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The Quality of Autism Spectrum Disorder Diagnosis: Families' Views

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Abstract: The birth of a child diagnosed with autism spectrum disorder (ASD) tends to strongly disrupt family dynamics and functioning. However, the severity of the impact may be softened if the family feels supported during the diagnostic process. The Valencia region (Spain)—where this study is located—recently put in place a protocol to improve ASD detection and support for families. The aim of this study was to identify these families' views on the quality of the process experienced and the operation of the new system. The participants were 34 families with a child who had been diagnosed with this condition. A mixed methodological approach was adopted. A descriptive analysis and an interpretative-phenomenological study were performed using SPSS v. 25 and AQUAD 7, respectively. The results showed that while families seemed to be relatively satisfied, there is still room for improvement in some important areas such as guidance and emotional support, the training of the professionals involved, and waiting time. It was concluded that significant improvements must be implemented in the new diagnostic model to successfully meet the demands of families in a context characterized by a paucity of studies.

Keywords: autism spectrum disorder; ASD; diagnosis; family; parent–child; quality; infancy; early identification; early intervention

1. Introduction

According to the American Psychiatric Association [1], autism spectrum disorders (ASDs) can be defined as a heterogeneous group of neurodevelopmental disorders with varying etiology characterized by difficulties faced in communication and social interaction as well as by the subject's repetitive and restrictive behavior patterns, interests, and/or activities. Both the limiting effect of ASD and the exponential growth in its prevalence have been highlighted by numerous studies in different countries [2–5]. This has made ASD diagnosis an issue of special importance for families with children affected by this disorder. Various studies have argued that early identification and intervention is not only related to considerable improvements in the prognosis, but also to a significant increase in parent well-being [6–8]. In addition, the family context plays an essential role in any psychoeducational intervention aimed at addressing the disorder [9]. The literature review by Matson and Konts [10] on the strategies used in ASD and the settings where they take place, stressed the growing trend toward a family-centered approach. In accordance with this model, the goal pursued with this intervention does not focus so much on the children with ASD, but rather on the contexts in which they live, especially their families, since this can help them learn and perform the activities of daily living in their natural environment [11]. Due to the potential that this new paradigm has for the development of both children and their environment, professional efforts have increasingly focused on the family unit rather than only on the child [12]. However, the early care traditional approach—largely characterized by the expert role of professionals, the subsidiary role played by families, and a minor-centered

intervention—still seems to prevail in Spain [13]. In light of the above, and considering the limited number of studies devoted to the families' experiences during the diagnostic process [14], there is a need to better understand their perception of the quality of this process. This is especially true of the Valencia region (Spain) where this study took place. Their views could also prove helpful in assessing the changes that were recently introduced in the detection protocol used in this region.

1.1. Waiting for the Diagnosis

The birth of a child with ASD is very often a potentially disruptive factor in family dynamics [15]. Following an apparently normal development period, family members and those closest to them begin to identify certain behaviors that differ from the usual development patterns around the child's first or second year of life [16]. Symptoms such as a tendency to social isolation, a lack of communicative intent, the rejection of emotional contact, and some stereotypical behaviors can lead the family to seek health professional support as they start to become aware of the disorder [17]. Throughout this process, parents usually begin to feel a certain degree of frustration and helplessness, especially because of the length of time between initial concerns being noted and the final diagnosis being received [14]. While variations exist across countries, the delay remains excessive despite a considerable reduction in the length of this process in recent decades. By way of example, in contrast to Canada, where diagnosis takes approximately seven months [18], in other countries such as Taiwan [19] and the United Kingdom [6], parents must wait up to three years to obtain the evaluation results, during this time, they usually visit three or four specialists [20,21]. This delay is probably the result of unsuitable detection practices and a slow response by professionals when dealing with family concerns [22]. According to the study by Wong, Yu, Keyes, and McGrew [23], the families felt that significant improvements were necessary regarding the waiting times before the first appointment with a consultant, the large number of medical tests required, and the difficulty in obtaining a consensus from the specialists involved during the pre-diagnosis stage, among other things.

Another factor that determines the duration of this stage is the identity of the person who perceives and detects the first symptoms. In 50% of the cases, it is family friends or the extended family who identify the child's odd behavioral patterns [24]. According to Crane et al. [6], parents usually ignore the early warning signs and refuse to accept that there is anything wrong with their child as they believe that it is only a matter of time until their child reaches their developmental milestones. For this reason, the presence of someone with experience and knowledge in raising young children, like a grandmother, may eventually shorten the diagnostic process by up to five months [24]. However, other studies such as the one authored by Xavier et al. [17] noted that parents detect the initial signs of atypical behavior and are the first to set off the alarm in 65% of cases. When faced with this situation, they do not often directly consult professionals specialized in neurodevelopmental disorders, instead, they talk to a pediatrician or general practitioner, who may refer the case for a more in-depth clinical study if they deem it appropriate [21]. Regardless of the possible differences between the various experiences, most families believe that this process is long and complex, and that this delays the acceptance of the disorder and the start of an intervention [25].

