Journal of Clinical and Developmental Psychology, 1(3), 2019, 30-44

University of Messina

ISSN 2612-4033

Journal of Clinical & Developmental Psychology

Journal homepage: http://cab.unime.it/journals/index.php/JCDP/index

Parents of Children with Autism Spectrum Disorder: a systematic review

Saccà A.[1]*, Cavallini F.[2], Cavallini MC [2]

[1] TICE Live and Learn, Parma, Italy
[2] TICE Live and Learn, Piacenza, Italy

ABSTRACT

Background: Having a child with Autism Spectrum Disorder can affect family wellbeing and caregiver’s parenting skills. The present review aims to explore the main difficulties reported by parents of children with autism and the most used interventions to provide them support to date. *Methods:* 26 research articles published from 2006 to 2019 were selected and compared, specifically 10 quantitative and 16 qualitative studies, in which the following topics were discussed: parental stress in the presence of autism, presence of guidelines for intervention and relative difficulties to the achievement of the diagnosis.

Results: The results of the review analysis indicate that parental stress is one of the difficulties in assuming a primary role. Parents caring for a child with Autism Spectrum Disorder have been shown to experience significantly higher levels of stress than parents of typically developing children. *Conclusions:* The presence of guidelines and the difficulties in achieving a diagnosis are closely related to the issue of parental stress, increasing or decreasing the perceived stress of parents.

Keywords: *Autism, Parents and children with Autism; Parental difficulties*

---

* *Corresponding author*: Angela Saccà, TICE Live and Learn, Parma, Italy
E-mail address: angela93.sacca@gmail.com

https://doi.org/10.6092/2612-4033/0110-2174

Introduction

The term "Autism" identifies a neurodevelopmental disorder, characterized by a serious impairment of both the verbal and non-verbal socio-communicative abilities of the child, but also of his behavioral repertoire, characterized by lack of interests and repetitive activities.

Autism is certainly one of the most difficult developmental syndromes to understand due to the wide range of symptoms that affects the functionality of the subject throughout the course of life.

In recent years, scientific research has increasingly focused on analyzing and interpreting the complexity of the behavior of children with autism, underlining how the interaction with a child with autism is always qualitatively different than the one with a child with a typical development, regardless of their level of development.

Children with autism are physically healthy and developed like their peers, but their performance profile is uneven due to the manifestation of a series of symptoms which led many psychologists to speak not about autism but about autistic syndrome.

The complexity of the disorder inevitably affects the family context and parenting skills (in couples and individuals) of coping with disability. In the presence of the disorder, the family is forced to face more problems than families of children with typical development. These problems can be summarized concretely in three aspects: a) lack of interaction with the child, b) behavioral problems and c) social misunderstanding. All this translates into a continuous state of tension and stress that in can deteriorate the mental and physical health of parents and children.

In the presence of a child with a disability, such as Autistic Spectrum Disorder, family life can be more complex depending on some variables: nature and severity of the disability, personality traits, intra-family perceived support, social support and resources that the community provides to deal with disability.

Alongside the stressful factors associated with the symptoms of disorder, there are other factors related to the surrounding social environment. These include false beliefs about the disorder, misunderstanding and social rejection, which could lead other individuals to a consequent avoidance of interactions with the autistic child and his caregivers.

The following review aims to investigate how much scientific research has revealed about parents of children with ASD, their common traits and the problems they face daily basis.

The starting point is the analysis of the family and the presence of the disorder in a wider perspective, in order to find out how much is known through literature to date.

Specifically, this review analyzes the studies that investigated the daily difficulties that parents of children with Autistic Spectrum Disorder have to face. Particular attention is paid to the difficulty of being able to reconcile the responsibilities and commitments associated with personal or work activities with the management of family life.

Method

Article selection criteria

A systematic research was carried out on the existing articles in the literature in order to discover the theoretical framework in which the Autistic Spectrum Disorder family was studied from a more general point of view, what is done to date and what are the core topics discussed in relation to this kind of families.

The goal was to have an initial picture with broad horizons, in fact no limits were set regarding language in which the articles were written, type of article or the geographical area of the studies. The only criteria that determined the choice of the articles were the presence as a sample of parents and/or children with Autism and the year of publication of the article, from 2006 to date.

Various electronic databases have been used for the research of scientific articles such as Psychological and Behavioral Science, PsycInfo, Google Scholar and the Library Systems of the University of Parma and Pavia, within which the key words have been inserted: Family, Autism, Caregiver and children with autism, presence of autism in the family.

As illustrated in Figure 1, 200 articles were identified in the database through those keywords in which these words were contained and to which were added other 4 articles coming from the Google search engine.

Following the identification of the articles, a macro-phase of selection and analysis consisting of three steps was started. The first one involved the elimination of 90 duplicates, through the comparison of titles and authors. Second and third steps concerned respectively screening and evaluation of the eligibility of the articles.

From the screening phase of abstracts and objectives of the studies, 20 studies were excluded; otherwise, of the remaining 60 articles, eligibility was assessed through a complete text analysis. From the more detailed analysis of the entire article, 26 research articles were considered suitable and 34 studies were eliminated for irrelevant arguments.

