Difficulties and Psychological Experiences of Parents of Children with Autism Spectrum Disorders (ASD): A Cross-Sectional Study

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Abstract: *Introduction:* Autism spectrum disorders are brain development disorders with multifactorial etiology, identified by difficulties in communication and social interrelation, like recurrent and stereotyped attitudes, activities, and interests. Families with children with developmental disorders may experience more difficulties than families with children without disorders. Therefore there is a need Finding ways to reduce or manage parental stress for improve the family's quality of life through the evaluation of the causes. This study aims to analyze the difficulties experienced by caregivers and the perceived inclusion and inclusion of parents and children with autism spectrum disorder (ASD) within the social fabric, therebyexamining the difficulties parents face in daily life.

Materials and Methods: A cross-sectional study was conducted online through snowball sampling untildata saturation from November 2020 - March 2023, through the administration of an online questionnaire made through a Google form and disseminated through social media. Data analysis using the Statistical Package for Social Science (SPSS) Software version 17.

Results: 404 parents of children with ASD 94.8% of whom are mothers with an average age of 40.23 years. The prevalence of parents correctly defined autism as "a neurodevelopmental disorder characterized by difficulties in social interaction and communication, limited interests, and repetitive behaviors". At final diagnosis, the study results reported for 87.9% of parents sadness and grief at diagnosis, followed by fear (83.9%).

Conclusions: Research in this area is critical as it can assist health care providers and scholars in understanding the unique issues parents face in raising a child with ASD, as well as support parents themselves in identifying factors that contribute to their stress level in order to take the right steps to reduce it and improve their overall well-being.

Keywords: Autism spectrum disorder (ASD), Children, Experience, Parent, Psychological difficulty.

INTRODUCTION

Autism spectrum disorders are brain development disorders with multifactorial etiology, characterized by difficulties in communication and social interaction,as well as repetitive and stereotyped behaviors, activities, and interests [1]. In recent decades, there has been a steady growth in the prevalence of Autism Spectrum Disorder (ASD) [2], incidences found by the Atlanta CDC in2016 show 1 in 54 children worldwide with ASD. In Italy, on the other

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*Address correspondence to this author at the Department of Mental Health, Local Healthcare Company Bari, Italy, Via X marzo, 43, 70026 Modugno, Bari, Italy; E-mail: vitaleelsa@libero.it hand, it is estimated that 1 in 77 children have an autism spectrum disorder with a higher prevalence in males of 1 in 4. Studies in Asia, Europe, and North America, on the other hand, have identified people on the Autism Spectrum with an average of 1% to 2% [3]. The value of different countries varies between 4.4 and19.7‰. which has led to claims of an "epidemic" of autism, linked to the expansion of the concept of autism, changes in diagnostic protocols, and a new diagnosis (whereby a child previously identified with intellectual disability or language disorder, is reclassified into the autism spectrum. Individuals with ASD require constant care throughout their lives, and their caregivers face a number of daily challenges, such as stress, financial difficulties, psychological adjustment, andincreased emotions [4]. Families with children with developmental disorders may experience more difficulties than families with children without disorders (TD) [5, 6], such as behavioral problems, health difficulties, low adaptive capacity, increased need for health and mental health services, difficulties with educational placement [7], and lack of interaction with their child. This can lead to difficulties in understanding themselves and their child, failures in applying intuitive parenting behaviors, processing the diagnosis, and the need to adapt to new family dynamics [8]. In a recent study conducted in Bangladesh, a mean stress score of 53.3 with a range of 14 to 80 was foundamong the 906 caregivers of children with neurodevelopmental disabilities involved in the study. The most stressful situations for caregivers were the time of initial diagnosis, thoughts about thecauses of the disability, organization of work, and long-term plans for the child [9]. Psychological stress and burnout in parents of children with autism have been associated with problems ofdepression, anxiety and decreased family cohesion. These factors can have a significant impact on