1.2. Diagnosis Verification

In 50% of the cases, ASD is diagnosed by experienced clinicians [21]. Families report varying degrees of satisfaction with the care received until that point, ranging from those who received the necessary guidance and support to those who recalled it as a deeply traumatic episode [14]. In fact, although some parents admit to having been relieved when they received the final diagnosis, most families compared this news to an emotional roller coaster often dominated by commotion and sorrow [25,26]. This was also the opinion expressed by mothers in the study undertaken by Nealy, O'Heare, Powers, and Swick [27], who, after the initial shock triggered by the diagnosis, recognized that they had fallen into a severe state of depression.

In addition to the emotional pain of the diagnosis, parents become concerned about the future of their child, the patterns of child rearing, the difficulties in accessing educational services, and the economic expense associated with the intervention. This tends to cause high levels of stress and anxiety [28], which are greater in families with children with other types of vulnerabilities [29]. For instance, a study performed on 138 South Korean mothers of children with ASD confirmed that they tended to suffer from remarkably severe stress rates [30]. Similar results were found by Miranda, Mira, Berenguer, Rosello, and Baixauli [31] in Spain, who demonstrated that symptom severity is a key variable in mothers' distress and coping strategies. Nonetheless, even though studies have especially referred to the impact caused by ASD on the mother, insofar as she usually acts as the main caregiver, fathers are not exempted from affliction and suffering. As evidenced by Paynter, Davies, and Beamish [32], fathers often experience anxiety, and particularly show numerous depression-related symptoms. It is common for parents to seek mutual support and understanding, which can help them cope with the new situation. Benson [33] claimed that after the initial shock subsides, the distance between the parents vanishes and the couple's relationship emerges strengthened.

However, in addition to providing marital support, if professionals adopt a constructive attitude and inform parents of the diagnosis in a positive manner, this seems to result in a better management of both the new situation and the emotions related to it. Therefore, when a warm and safe environment is created, specialists have a collaborative attitude, and enough information is provided, the family feels much more satisfied [34–36]. In contrast, if clinicians use complex, barely intelligible language or provide too much information, and/or the diagnosis is provided in a cold, hostile environment (e.g., a hospital corridor), the family's impression is that they are not being heard, which aggravates their loneliness and frustration [25,37]. In this respect, the most important criticisms of, and reservations about, the diagnostic process apparently revolve around: (1) the attitudes of professionals; (2) the families' difficulties in becoming fully involved in the process; (3) the excessive waiting time; and (4) the support given to families after the diagnosis [6,14,35]. Some of their suggestions for optimizing the diagnostic process include a more collaborative attitude by early care services and a reduction in the number of specialists to be visited before obtaining a final result, alongside more useful and valuable information about the disorder and the type of intervention to be carried out [14,26]. In light of the above, and with the aim of improving the detection and identification mechanisms of children with ASD, the aim of this study was to gain a better understanding of families' views about the diagnostic process experienced in the region of Valencia, Spain. Some changes have been recently implemented in the diagnostic process in this region and this issue has not been studied to date.

2. Materials and Methods

A mixed methodological approach was used that combined the strengths of the qualitative and quantitative traditions.

2.1. Context Description

Following the publication of the *Comprehensive and coordinated efforts for the management of autism spectrum disorders* in 2014 [38], the region of Valencia, Spain designed a protocol to provide standardized, comprehensive care for children diagnosed with ASD [39]. Until then, the diagnostic process lacked standardized criteria that were applicable throughout the entire region. This resulted in significant discrepancies between the intervention procedures and the systems of communication and coordination used by the professionals involved in different geographical areas. In addition, having specialized training in ASD was merely optional, which meant that most of the professionals only relied on their clinical experience in this field. The process was also largely led by hospital neuropediatric services, which were ultimately responsible for the diagnosis. Consequently, the procedure became markedly propedeutic and healthcare-oriented in nature.

In light of this situation, one of the key elements in this new protocol was the optimization of diagnostic processes through a more effective system of communication between the professionals

involved and the implementation of several detection mechanisms that ultimately sought to reduce the families' waiting time [39]. When the first warning signs are identified either by the family or by education or healthcare professionals, an action plan is put into effect to ensure an early and effective diagnosis and intervention procedure. If signs of ASD are detected in an educational setting, the psychopedagogical services will carry out an evaluation and propose an intervention as well as refer the case to the primary care health center. Should the initial suspicions arise within the primary care center under the Children's Health Program, professionals perform an initial physical examination and an exhaustive evaluation of the child's clinical history. They may also request consultations with other medical specialists. If there is any suspicion of ASD during this stage, the child will be referred to the Development and Early Care Center (0–6 years) to assess the level of development and the intervention required, and to the Children and Teenagers' Mental Health Unit, the body responsible for carrying out the clinical evaluation and confirming the diagnosis based on the information provided by the healthcare, school, and early care areas. In practice, this protocol also requires that all of the professionals involved receive specialized training, especially in the management and use of assessment instruments such as the Autism Diagnostic Observation Schedule (ADOS) and the Autism Diagnostic Interview-Revised (ADI-R) [39].