Overall, the following review presents a comparison of 26 research articles, including 16 qualitative studies and 10 quantitative studies (Figure 1).

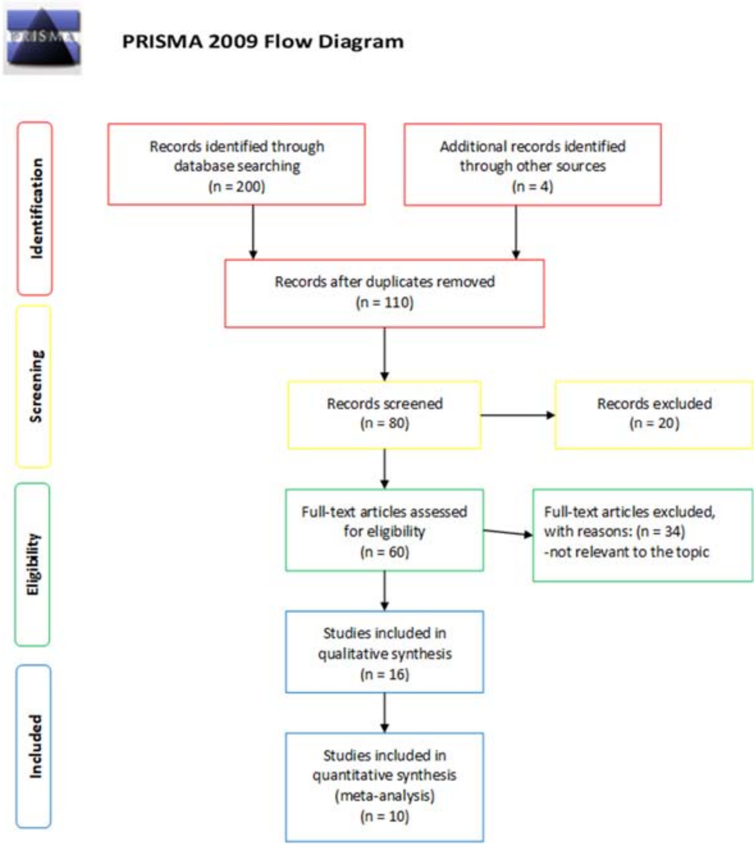

Figure 1. Flow diagram

Analysis of selected articles

The issue of parental and relational stress in the presence of Autism has immediately emerged as one of the most salient and most investigated topics in literature. Also, in the following review its importance stands out, in fact of the 26 selected articles, 14 dealt with problems of family stress in the presence of the disorder and the remaining 12 articles dealt with two other issues closely related to stress that are of considerable importance: the presence of guidelines and projects that could compensate the lack of knowledge and support and the problems related to the achievement of the diagnosis of autism.

From the comparison of the studies it was possible to subdivide into 3 macro-categories the difficulties reported by parents with ASD children: a) problems related to stress; b) guidelines and projects useful for greater parental support; and finally, c) achievement of the diagnosis.

As shown in the table 1, the first 10 research articles are experimental studies which have focused mainly on the analysis of parental stress (Davis & Carter, 2008; Herlihy, Knoch, Vibert, & Fein, 2015; Kasari, Lawton, Shih, Barker, Landa, Lord, & Senturk, 2014; Lecavalier, Leone, & Wiltz, 2006; McStay, Dissanayake, Scheeren, Koot, & Begeer, 2014; Padden, & James, 2017; Richards, Mossey, & Robins, 2016). The remaining three articles, on the other hand, concerned the theme of the guidelines and projects (Deeb, 2016), and difficulties relating to the diagnosis (Connolly & Gersch, 2013; Pijl, Buitelaar, de Korte, Rommelse, & Oosterling, 2017).

1	Davis & Carter, 2008	experimental	quantitative
2	Herlihy, Knoch, Vibert, & Fein, 2015	experimental	quantitative
3	Kasari, Lawton, Shih, Barker, Landa, Lord, & Senturk, 2014	experimental	quantitative
4	Lecavalier, Leone, & Wiltz, 2006	experimental	quantitative
5	McStay, Dissanayake, Scheeren, Koot, & Begeer, 2014	experimental	quantitative
6	Padden, & James, 2017	experimental	quantitative
7	Richards, Mossey, & Robins, 2016	experimental	quantitative
8	Deeb, 2016	experimental	quantitative
9	Connolly & Gersch, 2013	experimental	quantitative
10	Pijl, Buitelaar, de Korte, Rommelse, & Oosterling, 2017	experimental	quantitative
1	Ausderau & Juarez, 2013	theoretical	qualitative
2	Chu, Mohd Normal, McConnell, Tan, & Joginder Singh, 2018	theoretical	qualitative
3	Rao & Beidel, 2009	theoretical	qualitative
4	Zuckerman, Lindly, & Sinche, 2015	theoretical	qualitative
5	Cain, Kaboski, & Gilger, 2019	theoretical	qualitative
6	Cridland, Jones, Caputi, & Magee, 2015	theoretical	qualitative
7	Levy, Frasso, Colantonio, Reed, Stein, Barg, & Fiks, 2016	theoretical	qualitative
8	Sealey, Hughes, Sriskanda, Guest, Gibson, Johnson Williams, & Bagasra, 2016	theoretical	qualitative
9	Crane, Chester, Goddard, Henry, & Hill, 2016	theoretical	qualitative
10	Zablotsky, Colpe, Pringle, Kogan, Rice, & Blumberg, 2017	theoretical	qualitative
11	Da Paz & Wallander, 2017	review	qualitative
12	Hayes & Watson, 2013	review	qualitative
13	Saini, Stoddart, Gibson, Morris, Barrett, Muskat, & Zwaigenbaum, 2015	review	qualitative
14	DePape, & Lindsay, 2015	review	qualitative
15	Zappella, 2017	review	qualitative
16	Zwaigenbaum, Bauman, Fein, Pierce, Buie, Davis, Kasari, 2015	review	qualitative

