are not informed or don't have people around you who knows about the problem, you waste valuable time. I believe that all children should be given a screening test around the age of 3 years old to identify symptoms and plan early intervention'.

'In the province there are no specialists who are well informed about autism. Parents are looking for the solution alone. The state doesn't give the direction. In addition there are many different specialists and the parent gets confused at the end. Many times parent's psychotherapy is not recommended and it is false'.

'No information about the everyday life with a child with autism and what to expect from it.. Unfortunately all the types of pervasive developmental disorder are put under the umbrella of autism. Each child is different although some characteristics are the same. It is sad that even the doctors themselves do not know enough about mild symptoms of autism. There is no awareness in contrast with other countries'.

Discussion

This is the first Greek study exploring aspects of the diagnostic process of ASD with reference to parents and children. A large number of parents took part voluntarily in the study which shows an increasing interest about autism among parents from different parts of Greece. The sample of the ASD children in this study shares common characteristics with the sample of an older Greek study [36] in terms of sex, type of ASD and educational placement of the children.

This study calculated the age at which the child presented the first warning signs of autism, the age of the first evaluation and the age of the final diagnosis. On average, families first became concerned just after the child's second year of life (at the age of 2 years and 3 months). This finding has also been reported within the recent extant literature [37]. The first evaluation was conducted on average at 2 years and 11 months while the final diagnosis was obtained at 4 years. For the latter, the standard deviation was 26 months (more than two years) which means that some children (and consequently their families) still experience long diagnostic delays between first evaluation and final diagnosis. However, in comparison with the study of Stampoltzis et al. [38], the present study suggests a small improvement in the time of diagnosis over the last years. Although research suggests that the average age of diagnosis is decreasing over time, it is still relatively high given the importance of early intervention.

Another aspect of the diagnosis which is also mentioned by others is that parents are often the first who recognize the early symptoms of ASD [21,37] (e.g delayed speech, difficulties in social communication, obsession or repetitive movements etc). Especially, mothers noticed more often children's difficulties than fathers. Although the parents are 'inexperienced' in the field of autism, they were the first to notice that 'something is different' in the child. This finding is enlightened by parent's comments in the qualitative part of the study.

The paediatrician was the first who noticed child's difficulties, more often in boys. This means that if doctors are properly trained, they can sustain parents in the path toward the diagnosis. Public hospitals, KEDDY and psycho-educational centres were preferred by parents for the final assessment, while private doctors (paediatricians or family physicians) were preferred for the first assessment. Maybe the later are easily accessible and do not have long waiting lists. Geographical area seems to have an effect on the diagnostic process. The capital of Greece has the most diagnostic centers and attracts parents from all over Greece. Parents from small cities or villages have difficulties in accessing diagnostic services and this result is supported by the personal account of the parents in the qualitative part of the study. A similar comment is made by Gething suggesting that parents who live in rural areas may have to cope with the unavailability of services due to scarcity of trained and experienced professionals in their area, difficulties in transportation and increased expense for accessing services [25,37].

Another issue explored in our study is how many specialists families see during the process of getting an ASD diagnosis. Greek parents although they trust the public health institutions for assessment, they see and seek help from a variety of professionals (50% the families saw two or three professionals, 13% of them saw four to five professionals and 10% more than five). Essentially, the more specialists a child saw during the diagnostic process, the older he or she was when finally receiving the diagnosis. However, parents may include in this count the specialists they visited for counseling or discussing suitable interventions for their child after the diagnosis, and this may have been construed as part of the diagnostic process. Further research is needed to investigate this. Goin-Kochel et al. [24] found in their study that parents reported visiting, on average, between four and five clinicians en route to the ASD diagnosis.

The communication of the diagnosis to parents is a crucial point and a very important moment. Information, explanations, help and understanding are necessary as well as sufficient time to understand the diagnosis [22]. This is not always the case, as illustrated by the parent's reports especially by parents whose children are now older. Some parents are still feeling the impact, remembering the expression and the style of delivery of the diagnosis (see themes b and e of the qualitative part of our study).

The present study also survey parent's feelings of the assessment and diagnostic process. Parents seem to be moderately or little satisfied from the diagnostic process, a finding which is not surprising because it is linked with several difficulties they face in their way to diagnosis. The question about satisfaction has been further broken down into different aspects of the process, such as satisfaction from the information or advice given after the diagnosis. In these questions a similar picture was revealed. For the majority of parents, the assessment didn't satisfy their expectations and wasn't enough informative and helpful. Our finding is in accordance with many foreign studies revealing similar experiences [16,22,24].