2.2. Sample Description

This study was made possible thanks to the participation of 34 families with children diagnosed with ASD—one representative from each household—belonging to six associations that serve this population segment in the Valencia region (Spain). Regarding the demographic characteristics of our sample, 52.9% of participants were between 41 and 50 years old at the time of the study (Figure 1), and 79.4% were women, a percentage that is consistent with the traditional image of the mother as the main caregiver. In fact, 27 of the participants (79.41%) were mothers and only seven participants (20.59%) were fathers of children with ASD.

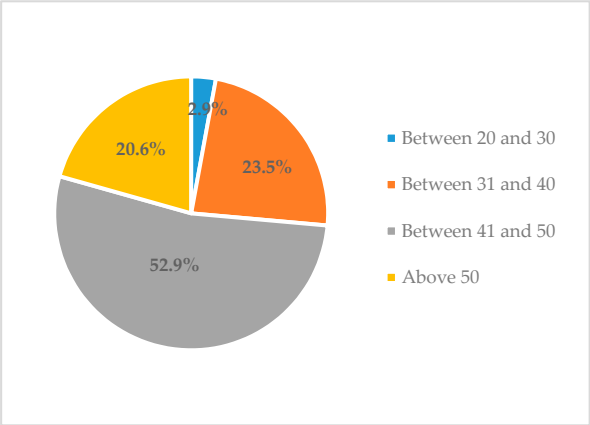

Figure 1. Age range of the participants.

2.3. Tools

Data collection consisted of a written survey and an (oral) semi-structured interview. An adaptation of the questionnaire proposed by Orellana [40] was employed to record the families' views about the quality of the ASD diagnostic process they had experienced. This scale comprised 20 items grouped together around five factors (initial stages of diagnosis; diagnostic process; communication of diagnosis; degree of satisfaction; and proposals for improvement). Three items were included in addition to those in the original instrument to assess the socio-demographic characteristics of the sample. The questionnaire was also adapted to the Spanish language.

The final questionnaire contained two types of questions. There was a set of multiple-choice closed items, some of which were intended to obtain socio-demographic information (three items); the rest of

the questions were related to the identification of early symptoms (three items), the diagnostic process (three items), and the degree of satisfaction with the diagnostic process (one item). The second group of questions were 13 Likert-type items focused on the circumstances in which the disclosure of the diagnosis occurred (seven items) and possible proposals for improvement (six items). After analyzing the reliability of the tool, the Cronbach's alpha coefficient for all items was 0.801. The rationale for formulating the items referred to the communication of the diagnosis in opposition to each other was to address the need to identify potential extreme behaviors on the part of specialists at this stage of the process.

The scores for the responses to these questions ranged from 1 ("I totally agree") to 5 ("I totally disagree"). This questionnaire adaptation was validated by three experts in psychoeducational research at the University of Alicante, where the authors are employed.

After designing the final questionnaire, the online survey was prepared using the Google Docs application to facilitate its dissemination among the families. This tool was chosen because it was suitable to the purposes of the study and also due to its advantages including user-friendliness, low economic cost, anonymity of answers, ability to store data automatically, and ability to send multiple invitations [41].

The interview was used to obtain additional information to that collected through the questionnaire. It consisted of four questions about the identification of the initial symptoms, the waiting period until the diagnosis was received, the feelings and emotions following the disclosure of the diagnosis, and the impact on family dynamics.

2.4. Procedure

To access the sample, an initial online search was carried out to find associations related to psycho-educational care and ASD based in the Valencian region. The initial list included 13 organizations from its three provinces, namely Alicante (5), Valencia (6), and Castellón (2). After collecting their contact details, an email was sent to inform them of the study's objective as well as a link to the questionnaire for the families to be able to complete it. Only two organizations responded at first and expressed their willingness to participate in this study. In light of the small response, an attempt was made to contact the 11 remaining organizations via phone with a view to enlarging the sample; only 10 of them were successfully reached. Of these, only four decided to collaborate and circulate the survey among their members. The reasons provided for their refusal were mainly that they were already participating in other studies, the unavailability of diagnostic units, and/or the fact that early care services did not form part of their activities. The questionnaire remained accessible on the website for five months, during which a member of each family that decided to take part was able to complete it.

To ensure that the interviews could be successfully conducted, the questionnaire contained a message in which those willing to participate were encouraged to contact the research team via email. Only five of the 34 participants showed interest in doing so. All interviews were carried out individually via Skype by one of the research group members. The interviews lasted 15 min on average and were conducted after the questionnaire was administered. They were scheduled based on the availability of each of the five participants.

The study complied with the main principles contained in the Declaration of Helsinki regarding research ethics. Our subjects gave their consent to take part in this study and they were assured that their participation would be anonymous, voluntary, and confidential.

2.5. Data Analysis

The software package SPSS v. 25 was considered an optimal resource for conducting a descriptive analysis of the data obtained from the questionnaire. An interpretative phenomenological study [42] was used for the analysis of the qualitative data obtained. To this end, all interviews were transcribed verbatim and coded with the help of AQUAD 7 [43]. An inductive approach was taken to data analysis. Those text segments more closely related to the research objective were identified through this process.