Table 1. Summarizes the main characteristics of the 26 selected articles.

As regards qualitative research, it constituted a large part of the studies compared in the review. Specifically, the issues of parental stress and guidelines and projects were investigated by the same number of studies, seven studies for stress (Ausderau & Juarez, 2013; Chu, Mohd Normal, McConnell, Tan, & Joginder Singh, 2018; Da Paz & Wallander, 2017; Hayes & Watson, 2013; Rao & Beidel, 2009; Saini, Stoddart, Gibson, Morris, Barrett, Muskat, & Zwaigenbaum, 2015;

Zuckerman, Lindly, & Sinche, 2015) and seven studies for guidelines (Cain, Kaboski, & Gilger, 2019; Cridland, Jones, Caputi, & Magee, 2015; DePape, & Lindsay, 2015; Levy, Frasso, Colantonio, Reed, Stein, Barg, & Fiks, 2016; Sealey, Hughes, Sriskanda, Guest, Gibson, Johnson Williams, & Bagasra, 2016; Zappella, 2017; Zwaigenbaum, Bauman, Fein, Pierce, Buie, Davis, Kasari, 2015). In contrast, only two theoretical studies have addressed the achievement of the diagnosis (Crane, Chester, Goddard, Henry, & Hill, 2016; Zablotsky, Colpe, Pringle, Kogan, Rice, & Blumberg, 2017).

In the rest of the review, the features relating to the nationality of the articles, the participants and the methodologies mainly used will be presented in more detail.

Analysis of the characteristics of the subjects selected in the various researches

Specifically (Figure 2), referring to the topic of stress in the presence of Autism, most of the selected studies involved participants of American origin (n = 12), while the rest were of Dutch origin (n = 1), British (n = 1) and Malaysian (n = 1).

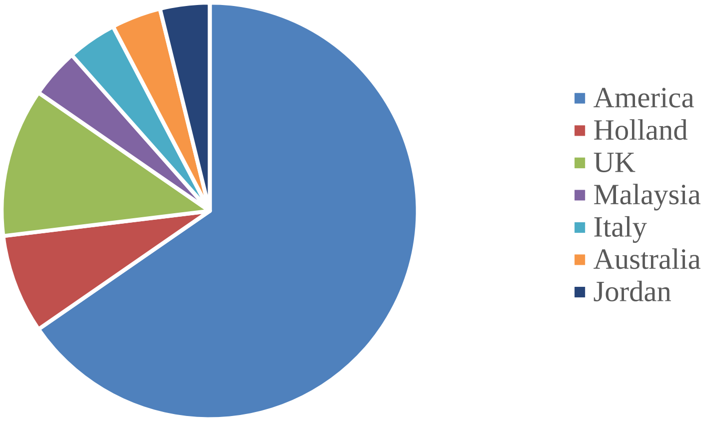

Figure 2. Participant Nationalities

Also, for guidelines and projects, most of the studies were carried out in America (n = 5), others were of Italian origin (n = 1), Australian (n = 1) and of Jordan (n = 1). Finally, the topic of diagnosis involved four studies, of American origin (n = 1), Dutch (n = 1) and British (n = 2).

Altogether (figure 3) the participants in the studies concerning the first topic were 1432 parents (mothers = 773 and fathers = 659) and 3518 children (with ASD = 1420 and without ASD = 2098).