parents' quality of life, well-being and satisfaction [10]. The diagnosis of autism can be complexand is often not made during childhood, causing anxiety and stress in parents trying to understand the cause of their child's problems. In many cases, the initial diagnosis may be incorrect, causing feelings of confusion, hopelessness, blame, and guilt. Clear, step-by-step communication about the diagnosis is essential to support parents and understand their experience. The diagnosis of autism has a significant impact not only on the life of the diagnosed child, but also on the emotional harmony of the whole family [11]. Following diagnosis, parents of children with autism face a number of logistical and bureaucratic challenges as they try to find the right therapeutic interventionprogram to support their child [11]. Families often find it difficult to master the complexity of the systems and services for children with ASD and at the same time, they feel great pressure to do so [12]. Many parents report that much of their stress and emotional exhaustion stems from struggling to obtain needed services, dealing with complex policies and negative social attitudes, and continually communicating with education and health professionals [13]. The relationship between parent and child is a critically important context for children's early social, emotional, and communicative development. Even small variations in children’s attachment-related behaviors can have a major impact on parents' emotional attachment to their child, which can have lasting consequences on parents' ability to support their child across the lifespan.

Parent training, also known as Parent Training (PT), represents an intervention technique that aims to teach parents skills needed to counteract problematic family situations [14]. Despite this, the effectiveness of PT is constrained by parents' predisposition to engage in the learning process; if parents are faced with external stressors, psychopathology or poverty, they may find it difficult to acquire skills through treatment, resulting in a reduced impact on their children's behavior.

Parental stress in families with children with autism is a common and burdensome experience that requires attention and intervention. Finding ways to reduce or manage parental stress can significantly improve the family's quality of life [15]. There have been studies regarding the association between emotional and behavioral problems in children with autism spectrum disorder and psychological distress in their parents, but these are missing from the Italian literature. Each country has its own different approach and culture in stress management as well as in ASD knowledge, so it would be useful to investigate these issues in the Italian context as well.

To that end, this observational study, with a large sample of caregivers of children with ASD, aims to analyze the difficulties experienced by caregivers and the perceived inclusion and inclusion of parents and children with autism spectrum disorder (ASD) within the social fabric, thereby examining the difficulties parents face in daily life.

Objectives

Primary objective of the study is to understand the degree of knowledge, practices, and attitudes of family members toward their children with autism spectrum disorder (ASD). Secondary objective is to raise awareness of this issue, with the intent of taking steps to increase public awareness and understanding of this condition.

MATERIALS AND METHODS

Study Design

Cross-sectional observational study, conducted online through snowball sampling untildata saturation. The study was conducted from November 2020 - March 2023.

Study Procedures and Tools Used

The study was conducted through the administration of an online questionnaire made through a Google form and disseminated through social media.

Recruitment Criteria

Parents of children and youths with autism spectrum disorders who consented to complete the questionnaire were recruited into the study. Parents/caregivers who did not give consent were excluded.

The Questionnaire

The survey instrument included three main sections. The first section included the socio-demographic characteristics characteristic of the respondents. The second section of the questionnaire asked the respondents some questions regarding autism and their child's daily experience and all the nuances. The third section includes the Perceived Stress Scale (PSS; Scale for Perceived Stress) [16], the most widely used psychological instrument for measuring stress perception. For each items proposed a Likert scale was associated varying from 1, as the lowest perceived levels and 5, as the highest perceived levels.

Ethical Considerations

A clear explanation of the study was stated at the beginning of the questionnaire. It was underlined that the study and its relating participation was free. Moreover, to ensure that the questionnaires were anonymous, participants' responses were de-identified. None ethical committee authorization was received since the present study focused on caregivers (parents) of patients.

Table 1: Sampling characteristics (n=404)

Sampling Characteristics	n (%) / µ±s.d.
Gender	
Female	383(94.8)
Male	21(5.2)
Age	
Until 30years	28(6.9)
31-40 years	184(45.5)
41-50 years	173(42.8)
51-60 years	17(4.2)
Over 61 years	2(0.5)
Marital status	
Married	285(70.5)
Cohabitant	79(19.6)
Divorced	23(5.7)
Widower	1(0.2)
Single	16(4)
Religious belief	
Christianity	330(81.7)
Islam	2(0.5)
Buddhism	1(0.2)
Judaism	2(0.5)
Atheist	69(17.1)
Work Employment	
Unemployed	42(10.4)
Part-time	94(23.3)
Full-time	109(27)
Independent	48(11.9)
Housewife	109(27)
Retired	2(0.5)
Did the condition of your child require youto choose part-time work?	
Yes	224(55.4)
No	180(44.6)

Statistical Analysis

Descriptive analyses were performed for all qualitative and quantitative variables using Statistical Package for Social Science (SPSS) software version 17. Continuous variables were described by mean and standard deviation (SD), while categorical variables were reported by frequencies and percentages. In addition, inferential statistical analysis was conducted and *chi square* tests were performed to assess any associations existed between the items proposed and the perceive stress scale. Specifically, it was used chi-square goodness fit in the case of 3 or more modalities, and binomial test for variables with two modalities only. All p-values less than 0.05 were considered as statistical significant.