A series of codes emerged from the segments grouped together and organized around different themes, which eventually led to the categories and codes that shaped the data analysis. This was validated by the three experts in psycho-educational research who had previously approved the questionnaire adaptation procedure. An overall narrative ultimately emerged by combining the various themes around which the participants' accounts revolved.

3. Results

The results are reported in the order that they were obtained. Therefore, quantitative findings appear first, followed by those of a qualitative nature. The quantitative data were organized around the various dimensions included in the questionnaire.

3.1. Quantitative Results

The initial ASD symptoms were mostly identified after the children were aged 12 to 24 months, although certain signs were identified before the first year of life in some cases (Figure 2). It is also worth highlighting that nine out of the 34 participating families (26.5%) observed no signs whatsoever until more than two years had elapsed.

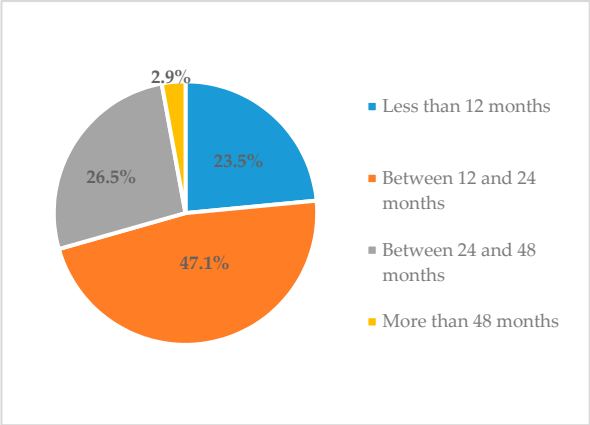

Figure 2. Age at which the first symptoms were identified.

The first to notice the symptoms were the children's parents who, in most cases (70.6%), observed some unusual behavioral or developmental signs (Figure 3). Some professionals at the infant school attended by the children identified some signs that aroused their suspicions. Only a few cases were detected by the extended family, at school, by the pediatrician, or by other people in the family environment.

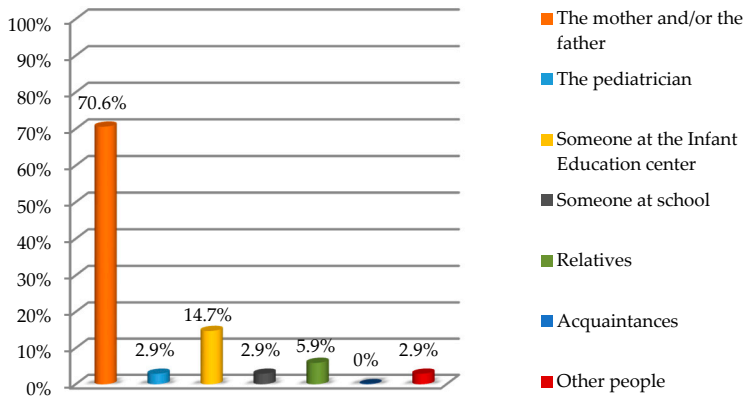

Figure 3. First person(s) to notice the symptoms.

When the first concerns appeared, the pediatrician referred the family to another consultant in 41.2% of cases (Figure 4). The pediatrician's response was not satisfactory in a relatively high percentage of examples (44.1%), either because they simply advised the family to be patient without giving any other recommendation or because they failed to take the parents' concerns into account.

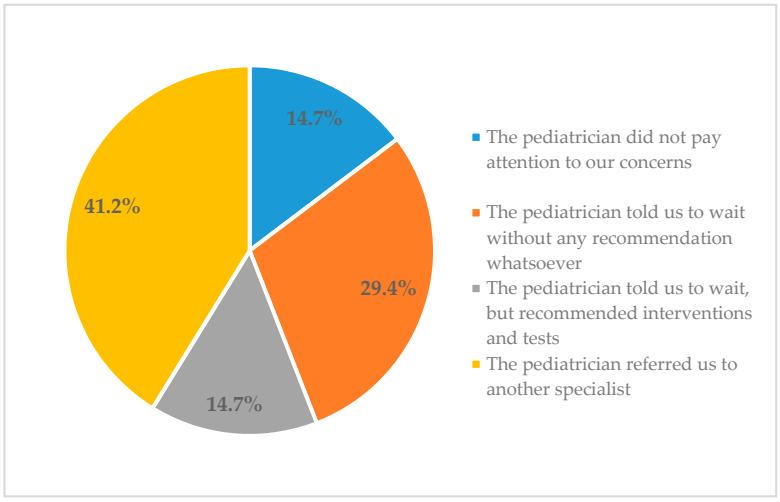

Figure 4. Pediatricians' responses.

Even though there was great variation in the number of clinicians consulted during the diagnosis process until a final decision was communicated (Figure 5), the largest proportion of families reported that they had visited three specialists. However, a fairly large number needed to consult five or more specialists, and only 14.7% obtained a diagnosis from the first physician who evaluated the case.