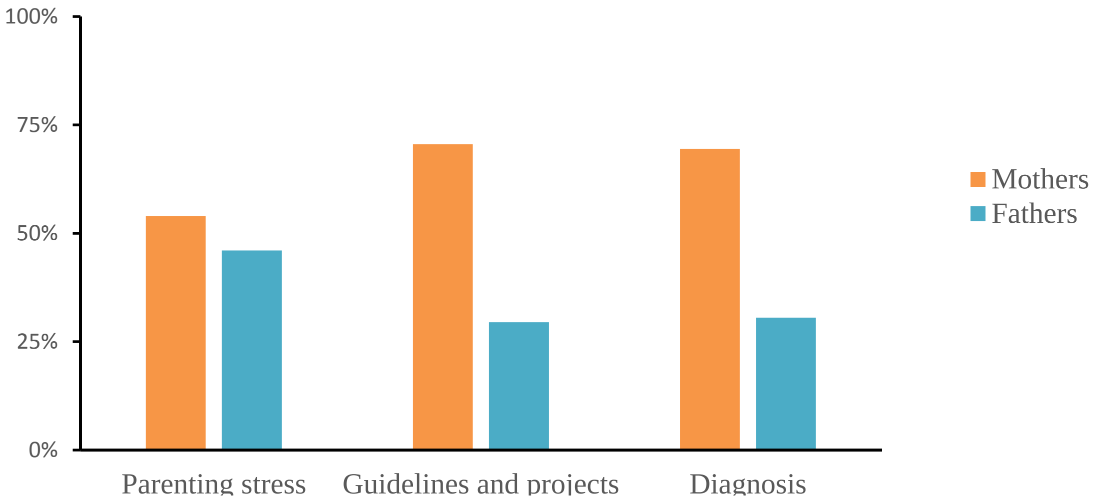

Figure 3. Percentage of mothers and fathers participating in the specific issues.

The latter were the participants in a qualitative study in which it was intended to evaluate the age of children when first parents concerning occurs and the age of children when parents contact services for the first time. For the second theme (guidelines and projects) the main protagonists were parents, with a total number of 703 (mothers= 496 and fathers = 207). In addition to these, 696 children with ASD were considered with a six-year longitudinal study to analyze their school performance. During the first study the children were from 3 to 6 years of age, in the last study they had turned from 8 to 11 years. Other participants related to the theme of the guidelines were 50 Italian children with ASD. On them a review was concentrated (Zappella, 2017) from which the ABA method emerged as a useful tool to improve academic performance and social inclusion. Finally, the sample of the diagnosis related articles were 5267 children (with ASD = 4545 and without ASD = 722) and 2339 parents (mothers = 1625 and fathers = 714).

Analysis of activities Types

The interventions implemented in the selected studies were different due to the individual research objectives that each study aimed to achieve. Referring only to experimental articles and theoretical studies, it is possible to identify the main investigative tools both for the collection of information related to the investigated topic as for qualitative studies, and for the assessment of pre and post - intervention skills in experimental studies.

Regarding qualitative studies, the main tools used were interviews, mostly semi-structured, and the administration of questionnaires. Both tools allow the collection of a good amount of information. In fact, the interviews have revealed topics such as poor general knowledge of Autism Spectrum Disorder, the impact that the disorder has on parents' lives and the challenges perceived by them. Although the interviews are very useful in deepening sensitive topics and also allow us to gather information that is not only verbal, the questionnaires were the preferred tools by the studies of the selected articles. In fact, they have many advantages and allow the collection of a large amount of information in a short time, such as personal information of parents and children, the story of diagnostic process, the degree of satisfaction after the diagnosis and much more.

In experimental studies, in addition to the collection of basic information, we proceed with the organization of an intervention plan, with a pre and post assessment of the caregivers' abilities object of interest.

In experimental studies, the most used tools to investigate the issues illustrated above, such as parental stress between parents with ASD children and parents with children with typical development and the relationship between stress levels and children's behavioral problems, were: a) Parental Stress Index - Short Form - (Abidin, 1990), with which is possible to investigate feelings and experiences of parents on three scales: parental stress, dysfunctional parent-child interaction and difficult child characteristics; b) Schedule-Generic Autism Diagnostic Observation (ADOS-G; Lord, Risi, Lambrecht, Cook, Leventhal, DiLavore, Pickles, & Rutter, 2000), a semi-structured observation program for assessing the social and communicative functioning of children with suspicion of autism; c) Autism Diagnostic Interview-Revised (ADI-R; Lord, Rutter, & Le Couteur, 1994), an interview that aims to obtain a complete range of information about the diagnosis of autism and to assess autism spectrum disorders; d) Mullen Scales of Early Learning (Mullen 1995), a scale that provides an assessment of the child's overall development; and finally e) Child Autism Rating Scale (CARS; Schopler, Reichler, Renner, 1995), which investigates the severity of the symptoms of children with Autism Spectrum Disorder.

Among the intervention plans, some strategies proved to be effective and allowed the acquisition of further information useful for future research: a) the psychological support cycle of meetings for parents; b) providing instruction curriculum for the better management of behavioral problems of children with autism; c) focus group sessions and training programs for parents, in order to acquire strategies to manage both daily life and stress caused by the deficit of their child, and finally, d) the implementation of programs of early detection of the symptoms of the disorder, through the training of parents, teachers and a multidisciplinary team.

Results of experimental research on parental stress

The experimental studies that analyze parental stress were 7 in which, despite object differences, parental stress in the presence of an autistic child was a relevant factor.