RESULTS

Socio-Demographic Characteristics

To the survey disseminated online through various social media and then extended to all those parents with children with ASD afferent to these platforms, of these decided to voluntarily fill out the questionnaire.

404 parents of children and/or youth with ASD. The female population accounts for 94.8% (n=383) of the sample, while the male population accounts for 5.2% (n=21). The average age of the population is 40.23 years. The majority of the population 70.5% (n.285) are married. 39.1% (n=158) reside in the North, 21.5% (n=87) in the Center, and 39.4% (n=159) in the South. 90.1% (n.364) of respondents live with their partners, 5.4% (n.22) live alone, 4% (n.16) live with their parents of origin, and 0.5% (n.2) live with friends or roommates. 67.8% (n.274) have other children, while 32.2% (n.130) do not. 10.4% of respondents are unemployed, 23.3% have part-time jobs, 27% have full-time occupations, 11.9% are self-employed, 27% perform homemaker duties, and 0.5% are retired. The average weekly working hours of parents is 20.38 hours.

Difficulties Experienced by Caregivers: Factors that Affected Stress Levels (Table 2)

The Table **2** shows a statistically significant association between the factors that affected stress levels. The main ones were feeling unable to have control over important things in their lives and social-health services (p-value = 0.028); lack of psychological support "sometimes" (p >0.001); and knowledge of ASD "sometimes." Statistically significant results were also found between feeling nervous or stressed and psychological support (p-value > 0.001) "sometimes." There is a statistically significant association between lack of confidence in coping with personal problems and need for psychological support (p-value greater than 0.001) and between coping with autismand need for psychological support (p-value = 0.001). Other significant statistical association emerges between feeling of not being in control of one's life and the use of social and health services (p-value = 0.044). The absence of psychological support was found to be a determining factor for this type of problem, as evidenced by a p-value of less than 0.001. Another significant correlation was found between the feeling of not being able to manage all the activities and tasks related to caring for a child with autism, and the use of social-health services (p-value = 0.020). In addition, there was a distinct lack of psychological support, the impact of which on parents' mental health is indicated by a p-value exceeding 0.001. The table shows an association of statistical significance between feelings of inability to handle troublesome situations and lack of psychological support (p-value > 0.001), as well as inadequate management of autism "sometimes" (p-value = 0.006); between inability to handle a situation and the availability of social-health support services (p-value > 0.001) and also suboptimal management of autism "sometimes" (p- value > 0.001); the need for social-health services and feeling angry about events beyond one's control (p-value less than 0.001), as well as the above feeling and suboptimal management of autism (p-value = 0.047). Finally, the table shows a significant statistical relationship between the perception of feeling overwhelmed by difficulties and the need for social and health support (p- value > 0.001), as well as inadequate management of autism spectrum disorder "sometimes" (p-value >0.001). The most challenging time of the day for the parent is for 30.4% in the evening, 16.8% during meals, 13.9% in the morning, and 6.9% "at any time".

Caregivers' Knowledge of and Reactions to Diagnosis Toward Individuals with ASDs

In this study, the prevalence of parents (88%) correctly defined autism as "a neurodevelopmental disorder characterized by difficulties in social interaction and communication, limited interests, and repetitive behaviors." The level of knowledge with respect to autism spectrum disorders appears to be 38.6 percent (n.156) fair, 26.5 percent (n.107) good, 26 percent (n.105) sufficient, and 8.9 percent (n.36) insufficient. Although the majority of the sample felt they knew how to manage psychological/behavioral and clinical/medical issues of their child, 90.1% (n.364) of the participants would like more information about autism spectrum disorders.