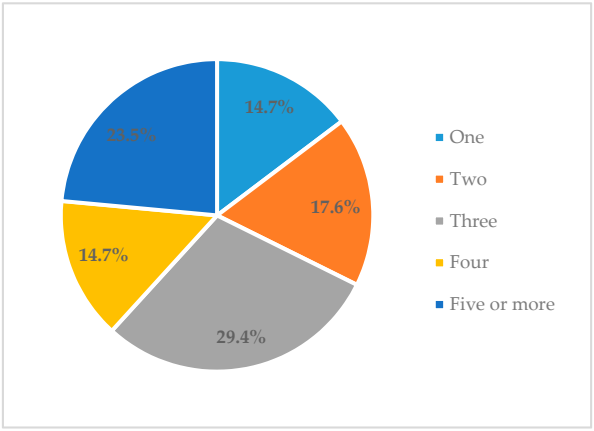

Figure 5. Number of specialists visited until a final diagnosis was received.

Despite the average diagnostic process lasting between one month and one year in most cases, the process lasted between one and two years for 32.4% of the families; and some even had to wait longer than two years (Figure 6).

A wide range of experiences were reported across families concerning how the diagnosis was communicated (Table 1), as shown by the high level of dispersion in the participants' answers. The most positive personal experiences in relation to the disclosure of the diagnosis evidently had to do with the time immediately following the diagnosis, since items four, six, and seven obtained a slightly higher score—despite not being clearly defined—while items three and five had the lowest assessments. This follows from the above that, in most cases, specialists in early care left some time after the diagnosis for the family to ask any questions they might have (item four), provided information about the intervention and possible support services (item seven), and tried to maintain a positive and

encouraging discourse (item six). A lower degree of consensus existed on the environment where the communication of the diagnosis took place, and on the consideration of families' emotions by the person in charge of transmitting the news (item two). In fact, the response percentages around one and five were practically the same. Despite that, participants did not fully recognize that the specialist had given them the evaluation results in a cold, hostile, and unempathetic way (item one), since the highest percentages were around 1.

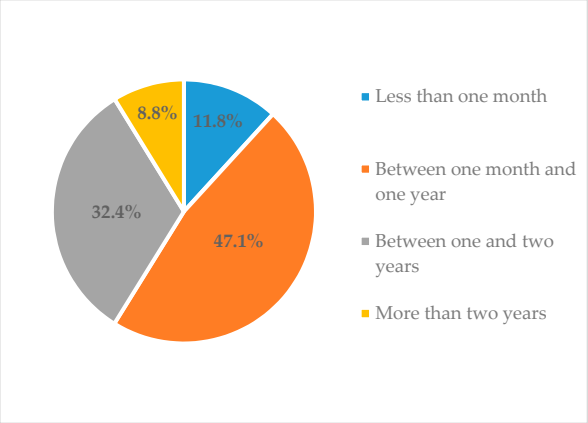

Figure 6. Average duration of the diagnostic process.

Table 1. Communication of the diagnosis.

Items	1(%)	2(%)	3(%)	4(%)	5(%)	*M*	SD
1. The physician informed me of the diagnosis in a cold and unempathetic way.	29.4	14.7	23.5	17.6	14.7	2.74	1.442
2. The physician informed me of the diagnosis in a sensitive way and considered my emotions.	23.5	8.8	26.5	17.6	23.5	3.09	1.485
3. I was hastily informed of the diagnosis and had little time to ask questions.	38.2	11.8	23.5	11.8	14.7	2.53	1.482
4. The physician gave me time to ask any questions that I had.	8.8	17.6	17.6	20.6	35.3	3.56	1.375
5. After communicating the diagnosis, the meeting ended without any further guidance.	41.2	20.6	20.6	5.9	11.8	2.26	1.377
6. After communicating the diagnosis, positive and hopeful messages were provided.	20.6	8.8	32.4	14.7	23.5	3.12	1.431
7. After communicating the diagnosis, I was given advice on possible support measures and resources.	14.7	8.8	23.5	29.4	23.5	3.38	1.349

As Figure 7 shows, as for the families' satisfaction with the diagnostic process, 35.3% of them considered that the quality had generally been acceptable. However, some 38.2% described the quality of the diagnostic process as being low or very low, and only 26.4% described it in positive terms.

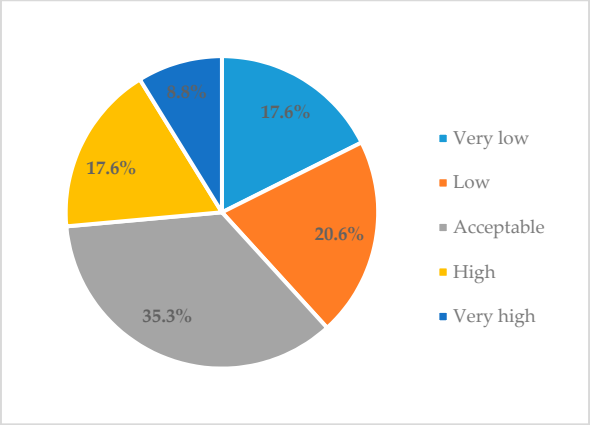

Figure 7. Satisfaction with the diagnostic process.