Only two studies have analyzed the difference between the levels of stress perceived by parents of children with autism and those perceived by parents of children with typical development (McStay, Dissanayake, Scheeren, Koot, & Begeer, 2014; Padden, & James, 2017), while two other articles (Davis & Carter, 2008; Lecavalier, Leone, & Wiltz, 2006) dealt with the relationship between parental stress and behavioral functioning levels of children with ASD.

The results of all four studies converge in supporting the hypothesis that parents caring for a child with Autism Spectrum Disorder experience significantly higher levels of stress than parents of typically developing children. Furthermore, the relationship between parental stress and behavioral problems in children is highlighted. The latter factor, in fact, would significantly affect caregivers' perceived stress due to children's lack of attention, restricted interests and hyperactive behavior (McStay, Dissanayake, Scheeren, Koot, & Begeer, 2014).

In addition to these interesting and widely investigated results, other three studies dealt with some of the new topics that have been discussed only in recent years.

The first topic examines the difference in the parents' concern in relation to therapeutic intervention and specialist consultation. Results indicate that parents' concerns differed according to their child's diagnosis, but were independent of parental education, ethnicity and employment status (Richards, Mossey, & Robins, 2016).

The second topic was the evaluation of the effects of the interventions with parents on the deficits of a child with ASD (Kasari, et al., 2014). The results do not indicate significant differences with respect to gender, age and the presence of siblings, but an interesting data concerned the child's play. While the functional game did not change in the course of the treatment with parents, performance in symbolic game differ improved. Unfortunately, from the follow-up data emerged that the improvement was not maintained over time.

Finally, one last topic was the effect for parents of the presence of a brother for the child with autism (Herlihy, Knoch, Vibert, & Fein, 2015). Different reflections emerged: the presence of a brother for the child with autism does not appear to be significant for parental stress, while it seems to represent an important factor for the identification of problems and the request for cars following concerns about child development. Parents with an older child diagnosed with autism had earlier concerns about the younger brother and their request for help is earlier compared to other groups of parents.

Results of qualitative research, parental difficulties

Qualitative studies, including that of Zuckerman, Lindly, & Sinche (2015), have investigated parents' concerns and the difficulties reported by them from another perspective.

Specifically, the authors were interested in evaluating the difference between the age of children with ASD when parents started to show concerns and the age of children when parents first turned on services. Despite the early concerns of parents about the presence of autism, in most cases the diagnosis were delayed by almost 3 years from the first contact between parent and services, Furthermore, before the diagnosis, more than half of the parents received reassurance from pediatricians about their concerns (Ausderau & Juarez, 2013; Zuckerman, Lindly, & Sinche, 2015).

This result reveals an important factor: parents often face the difficulty of living with a child with autism without finding immediate answers from professionals.

This aspect has been investigated in another theoretical study (Chu, Mohd Normal, et al. 2018) in which, confirming the previous results (Ausderau & Juarez, 2013; Rao & Beidel, 2009), a little general knowledge of autism and its impact on lives has emerged both by the population and by the services offered by society.

As it can be seen from the studies cited above and from other qualitative studies and reviews analyzed below, the issue of parental stress in the presence of autism disorder continually gives hints for further studies. What all articles related to this topic agree on is that families of children with Autism Spectrum Disorders experience more parental stress than families with typically developing children or those with diagnoses of other disabilities (Hayes & Watson, 2013).

Furthermore, this parental stress can also affect the couple's relationship and the family system, which may require more support to cope with the condition of disability.

In relation to this aspect in two exhibitions (Da Paz & Wallander, 2017; Saini, et al., 2015) the couple's relationship and the interventions carried out to improve the parents' well-being were examined. Specifically, it has been shown (Saini, et al., 2015) that parental stress can cause the interruption of the couple's relationship in families of children with autism spectrum disorder, on which, however, it is possible to intervene through teaching the partners operational strategy, such as developing common goals, increasing respect among partners, ensuring social support and reducing stress. All of these are important strategy to maintain couple relationship. The importance of teaching strategies to parents was also emphasized in another review (Da Paz & Wallander, 2017), which showed some important projects that appeared promising: Stress Management and relaxation techniques, expressive writing, Mindfulness, Stress Reduction, Acceptance and Commitment Therapy.

Results of research on the guidelines for the intervention and the achievement of the diagnosis

Another macro-enhancement that stands out as a protective factor from the literature analysis was the presence of guidelines and projects that could compensate the lack of knowledge and provide support to parents of children with Autism. In particular, this topic was discussed in 4 theoretical studies (Cain, Kaboski, & Gilger, 2019; Cridland, Jones, Caputi, & Magee, 2015; Levy, Frasso, Colantonio, Reed, Stein, Barg, & Fiks, 2016; Sealey, Hughes, Sriskanda, Guest, Gibson, Johnson Williams, & Bagasra, 2016), 3 literature reviews (DePape, & Lindsay, 2015; Zappella, 2017; Zwaigenbaum, Bauman, Fein, Pierce, Buie, Davis, Kasari , 2015) and 1 experimental study (Deeb, 2016).