Instead, the reaction felt to the diagnosis by parents is mostly sadness and grief, with 87.9% of responses; followed by "request for further clarification" 85.4%, fear 83.9%, "relief and confirmation of many doubts and concerns" with 53%, anger and rage with

Table 2: How Environmental Conditions Influenced Stress Perceived by ASD Children's Parents

Support Received/SPSS Levels	Perceived Stress Scale Levels					p-value
item no.1	**Nevern(%)**	**Almostn(%)**	**Sometimesn(%)**	**Enoughn(%)**	**Alwaysn(%)**	
General practitionersand/or pediatrician						
yes	23(5.7)	29(7.2)	54(13.4)	16(4)	6(1.5)	0.485
no	34(8.4)	63(15.6)	136(33.7)	28(6.9)	15(3.7)	
Social/health services						
Yes	24(5.9)	23(5.7)	39(9.7)	11(2.7)	5(1.2)	0.028*(C)
no	33(8.2)	69(17.1)	151(37.4)	33(8.2)	16(4)	
Psychological support						
Yes	16(4)	63(15.6)	143(35.4)	38(9.4)	19(4.7)	<0.001**
no	41(10.1)	29(7.2)	47(11.6)	6(1.5)	2(0.5)	(C)
ASD management						
Yes	52(12.9)	76(18.8)	137(33.9)	32(7.9)	14(3.5)	0.014*
no	5(1.2)	16(4)	53(13.1)	12(3)	7(1.7)	(C)
Knowledge on ASD						
Yes	45(11.1)	85(21)	175(43.3)	41(10.1)	18(4.5)	0.036*
no	12(3)	7(1.7)	15(3.7)	3(0.7)	3(0.7)	(C)
item no.2	**Never**	**Almost**	**Sometimes**	**Enough**	**Veryoften**	**p-value**
General practitionersand/or pediatrician						
Yes	17(4.2)	19(4.7)	59(14.6)	20(5)	13(3.2)	0.611
no	25(6.2)	46(11.4)	141(34.9)	35(8.7)	29(7.2)	
Social/health services						
Yes	19(4.7)	16(4)	46(11.4)	10(2.5)	11(2.7)	0.028*
no	23(5.7)	49(12.1)	154(38.1)	45(11.1)	31(7.7)	(C)
Psychological support						
Yes	11(2.7)	41(10.1)	140(34.7)	48(11.9)	39(9.7)	<0.001**
no	31(7.7)	24(5.9)	60(14.9)	7(1.7)	3(0.7)	(C)
ASD management						
yes	38(9.4)	57(14.1)	149(36.9)	38(9.4)	29(7.2)	0.013*
no	4(1)	8(2)	51(12.6)	17(4.2)	13(3.2)	(C)
Knowledge on ASD						
Yes	32(7.9)	60(14.9)	183(45.3)	51(12.6)	38(9.4)	0.035*
no	10(2.5)	5(1.2)	17(4.2)	4(1)	4(1)	(C)
item no.3	**Never**	**Almost**	**Sometimes**	**Enough**	**Veryoften**	**p-value**
General practitioner and/or pediatrician						
yes	4(1)	11(2.7)	58(14.4)	26(6.4)	29(7.2)	0.260
no	3(0.7)	13(3.2)	142(35.1)	61(15.1)	57(14.1)	
Social/health services						
yesno	4(1)	10(2.5)	51(12.6)	16(4)	21(5.2)	0.052
	3(0.7)	14(3.5)	149(36.9)	71(17.6)	65(16.1)	
Psychological support						
yes	2(0.5)	10(2.5)	126(31.2)	63(15.6)	78(19.3)	<0.001**
no	5(1.2)	14(3.5)	74(18.3)	24(5.9)	8(2)	(C)
ASD management						
Yes	6(1.5)	22(5.4)	151(37.4)	69(17.1)	63(15.6)	0.353
no	1(0.2)	2(0.5)	49(12.1)	18(4.5)	23(5.7)	