Regarding proposals for improvement (Table 2), the participating families largely stated that the process should be optimized, as the highest response rates in almost every category item were concentrated around four and five. They argued that more information and guidance should be provided after the communication of the diagnosis (item five) and stressed that early care professionals should offer more emotional support after the news has been transmitted (item six). To a slightly lower extent, participants also showed a positive attitude toward making improvements when the diagnosis is communicated (item four), increasing the level of emotional support throughout the process (item three), and providing better training for the specialists responsible for the evaluation (item one). Finally, a considerably high score was also found in connection with the need to reduce the waiting time between the first signs being identified, and a final diagnosis being received (item two).

Table 2. Suggestions and proposals for improvement.

Items	1(%)	2(%)	3(%)	4(%)	5(%)	*M*	SD
1. Reinforce the training of the physicians involved.	0.0	0.0	5.9	11.8	82.4	4.76	0.554
2. Shorten the average time elapsed between the identification of symptoms and the final diagnosis.	0.0	0.0	8.8	11.8	79.4	4.71	0.629
3. Increase emotional support throughout the process.	0.0	0.0	5.9	11.8	82.4	4.76	0.554
4. Improve the actual communication of the diagnosis.	0.0	0.0	2.9	17.6	79.4	4.76	0.496
5. Provide more information and guidance after the diagnosis.	0.0	0.0	0.0	5.9	94.1	4.94	0.239
6. Strengthen emotional support after the diagnosis.	0.0	0.0	5.9	8.8	85.3	4.79	0.538

3.2. Qualitative Results

The analysis of the data collected in the interviews made it possible to further examine the findings previously obtained from the questionnaire. The information was therefore reorganized into three thematic areas, which in turn corresponded to the three key stages that made up the diagnostic process. They were shaped around the experiences that the families had during the pre-diagnosis stage, the communication of the diagnosis, and the stage thereafter. Illustrative extracts were selected from the narration built from participants' accounts and used for explanatory purposes.

3.2.1. Families' Experiences during the Pre-Diagnosis Stage

In most cases, it was the mothers who identified the early symptoms.

> He was a lazy kid who slept a lot; he did better with the feeding bottle and, when he was awake, he laughed all the time and for whatever reason. He seemed to be completely normal until he was 2 years old. He said 'mamá [mum],' 'tete' [brother], 'coche' [car], 'agua' [water], 'pan' [bread] and so on, and then shortly after his second birthday, he stopped. He unlearnt what he had already learnt, it was as if he had forgotten it. It was then that I started to take action (Mother 3).

When faced with such a difficult situation, these mothers were not only frightened and concerned about what was happening to their children, but also felt questioned and misunderstood by those who believed that their development was completely normal.

> Neither pediatricians nor nurses detected any symptoms, it was only me who realized that there was something happening, and even my family told me there was nothing wrong with the child (Mother 2).

> Being told by everyone that you see things that are not there is a real torture (Mother 4).

For this reason, the families not only wanted to understand what was wrong with their child, but also somehow wished to be freed from the guilt that other people's remarks caused them.

> Besides, for a long time I had to put up with comments such as "the problem is that you don't know how to raise your child" and others that make you feel that you are not a good mother and that it is your fault (Mother 1).

All participants agreed that the most painful time was waiting for the diagnosis, even more so than the actual delivery of the diagnosis.

> The diagnosis is a huge blow, but it is also a relief because then you finally get to know what is happening to your child. The months when you don't know are the worst part (Mother 1).

> The waiting time for diagnosis and treatment is appalling. Families go through a lot of stress and anxiety until they are finally seen (Mother 5).

According to the views expressed by the participants, this delay in the process is usually caused by the indifference of some specialists and by the poor coordination between the practitioners involved and the lack of training of the medical staff in charge.

> There was a long time from when we first mentioned it until we were heard and referred to specialists (Mother 1).

> There is a total lack of coordination between pediatricians, psychologists, and neuro-pediatricians. Each practitioner tries to solve the situation differently, which confuses parents even more (Mother 4).

> It is very important to train pediatricians, family doctors, and health practitioners on how to treat children with ASD, since these professionals most often don't know how to take the right course of action during consults (Mother 3).

Throughout this process, the families endured a long and painful journey through different specialists' offices.

> The neuro-pediatrician confirmed the pediatrician's suspicion and referred me to a non-profit association for diagnosis. Thanks to the orthopedic surgeon, who suggested an early care center that we could visit, we had a diagnosis and better care than that received from the neuro-pediatrician, who simply told us there was nothing else he could do (Mother 1).

Due to this, some families decided not to use the public healthcare system and resorted to private doctors in the hope that they would obtain faster, more professional care.

> My son was diagnosed privately, it cost me 400 euros; maybe that was why everything went faster and the psychologists who worked with him made greater efforts (Mother 2).

> We obtained the diagnosis because we went to a specialist private practice after seeing that neither the school's psychologist nor the neuro-pediatrician were able to give us any support, information or guidance, or an explanation about the disorder; nothing at all. They were poor professionals with zero empathy. The truth is that we have received everything from the specialist practice that we took our champ to (Mother 5).