All these studies support what has already been said, that is a lack of generalized knowledge about autism disorder and about the consequences that it can generate in caregivers.

Starting from a greater education on the scientific studies carried out on the etiological, genetic and environmental factors of the development of the disorder (Sealey et al., 2016), but also from the concrete experiences reported by caregivers, it is possible to promote social awareness and greater knowledge (Cridland, Jones, Caputi, & Magee, 2015).

First of all, training courses should be carried out by specialized personnel who provide support to families in these conditions and by parents who have to face life as parents of children with autism.

This lack of knowledge inevitably affects the lives of parents and children, as well as the process of recognition and diagnosis of the disorder. In fact, a qualitative study showed that the opinion of pediatricians is fundamental for parents (Levy, et al., 2016), as they are professional figures to whom they refer for the care of their child. A non-recognition or, worse, a devaluation of the child's condition can lead parents to postpone investigations about the adequacy of their child’s abilities. This postponement is inevitably seconded by not wanting to accept the presence of a deficit and by a lack of parents’ knowledge, which is not associated with their education, the kind of disability or the parent’s age (Deeb, 2016).

Another context in which the lack of knowledge emerges is the scholastic one. There are different studies about the academic performance of students with ASD, if it changes over time and how it differs from their peers. From one of the selected qualitative studies (Cain, Kaboski, & Gilger, 2019) emerged that following an inadequate knowledge by the school service, students with ASD might not receive the appropriate or the educational support they need to develop the cognitive potential that they could achieve. How to deal with this problem was discussed in another review (Zappella, 2017), which indicated the ABA method as effective in school. In fact, it has made possible to obtain an improvement not only in the academic skills of students but also in relational skills, and also in the inclusion of children within the school context.

A last guideline, now well established in the literature, concerns the importance of the early detection autism disorder’s symptoms. This would allow timely interventions, which would affect social attention, IQ, language and severity of symptoms, increasing the potential benefits of treatments. From a review, in which 196 scientific articles were compared with a sample of American subjects, the implementation of a screening in children between 18 and 24 months was indicated as an advantageous tool for achieving an early diagnosis. This suggestion is in line with the current recommendations released by the American Academy of Pediatrics, but its realization requires a considerable cost. In fact, screening should be carried out periodically, allowing the identification of potential factors that would improve the effectiveness and efficiency of intervention approaches (Zwaigenbaum, et al., 2015).

The achievement of the diagnoses also emerged as another key point of the review, together with the stress and guidelines suggested by literature. It has been the subject of discussion in two experimental studies (Connolly & Gersch, 2013; Pijl, Buitelaar, de Korte, Rommelse, & Oosterling, 2017) and two theoretical studies (Crane, Chester, Goddard, Henry, & Hill, 2016; Zablotsky, Faults, Pringle, Kogan, Rice, & Blumberg, 2017).

Within the experimental studies, the following themes have been investigated: a) the importance of a timely diagnosis of ASD through the implementation of an early detection program (Pijl, Buitelaar, de Korte, Rommelse, & Oosterling, 2017) and b) the experiences and needs of parents whose children had been on the waiting list for an evaluation, investigated before and after a program that included focus group sessions (Connolly & Gersch, 2013). Regarding the first study, results show that the probability of being referred to a diagnosis before 3 years of age of children with ASD was higher when early detection programs were implemented. This would allow the implementation of a timely intervention that would improve the child's health and greater parental support during the first difficulties seen in children.

Results of the second study also indicate an improvement in the level of support perceived by parents following the focus group sessions. They acquired simple coping strategies that made them feel their children’s supporters while waiting for an evaluation. All parents within the focus groups reported having learned "a lot" about the diagnostic process and Autism Spectrum Disorder in general, favored thanks to the collective approach

Two qualitative studies (Crane et al., 2016; Zablotsky et al., 2017) also investigate the importance of diagnostic process. Both investigated the key factors influencing the parenting experiences of diagnostic process and the needs of post-diagnostic support, underlining the importance of early identification, through the use of an evolutionary screening that uses standardized tools. It might be particularly difficult for a parent to recognize specific ASD behaviors when they occur during early development. Therefore, parents should be encouraged to report all kinds of concerns to referring physicians, as suggested by the guidelines offered by the Council on children with disabilities of the American Academy of Pediatrics (AAP).

They should support parents in their concerns, reaching conclusions after making assessments based on reference scientific data. Two interesting results that emerge from theoretical studies and that could be useful for future research concern: a) the diagnostic delay, in which a negative correlation was found with the satisfaction of parents about the general diagnostic process and b) post-diagnostic support, identified as a significantly disturbing area for parents.

Conclusions

In accordance with the objective of the present literature analysis, that is the exploration of the difficulties mainly reported by parents who daily interface with the Autistic Spectrum Disorder in their children, in the following review the key points and the most difficult macro areas are presented.

Referring to the main difficulties that emerged, parental stress occupies a position of considerable importance. Indeed, it has been empirically shown that parents caring for a child with Autism Spectrum Disorder experience significantly higher levels of stress than parents of typically developing children. The presence of stress in parents inevitably affects the relationships that they establish both at an intra and extra-family level, increasing the difficulties arising from the presence of the disorder and establishing dysfunctional relationships with the child, which further increase children’s behavioral problems.