Knowledge on ASD						
Yes	6(1.5)	18(4.5)	182(45)	79(19.6)	79(19.6)	0.146
no	1(0.2)	6(1.5)	18(4.5)	8(2)	7(1.7)	
item no.4	**Never**	**Almost**	**Sometimes**	**Enough**	**Veryoften**	**p-value**
General practitionersand/or pediatrician						
yes	12(3)	26(6.4)	62(15.3)	19(4.7)	9(2.2)	0.762
no	19(4.7)	57(14.1)	126(31.2)	47(11.6)	27(6.7)	
Social/health services						
Yes	9(2.2)	24(5.9)	44(10.9)	15(3.7)	10(2.5)	0.825
no	22(5.4)	59(14.6)	144(35.6)	51(12.6)	26(6.4)	
Psychological support						
yesno	8(2) 23(5.7)	43(10.6) 40(9.9)	142(35.1) 40(9.9)	142(35.1) 46(11.4)	53(13.1) 13(3.2)	<0.001** (C)
ASD management						
yes	27(6.7)	75(18.6)	140(34.7)	48(11.9)	21(5.2)	0.001*
no	4(1)	8(2)	48(11.9)	18(4.5)	15(3.7)	(C)
Knowledge on ASD						
yes	25(6.2)	72(17.8)	174(43.1)	60(14.9)	33(8.2)	0.234
no	6(1.5)	11(2.7)	14(3.5)	6(1.5)	3(0.7)	
item no.5	**Never**	**Almost**	**Sometimes**	**Enough**	**Veryoften**	**p-value**
General practitionersand/or pediatrician						
Yes	10(2.5)	20(5)	55(13.6)	28(6.9)	15(3.7)	0.211
no	11(2.7)	37(9.2)	142(35.1)	46(11.4)	40(9.9)	
Social/health services						
yes	10(2.5)	19(4.7)	42(10.4)	16(4)	15(3.7)	0.044*
no	11(2.7)	38(9.4)	155(38.4)	58(14.4)	40(9.9)	(C)
Psychological support						
yesno	7(1.7) 14(3.5)	31(7.7) 26(6.4)	133(32.9) 64(15.8)	60(14.9) 14(3.5)	48(11.9) 7(1.7)	<0.001* (C)
ASD management						
Yes	18(4.5)	48(11.9)	153(37.9)	57(14.1)	35(8.7)	0.086
no	3(0.7)	9(2.2)	44(10.9)	17(4.2)	20(5)	
Knowledge on ASD						
Yes	16(4)	50(12.4)	181(44.8)	69(17.1)	48(11.9)	0.140
no	5(1.2)	7(1.7)	16(4)	5(1.2)	7(1.7)	
item no.6	**Never**	**Almost**	**Sometimes**	**Enough**	**Veryoften**	**p-value**
General practitionersand/or pediatrician						
yes	10(2.5)	16(4)	47(11.6)	32(7.9)	23(5.7)	0.088
no	12(3)	20(5)	133(32.9)	57(14.1)	54(13.4)	
Social/health services						
yes	12(3)	10(2.5)	44(10.9)	21(5.2)	15(3.7)	0.020*
no	10(2.5)	26(6.4)	136(33.7)	68(16.8)	62(15.3)	(C)
Psychological support						
yes	8(2)	20(5)	118(29.2)	67(16.6)	66(16.3)	<0.001**
no	14(3.5)	16(4)	62(15.3)	22(5.4)	11(2.7)	(C)
ASD management						
yes	21(5.2)	28(6.9)	139(34.4)	68(16.8)	55(13.6)	0.230
no	1(0.2)	8(2)	41(10.1)	21(5.2)	22(5.4)	
Knowledge on ASD						
Yes	17(4.2)	34(8.4)	163(40.3)	82(20.3)	68(16.8)	0.235
no	5(1.2)	2(0.5)	17(4.2)	7(1.7)	9(2.2)	

item no.7	Never	Almost	Sometimes	Enough	Veryoften	p-value
General practitionersand/or pediatrician						
yes	22(5.4)	21(5.2)	55(13.6)	21(5.2)	9(2.2)	0.117
no	24(5.9)	54(13.4)	122(30.2)	46(11.4)	30(7.4)	
Social/health services						
yes	18(4.5)	21(5.2)	35(8.7)	19(4.7)	9(2.2)	0.083
no	28(6.9)	54(13.4)	142(35.1)	48(11.9)	30(7.4)	
Psychological support						
Yes	14(3.5)	42(10.4)	127(31.4)	61(15.1)	35(8.7)	<0.001**
no	32(7.9)	33(82)	50(12.4)	6(1.5)	4(1)	(C)
ASD management						
yes	40(9.9)	67(16.6)	132(32.7)	45(11.1)	27(6.7)	0.006*
no	6(1.5)	8(2)	45(11.1)	22(5.4)	12(3)	(C)
Knowledge on ASD						
yes	37(9.2)	67(16.6)	164(40.6)	60(14.9)	36(8.9)	0.171
no	9(2.2)	8(2)	13(3.2)	7(1.7)	3(0.7)	
item no.8	**Never**	**Almost**	**Sometimes**	**Enough**	**Veryoften**	**p-value**
General practitioners and/or pediatrician						
yes	20(5)	27(6.7)	51(12.6)	21(5.2)	9(2.2)	0.667
no	30(7.4)	62(15.3)	123(30.4)	40(9.9)	21(5.2)	
Social/health services						
yes	18(4.5)	26(6.4)	34(8.4)	19(4.7)	5(1.2)	0.059
no	32(7.9)	63(15.6)	140(34.7)	42(10.4)	25(6.2)	
Psychological support						
Yes	18(4.5)	47(11.6)	131(32.4)	55(13.6)	28(6.9)	<0.001**
no	32(7.9)	42(10.4)	43(10.6)	6(1.5)	2(0.5)	(C)
ASD management						
yes	44(10.9)	79(19.6)	131(32.4)	37(9.2)	20(5)	<0.001**
no	6(1.5)	10(2.5)	43(10.6)	24(5.9)	10(2.5)	(C)