3.2.2. Families' Experiences in Relation to the Communication of the Diagnosis

The communication of the diagnosis was described by participants as a deeply traumatic and painful event, in which the practitioners involved were not always as empathetic and sensitive as they should have been.

> He asked me to sit down and then straight away told me that they believed the problem was that my son had autism. And from then on, you don't understand anything anymore, you just see Rain Man. It just threw me, this labelling stuff. Right after that, he said to me that my son would never know how to use a mobile, that he would be unable to speak, that he would not hug me or kiss me; and warned me to watch out, because 60% of couples who have children with autism end up separating; that he had plenty of books and information he could lend me, and so on and so forth. And at that moment I only wanted to go home, to run away from there. I found it hard to get into my car and drive home (Mother 3).

> I felt there was a total lack of sensitivity. I wished they had told me that I should have gone with my husband or someone else. I disliked the way they conveyed the news to me. Just imagine, my husband phoned me, and I couldn't even speak and explain to him what had happened; I just couldn't do it (Mother 4).

However, this experience cannot be generalized to every case. Some mothers' accounts also highlighted the support and help received from several specialists.

> Luckily, we were advised to see a psychologist who not only told us about the first steps to be taken and the places we needed to go to, but also spent a whole month observing my son and explaining to us what he should be able to do but couldn't do (Mother 2).

> Alongside the psychologist's efforts and support, we were helped by an amazing social worker who, in spite of the initial uncertainty and shock, managed to guide us, told us which benefits to apply for, where to go and so on. She was extremely important at that moment (Mother 1).

Despite suspicions that their children may have had ASD, the confirmation of the diagnosis had a significant emotional impact in all cases, which even resulted in some depressive disorders.

> The educational psychologist referred me to an association that did really good work, but I couldn't bring myself to call them. I preferred to digest it first and, the truth is I found it very difficult. At that time, I didn't know how to explain to people what was going on with my son. It is true that my parents and my parents-in-law knew where I was going and what for, but I felt incapable of telling other people (Mother 3).

> I could hardly sleep more than one hour at night and took medications for months. At that time, you can't understand what you have done for the world to treat you —and especially your child— like that (Mother 2).

3.2.3. Families' Experiences during the Post-Diagnosis Stage

As a result of the diagnosis, the participating mothers noted that they and their partners went through an initial distancing process, which was followed by an individual recovery, and finally resulted in them coming together again. From that moment on, the connecting link between them was the child, and above all, the fight to ensure the child's well-being, which became their main objective.

> The first two years were very hard for the two of us as a couple, an abyss opened up between us. At first, we disappeared as a couple, we saw each other as strangers and each of us ruminated over the situation on our own. I had never argued with my husband until then and, at that time, we began to argue about everything. With the passing of time, we backed each other up and became close again; we stopped arguing, as we realized that we had a common goal, our son. You need to be ok so that your child can be ok too (Mother 5).

Nevertheless, despite the improvement in marital life and the time elapsed since the diagnosis, the participating mothers recognized that the acceptance stage never came to an end. A systematic search for answers was therefore a constant element in their discourses.

> First, you must accept it yourself, and that is something you never do. Whoever says they do is lying, I think. You initially ask yourself, "why me?", and eventually, you wonder, "why my son?" "What have we all done to deserve this?" You start to look for causes, whether it was vaccines, pollution, too little or too much weight, mercury, white fish, cement and in the end, as I always say, it's your lot in life, it is down to your genes (Mother 3).

4. Discussion

The aim of this study was to investigate the families' opinions about the quality of the diagnostic process of children with ASD within the Valencia region, Spain, a geographic area where there has been little research on the topic to date.

The main findings showed that the participating families experienced a wide variety of differing situations, which demonstrated the lack of a homogeneous diagnostic model for the region. It is therefore necessary to make further efforts to unify the different actions to be taken. Even though individual variables (including the child's symptoms) were found to influence the detection process, the use of a harmonized protocol throughout the region would ensure minimum standards of coverage and quality in the diagnosis for all families who have children with ASD.

Furthermore, the results suggested that the participant families showed an acceptable level of satisfaction with the care received. However, some described the quality of the diagnostic process as low or very low, whereas a group of parents defined it in highly positive terms. This seems to contrast with other similar studies such as those authored by Boshoff et al. [25] or Pinto et al. [37], and might reflect some of the improvements implemented in the diagnostic process including a comprehensive and interdisciplinary approach to detection. Despite the above, the participating families believed that those improvements were insufficient and that the model still required numerous different improvements. Specifically, they stated that additional emotional support was required while waiting for the diagnosis; that the levels of training of and coordination between the specialists involved should be improved; that more information and guidance was needed after the diagnosis; and, most importantly, that the diagnostic process needs to be shortened. While these findings were consistent with those obtained in other studies [6,14,23,26,35], they showed that the new family-centered early care model [11,12] and the advances made in diagnostic processes in the Valencia region were reflected neither in professional practice nor in the parents' experiences.