Parental thoughts and feelings which accompanied the diagnosis were mixed, including shock, helplessness, confusion, anger and bewilderment. The process of adaptation is slow and full of 'setbacks'. The diagnosis creates worry about the future [15]. An unexpected finding in our study was that although the diagnosis helps parents to stop blaming themselves, more than half of the parents (60%) in our study continued to blame themselves after their child's diagnosis.

According to Siklos and Kerns [16] parents whose child is diagnosed with a chronic disability experience a serious crisis like a serious illness. A positive finding is that the majority of parents in our study seek help immediately after the diagnosis which means that they want to provide support to their child as soon as possible. This has a positive impact on children's later prognosis and better chances for higher functioning. Many studies highlight the importance of minimum delay and early intervention for children with ASD [9].

Most of the parents agreed with the positive consequences of the diagnosis, which helped them to understand and accept their child's behavior, take the right decisions about him/her and finally adapt to the new life situation. However, the siblings of the ASD child did not have a better understanding of their sibling's situation after the diagnosis. These themes are also discussed by the parents in the open-ended question as the direct parental quotes prove. The positive and negative reactions to the ASD diagnosis are discussed in detail by Mansell and Morris [15].

We now discuss the results elicited in the present study when we broke the sample into children diagnosed before 30 months of age and children diagnosed after 30 month, a classification also made in Barrie's study [21]. Parents whose children received an early diagnosis took different actions and held different attitudes in comparison to parents whose children are diagnosed after 30 months. The benefits of early diagnosis, which have already listed in the literature review of the present paper, are evident in the experimental part of this study. Early diagnosis is a key concept in the process of implementing therapeutic interventions for ASD children.

Analysis of the qualitative data of the study identifies five central themes about the experiences of the diagnostic process. Benefits of diagnosis are not analysed in depth while barriers towards diagnosis seem to attract parent's interest. The latter include: the distance from the diagnostic centers, the lack of knowledge and sensitivity from the professionals, the lack of specialists for interventions in small towns and the time they had to wait en route to diagnosis [20]. Parent's instinct and persistence emerged as an important factor which helped them to obtain an earlier diagnosis and provide their child with the benefits from early intervention. Finally, parents in the present study do not skip to advise other parents to be persistent and defend their children' rights. This trend is also reported by Barrie [21].

Limitations

The present study has several limitations and weaknesses. For privacy reasons, respondents were not asked to record the place they live. We are not sure which places of Greece are represented in the sample. Parents with ethnicity other than Greek are under-represented (only 2.6%). Most of the parents (69%) were well educated and were internet savvy together with being affiliated to autism local associations. So the results cannot be generalized to parents of children from rural areas and those who are not affiliated to support groups and networks. Another limitation is that the study includes families who received the diagnosis many years ago in comparison to families which received a recent diagnosis. The perceptions of the ASD diagnosis of the first group may not be vivid and accurate.

Conclusion

The present research is the first Greek study presenting aspects of the diagnostic process of ASD with reference to pre- and post diagnostic issues and parental perceptions. Many of findings confirm international research on the impact of ASD diagnosis on the family, showing that irrespectively of country of origin and language speaking, parents experience similar stages, concerns and challenges on their way to diagnosis. In addition, our study has many similarities with Kourkoutas et al. [32] study in relation to parent's feelings and reactions.

The basic conclusion is that there is an improvement in the age of ASD diagnosis but this improvement may not be generalized in other samples. However, it is an optimistic, positive trend. Greek parents are in a hurry to start interventions immediately after the diagnosis and this situation encompasses both advantages and dangers. Parent's feelings and thoughts after the diagnosis are mixed, but most of them finally managed to adapt their family life to the needs of the ASD child. Moreover, the study underlines the important role which professionals play during the diagnostic process. Clinicians working with families of children in the autism spectrum should be sensitive and keep in mind the many stresses of having a child with autism [16]. Professional manner and support seem to be important determinants of parental satisfaction.

There is much to be done to ensure a flexible, multidisciplinary approach to ASD diagnosis with minimum delay and cost where parent's concerns and accounts will be valued and reclaimed. Greek parents in the present study express their need for information about well-researched intervention strategies and training on issues related to ASD. Finally, the process of diagnosing and helping children with ASD remains a significant challenge for all those involved in their care and support. Autism local associations should expand their services to support every day parents and their children on the spectrum in the path of life [38-40].

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