Statistical significance: *p<0.05; **p<0.001; C=multiple chi-square test.

Table 3: Parents' Knowledge of and Reactions to ASD Diagnosis

Parental Knowledge of and Reactions to ASDDiagnosis	n (%)
Definition of autism	
A neurodevelopmental disorder characterizedby impaired social interaction and deficits inverbal and nonverbal communication resultingin narrowed interests and repetitive behaviors.	354 (88)
Other	50 (12)
How do you assess your level of knowledgeinautism spectrum disorders?	
Insufficient	36 (8.9)
Sufficient	105 (26)
Discreet	156 (38.6)
Good	107 (26.5)
Would you like more information aboutautism spectrum disorders?	
Yes	346(90.1)
No	40(9.9)
Do you think informative moments in which the characteristics of the child's cognitive andbehavioral functioning are explained, and knowledge of the disorder is promoted are useful?	
Yes	389(96.3)
No	15(3.7)

He considers it useful to have educationalmoments that involve both the definition of the"problem behaviors" he enacts your child and the search for useful strategiesto promote change?	
Yes	398(98.5)
No	6(1.5)
Emotion felt at the diagnosis moment	
Silence	201(49.8)
Anger	161(39.9)
Disbelief Request for further clarification Relief and confirmation of the many doubts andworries Shock Sadness/pain Fear Dissatisfaction	141(34.9) 345(85.4) 214(53) 169(41.8) 355(87.9) 339(83.9) 112(27.7)
Specify the degree of autism	
Severe	90(22.3)
Moderate	163(40.3)
Mild	92(22.8)
How difficult is it to take care of child withASD	
In no way	4(1)
Little	26(6.4)
Enough	202(50)
Very	172(42.6)
With whom does he communicate mosteasily?	
Mother	363(89.9)
Father	202(50)
Do you feel you know how to manage some of your child's psychological and/or behavioral issues?	
Yes	311(77)
No	93(23)
Do you feel you know how to manage some ofyour child's clinical and medical issues?	
Yes	249(61.6)
No	155(38.4)

39.9%, disbelief 34.9%, silence 49.8%, shock 41.8% and dissatisfaction 27.7%.

DISCUSSION

The aim of the study was to analyze the experienced difficulties, related stress, of parents with children with autism spectrum disorder (ASD).

It was conducted on a population of 404 parents of children with ASD, 94.8% of whom are mothers with an average age of 40.23 years. The largest proportion of the sample is married (70.5%) and residing in southern Italy (39.4%).