As for the pre-diagnosis stage, most of the participants claimed that they noted initial warning signs after 12 to 24 months. This is a minor time reduction compared with the findings from other studies in this field, according to which the initial signs were identified around the age of 23 months [21,22]. This slight reduction may have been caused by greater awareness and sensitization about the disorder,

resulting from the increased social visibility that both relevant associations and public institutions are trying to give to ASD [39]. Participants reported that they were the first to identify the symptoms. This matches the findings of Xavier et al. [17], but is in sharp contrast to those by Sicherman et al. [24], who claimed that the earliest signs were perceived by acquaintances, friends, or the extended family in half of the cases. A possible explanation may lie in the parents' greater capacity to detect the initial symptoms, either because the children with ASD had no siblings and may have received more attention from their parents, or because they had older siblings whose development served as a reference. Therefore, additional research is needed on the role that siblings and family structure play in the parents' identification of the early symptoms.

The participant families explained that, when faced with the first signs of ASD, they visited their pediatrician at the primary care health center, whose reaction was in most cases to implement the appropriate protocol and to refer the child to other health practitioners. Nevertheless, as was the case in the studies undertaken by Höfer et al. [21] and Gibbs et al. [22], there was also a high percentage of situations in which the healthcare professional chose not to take action and simply decided to wait, ignoring the families' concerns and failing to provide them with any further advice. For this reason, it is essential to improve primary care specialists' training in ASD, and to verify the detection protocols used in children's routine health checkups.

The number of specialists visited until a final diagnosis was received was found to be three. The number of specialists visited before a diagnosis rose to 3.4 and 4 in the studies by Höfer et al. [21] and Adib et al. [20], respectively. At first sight, then, the current study's finding seems encouraging and promising; it shows the effectiveness of the new protocol, at least to a minimal extent. Nonetheless, it should be noted that a numerous group of families consulted five or more clinicians, probably due to the shortcomings in implementing a homogenous, standardized protocol throughout the region. The waiting time from the identification of the first signs until the communication of the diagnosis fluctuated between one month and one year; in line with that found by Penner et al. [18] in Canada, where the diagnosis usually took seven months. The study described here, also revealed that a high proportion of participants had to wait two years until they received final confirmation; consequently, some even decided not to rely on the public health system. These results, which are consistent with those found by Chao et al. [19] and Crane et al. [6], once again highlighted the need to implement significant improvements in the action plan designed for the Valencia region, the main goal of which is to reduce the average waiting time.

Finally, families did not provide unanimous views regarding the communication of the diagnosis. This may have been caused by the heterogeneous elements that influenced the experience encountered by each family [14], and by the limited standardized application of the new model in the region. Even so, a group of participants reported that they were given a chance to have their questions answered, received encouraging messages, and were informed about possible support measures and resources. Despite this being the predominant view among participants, these types of measures were insufficient to support high-quality marital relationships and family dynamics after the communication of the diagnosis. In keeping with the recent findings by Benson [33], the study also identified the process of disintegration and recovery undergone by the members of the couple following the diagnosis. Despite the initial tendency for the parents to become distanced from each other, the relationship seemed to improve over the years because of the parents' desire to ensure their child's well-being and stability. In practice, this does not necessarily mean that the grieving and acceptance process is ever completely overcome, which stresses the need for professionals to provide additional support and guidance mechanisms after communicating the diagnosis.

Despite the study's findings and the benefits of the mixed methodology used, some limitations must be taken into account. First, it must be recognized that the small size of the sample makes it significantly difficult to generalize the results of the survey to other wider contexts and populations; using a larger sample would make it possible to compare the respective reactions and/or roles of fathers and mothers in these situations. In addition, the fact that participants were contacted through existing

ASD-related associations represent a weakness in the research, as the views of those families who were not part of an association were not included in the study, despite having also experienced the diagnostic process. Consequently, different strategies would be necessary to construct a sample that enables researchers to gain an understanding of the experience of that population group. Since family structure and composition may be a determining factor in parents' identification of the initial symptoms, it would also have been interesting to consider the family structure and composition in the data collection phase.

In sum, judging from the results obtained from the participants, and taking into account that the diagnosis stage was noted as being an additional source of stress, anxiety, and frustration for the core family [25,37], it is crucial for the institutions and actors involved in the process to consider the views of the family members involved. This study has highlighted the need to homogenize and universalize protocols to ensure that all the children with ASD and their families—regardless of their place of residence—benefit from a high-quality diagnostic system. As for the new detection model designed in the Valencia region (Spain), priority must be given to the implementation of far-reaching improvements regarding the coordination and training of the professionals involved, the information and guidance following the delivery of the diagnosis, and the emotional support to be provided after the diagnosis, since all these will no doubt help children with ASD and their families effectively exercise their rights.

It is proposed that the sample size could be increased in future studies in order to better understand the object of study. This would involve including families who were excluded from this study because they did not belong to an association. It would also be advisable to replicate the study in other contexts and settings with a view to contrasting the results and facilitating the optimization and generalization of the model. It would be pertinent to analyze to what extent the family structure—whether there are siblings and their ages—may have an impact on the identification of the initial signs by parents. Ultimately, it is suggested that the views of all professionals responsible for the process should be further investigated to find their opinions about the model and their needs in their practical application of the model. This could make a major contribution to perfecting and further developing the new procedure, thus improving the quality of ASD diagnosis.

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