The wide range of symptoms that distinguishes the child with autism and that accompanies him throughout his life, cannot fail to affect parents, who mainly suffer from lack of interaction with the child, his or her restricted and repetitive behavioral repertoire and social misunderstanding surrounding them. A parent who lives his role thinking to not be able to manage the child’s problems can feel overwhelmed and powerless, with inevitable repercussions on the family climate and the couple's relationship.

Overall, the analysis of literature on parents and children with autism allows to underling the importance of support that parents receive in deficit conditions. In fact, both the themes of the guidelines and the diagnosis can be linked to parental stress and to the support they experienced, as if they were subclasses that increase or decrease the difficulties of this experience. In literature there are numerous scientific evidences attesting that families, and mostly parents, if adequately supported, can reach good functioning levels, learning to use effective strategies to manage family situations and reconcile personal needs with family ones.

This review focused on the analysis of parents and children with autism by adopting a broader perspective to explore the problems that they have to face on a daily basis and that distinguish them from other parents. Future analyzes could deepen the most widely used interventions to offer greater parental support, including the behavioral parent-training (PT-behavioral) and Acceptance and Engagement interventions (ACT) that are significantly developing in recent years within the framework of parent education. The latter includes all the interventions and/or preventive families' programs with the aim of contributing to the improvement of relational and functioning problems presented within the family context.

References

Abidin, R. R. (1990). *The parenting stress index—Short form—Test manual*. Charlottesville: Pediatric Psychology Press.

Ausderau, K., & Juarez, M. (2013). The impact of autism spectrum disorders and eating challenges on family mealtimes. ICAN: *Infant, Child, & Adolescent Nutrition, 5(5),* 315-323. https://doi.org/10.1177/1941406413502808

Cain, M. K., Kaboski, J. R., & Gilger, J. W. (2019). Profiles and academic trajectories of cognitively gifted children with autism spectrum disorder. *Autism*. Online first https://doi.org/10.1177/1362361318804019

Crane, L., Chester, J. W., Goddard, L., Henry, L. A., & Hill, E. (2016). Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism, 20 (2),* 153-162. https://doi.org/10.1177/1362361315573636

Cridland, E. K., Jones, S. C., Caputi, P., & Magee, C. A. (2015). Qualitative research with families living with autism spectrum disorder: Recommendations for conducting semistructured interviews. *Journal of Intellectual and Developmental Disability, 40 (1),* 78-91. http://dx.doi.org/10.3109/13668250.2014.964191

Chu, S. Y., Mohd Normal, S. N. S. A. B., McConnell, G. E., Tan, J. S., & Joginder Singh, S. K. D. (2018). Challenges faced by parents of children with autism spectrum disorder in Malaysia. Speech, *Language and Hearing*, 1-11. https://doi.org/10.1080/2050571X.2018.1548678

Connolly, M., & Gersch, I. (2013). A support group for parents of children on a waiting list for an assessment for autism spectrum disorder. *Educational Psychology in Practice, 29 (3),* 293-308. https://doi.org/10.1080/02667363.2013.841128

Davis, N. O., & Carter, A. S. (2008). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. . *Journal of Autism and Developmental Disorders, 38(7),* 1278. https://doi.org/10.1007/s10803-007-0512-z

Da Paz, N. S., & Wallander, J. L. (2017). Interventions that target improvements in mental health for parents of children with autism spectrum disorders: A narrative review. *Clinical psychology review*, *51*, 1-14. https://doi.org/10.1016/j.cpr.2016.10.006

DePape, A. M., & Lindsay, S. (2015). Parents' experiences of caring for a child with autism spectrum disorder. Qualitative health research, 25(4), 569-583. https://doi.org/10.1177/1049732314552455

Deeb, R. M. A. S. (2016). Knowledge of Parents of Children with Autism Spectrum Disorder of Behavior Modification Methods and Their Training Needs Accordingly. *International Education Studies, 9(10),* 141-154. https://doi.org/10.5539/ies.v9n10p141

Hayes, S. A., & Watson, S. L. (2013). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders, 43(3),* 629-642. https://doi.org/10.1007/s10803-012-1604-y

Herlihy, L., Knoch, K., Vibert, B., & Fein, D. (2015). Parents' first concerns about toddlers with autism spectrum disorder: Effect of sibling status. *Autism*, *19 (1),* 20-28. https://doi.org/10.1177/1362361313509731

Kasari, C., Lawton, K., Shih, W., Barker, T. V., Landa, R., Lord, C., & Senturk, D. (2014). Caregiver-mediated intervention for low-resourced preschoolers with autism: an RCT. *Pediatrics*, peds-2013. https://doi.org/10.1542/peds.2013-3229

Lecavalier, L., Leone, S., & Wiltz, J. (2006). The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research, 50(3),* 172-183. https://doi.org/10.1111/j.1365-2788.2005.00732.x

Levy, S. E., Frasso, R., Colantonio, S., Reed, H., Stein, G., Barg, F. K., ... & Fiks, A. G. (2016). Shared decision making and treatment decisions for young children with autism spectrum disorder. *Academic pediatrics, 16(6),* 571-578. https://doi.org/10.1016/j.acap.2016.04.007

Lord, C., Risi, S., Lambrecht, L., Cook, E. H., Leventhal, B. L., DiLavore, P. S., Pickles, A., & Rutter, M. (2000). The autism diagnostic observation schedule-generic: A standard measure of social and communication deficits associated with the spectrum of autism. *Journal of Autism and Developmental Disorders*, *30*, 205–223.