The prevalence of parents correctly defined autism as "a neurodevelopmental disorder characterized by difficulties in social interaction and communication, limited interests, and repetitive behaviors". The data are in line with previous studies in which ASD-FAMs show a high level of knowledge about ASD and have fewer gaps on the topic than families with non-ASD children (17,18). Despite this as found in our study, 90.1% of parents would like to receive more information, as well asalmost all the sample would find it useful to have educational moments involving knowledge about the pathology, "problem behaviors," and finding useful strategies, as found in the study by Wang *et al*. [19] in which 70.3% of parents thought they did not know useful strategies for modifying "problem behaviors", thus reflecting insufficient parental efficacy. Early challenges for parents regarding ASD can emerge long before the child receives a formal diagnosis [20]: it is of paramount importance, education of parents about the early signs of ASD so that they can recognize them as early as possible if they manifest in their child's behavior, avoiding late diagnoses that are often associated with parental stress [21]. According to a recent publication, parents' search for answers usually begins with family physicians and often involves a long and confusing process in which they receive a misdiagnosis for their child, such as being labeled as deaf [22]. Parents' negative reactions to the diagnosis stem from two main aspects: the finding of the presence of a serious disorder and the characteristics of the diagnosis process itself. Estes *et al*. [23] pointed out that parents' perceived stress at diagnosis is greater in cases of autism than in parents of children with other types of developmental delay. This would also be due to the very characteristics of the disorder, such as cognitive delay, behavioral problems, irritable mood, hyperactivity, absent or reduced ability to take care of oneself, language deficits, social difficulties, and the need to be cared for throughout life [24,25]. At final diagnosis, the study results reported that 87.9% of parents reacted with sadness and grief to the diagnosis, followed by fear (83.9%) and the need for further clarification (85.4%) (26), with moderate (40.3%) and severe (22.3%) autism degrees. The reaction to the diagnosis also depended on the degree of autism, according to Moh and Magiati's study [26], this is a particularly relevant aspect, which influences parents' reactions and their perceived level of stress at the time of diagnosis. As also found in the study by Poslawsky *et al*. [27], in which parents with unresolved diagnosis reactions, with emotional reactions of overwhelm/depression and anger/concern, presented children with higher levels of autistic symptoms.

For most of the sample, caring for a child with autism is quite (50%) or very difficult (42.6%): most of the child's communication is through sentences (31.7%) and words (25.7%), while gestures are a common method (23.5%). The study by Ibrahimagic *et al*. [28], showed that the communication and language skills developed by children with ASD turn out to be associated with parental emotions/attitudes; in fact, it was found that lower receptive abilities turn out to be associated with higher levels of emotional symptoms, which in turn antecedes greater parental psychological distress [29].

The survey revealed that most individuals with autism communicate more easily with their mothers (89.9%) than with their fathers (50%). As shown in a recent study on the parent-child relationship and functioning of children with ASD, in which the emotional quality of the mother-child relationship has more widespread and robust associations than the father-child relationship: in fact, mothers are often the main carers of children compared to fathers in families of children with ASD as well as the main participants in the school life of children with ASD [30]. Parents who often face emotional, relational, and financial difficulties may feel isolated and overwhelmed by their child's needs, have trouble finding and paying for appropriate support services, and face the additional costs of therapy and treatment. However, many of them also report positive experiences, such as increased self-awareness, compassion, and personal gratification [31]. Although there is little specific information on suicide rates among parents of autistic children, one study revealed that mothers of children with autism spectrum disorders have a higher risk of mortality [32]. Specifically, they are 40% more likely to die from cancer than mothers of children without these disabilities, more than twice as likely to die from cardiovascular disease, and almost twice as likely to die from accidents. These increased risks are presumably related to the stress associated with caring for a child with these disabilities; therefore, it is important to consider the stress related to caring for a child with ASD when assessing parental mental health risks [32].

The majority of parents expressed a positive evaluation of the school experience of their children with autism, but also indicated the need for more training of teaching staff (59.7 percent) and the presence of a psychologist (34.9 percent) to improve communication and learning in the classroom. Many children with autism follow an individualized education plan (78%), but only 47.3% believe it accurately describes their child's needs. In 2021, a qualitative study was conducted in Saudi Arabia showing that participants had some knowledge and understanding of inclusive education [33]. Of interest is a study comparing teachers in two different countries, China and the UnitedKingdom. Public teachers working in the United Kingdom and the People's Republic of China filled out questionnaires that assessed the experience of teaching children with ASD and levels of knowledge of the disorder. The findings revealed that teachers who had experience working withchildren with ASD demonstrated a higher level of knowledge related to the disorder. In addition, teachers in the United Kingdom had significantly greater knowledge of ASD than teachers in China. Crucially, having adequate knowledge of these disorders allows for positive results in managingthem as well as recognizing signs and symptoms that may be a red flag for a social interaction issue. As reported in a study by Gomez *et al*. 2021, the increasing number of students with autism spectrum disorder

(ASD) in mainstream educational settings requires teachers to know how toidentify their needs, be able to adapt their educational processes, and facilitate their inclusion [34]. On the other hand, the importance in parents' need for information regarding what expectations they should have from their child's education was noted. Added to this is also the importance of teacher- parent cooperation, where parents expect teacher support in the development of their child with ASD in contrast instead to teachers who would like more cooperation from parents in developmental support at home as well [35,36]. In fact, the study by Đorđević *et al*. [37] found that parents of ASD children were less involved in their child's education in the school setting, and one of the influencing factors seems to be the parents' lack of subjective well-being, as well as to the child's emotional reactions.

In discussing the relationship with experts, it was pointed out that the attitude of professionals toward parents and the information they communicate are also of significant importance. In fact, parents are happiest with the diagnostic process if they have the opportunity to ask questions, receive useful information, and professionals show empathy [26]. In the case study, on the other hand, many parents do not feel supported by their primary care physicians and/or pediatrician (32.9%), social and health services (39.1%), and the staff of the facility their child attends (25.7%). Within the study conducted, significant statistical associations emerged between anxiety, stress and nervousness, and lack of psychological, social-health support as well as poor knowledge of ASD. The most stressful time for parents after discovering the diagnosis turns out to be just figuring out the right time and way to inform their child, worried about the negative impact this label may have on them, but at the same time a lack of sincerity can lead to "shock, disappointment and disbelief" in discovering that they are autistic, with negative emotions, especially in those whose parents were late in informing them of their diagnosis [38]. In a recent study [39], autistic parents did not expressa desire or need for professional support in disclosing the diagnosis to their autistic children, feelingthat they were already equipped due to their own knowledge and lived experience, in fact in anotherstudy [40] autistic mothers encountered difficulty, misunderstanding and fatigue, in communicating with professionals about their autistic children, in knowing what information to share, leading to anxiety and conflict.

Offering training programs to parents can be an effective way to give them the support and guidance they need to deal with the challenges of caring for a child with autism. These programs enable parents to gain a better understanding of their child's needs, develop strategies for managing problem behaviors, and connect with other parents in the same situation. In addition, trained health professionals can provide parents with valuable information and resources to cope with dailydifficulties and to help their child reach his or her maximum potential, such as behavioral therapies, educational interventions, and appropriate medications. These training programs and the support of qualified health professionals can be invaluable tools to help parents cope with the best possible care for their child with autism [41].

CONCLUSIONS

The objective of the study was to analyze the experienced difficulties, related stress, of parents with children with autism spectrum disorder (ASD). The study shows that parents of autistic children experience personal, marital, and parental stress, as well as relational stress with other children due to various factors, including the very nature of autism, characterized by lack of interaction, difficult temperament and language deficits. It is evident how and how difficult life is for parents or caregivers of a child with autism spectrum disorder. Their daily routines are disrupted upon the arrival of a diagnosis of ASD bringing challenges ranging from navigating the health care system to managing the emotional and financial burdens of caring for their child. Research in this area is critical as it can assist health care providers and scholars in understanding the unique issues parents face in raising a child with ASD, as well as support parents themselves in identifying factors that contribute to their stress level in order to take the right steps to reduce it and improve their overall well-being. An additional source of stress could be being a single parent; this finding is also particularly important in light of the high incidence of divorce among parents of children with autism, as suggested by some studies [42], an aspect not explored in our study and which would merit further investigation through additional multicenter studies.

STUDY LIMITATIONS

Possible bias selection associated with the choice to conduct an online survey and related to the chosen study design. In addition, the choice to conduct an online survey may have excluded parents/caregivers with little Italian background. The sample also consists mostly of mothers and unbalanced with fathers, so some results may be biased.

CONFLICT OF INTEREST

The authors declare no potential conflict of interests with respect to the research, authorship, and/or publication of this article.

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AUTHORS' CONTRIBUTION

All authors equally contributed to preparing this article.

DISCLOSURE OF POTENTIAL CONFLICTS OF INTEREST

The Authors declare no interest for publication.

RESEARCH INVOLVING HUMAN PARTICIPANTS AND/OR ANIMALS

The ethical characteristics of the study were set out in the questionnaire presentation. The questionnaire was designed in accordance with the principles of the Italian data protection authority (DPA). It was emphasized that participation was voluntary, and that the participant could refuse participation in the protocol whenever she wished. Those who were interested in participating were given an informed consent form, which recalled the voluntary nature of participation, as well as the confidentiality and anonymous nature of the information. In addition, to ensure that the questionnaires were anonymous, participants' responses were de-identified.

INFORMED CONSENT

Each participant gave the consent for participation.

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