Lord, C., Rutter, M., & Le Couteur, A. (1994). Autism Diagnostic Interview-Revised: a revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorders. *Journal of Autism and Developmental Disorders*, *24*(*5*), 659-685.

McStay, R. L., Dissanayake, C., Scheeren, A., Koot, H. M., & Begeer, S. (2014). Parenting stress and autism: The role of age, autism severity, quality of life and problem behaviour of children and adolescents with autism. *Autism*, *18*(*5*), 502-510. https://doi.org/10.1177/1362361313485163

Mullen, E. M. (1995). *The Mullen early learning scales*. MN. AGS: Circle Pines. https://doi.org/10.1080/09297040500473714

Oliva, P., Costa, S., & Cuzzocrea, F. (2012). Parenting Skills and Non-compliance: Parent Training for Families with Mildly Mentally Retarded Children. *Education*, *2* – Special Issue,13-19 https://doi.org/10.5923/j.edu.20120001.03

Padden, C., & James, J. E. (2017). Stress among parents of children with and without autism spectrum disorder: a comparison involving physiological indicators and parent self-reports. *Journal of Developmental and Physical Disabilities*, *29* (*4*), 567-586. https://doi.org/10.1007/s10882-017-9547-z

Pijl, M. K., Buitelaar, J. K., de Korte, M. W., Rommelse, N. N., & Oosterling, I. J. (2017). Sustainability of an early detection program for autism spectrum disorder over the course of 8 years. *Autism*. https://doi.org/10.1177/1362361317717977

Rao, P. A., & Beidel, D. C. (2009). The impact of children with high-functioning autism on parental stress, sibling adjustment, and family functioning. *Behavior modification*, *33* (*4*), 437-451. https://doi.org/10.1177/0145445509336427

Richards, M., Mossey, J., & Robins, D. L. (2016). Parents' concerns as they relate to their child's development and later diagnosis of autism spectrum disorder. *Journal of Developmental & Behavioral Pediatrics*, *37*(*7*), 532–540. https://doi.org/10.1097/DBP.0000000000000339

Saini, M., Stoddart, K. P., Gibson, M., Morris, R., Barrett, D., Muskat, B., ... & Zwaigenbaum, L. (2015). Couple relationships among parents of children and adolescents with autism Spectrum disorder: Findings from a scoping review of the literature. *Research in Autism Spectrum Disorders*, *17*, 142-157. http://dx.doi.org/10.1016/j.rasd.2015.06.014

Schopler, E., Reichler, R.J., Renner, B.R (1995). *The Childhood Autism Rating Scale (CARS): For diagnostic screening and classification of autism*. New York: Irvington.

Sealey, L. A., Hughes, B. W., Sriskanda, A. N., Guest, J. R., Gibson, A. D., Johnson Williams, L., & Bagasra, O. (2016). Environmental factors in the development of autism spectrum disorders. *Environment international*, *88*, 288-298. https://doi.org/10.1016/j.envint.2015.12.021

Zablotsky, B., Colpe, L. J., Pringle, B. A., Kogan, M. D., Rice, C., & Blumberg, S. J. (2017). Age of parental concern, diagnosis, and service initiation among children with autism spectrum disorder. *American journal on intellectual and developmental disabilities*, *122*(*1*), 49-61. https://doi.org/10.1352/1944-7558-122.1.49

Zappella, E. (2017). L'inclusione scolastica degli studenti con Disturbo dello Spettro Autistico: una rassegna degli interventi con il metodo ABA (Analisi Comportamentale Applicata). *Formazione & insegnamento. Rivista internazionale di Scienze dell'educazione e della formazione*, *15*(*1*), 373-388. https://doi.org/107346/-fei-XV-01-17_27

Zuckerman, K. E., Lindly, O. J., & Sinche, B. K. (2015). Parental concerns, provider response, and timeliness of autism spectrum disorder diagnosis. The Journal of pediatrics, 166(6), 1431- 1439. https://doi.org/10.1016/j.jpeds.2015.03.007

Zwaigenbaum, L., Bauman, M. L., Fein, D., Pierce, K., Buie, T., Davis, P. A., Kasari, C. (2015). Early screening of autism spectrum disorder: recommendations for practice and research. *Pediatrics*, *136* (Supplement 1), S41-S59. https://doi.org/10.1542/peds.2014-3667D