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Assessing Parental Stress and Quality of Life in Families of Pre-School Children with Autism Spectrum Disorder: A Systematic Review of the Assessment Tests Used

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ABSTRACT

Background: Several studies have focused on the differences between families of children with ASD (autism spectrum disorder) and children with typical development by analyzing psychological correlates of families of children with disabilities. Outcome literature emphasizes those parents of children with autism report high levels of stress and other complexities in adjusting to life.
Methods: The authors conducted a systematic literature review designed to explore the most widely used normative and qualitative tests and related reference constructs in the scientific literature during the period between 2009 and 2019.
Results: The literature found is very large and the authors decided to identify some categories within which to differentiate the studies collected and the relative tests that emerged that are stress, emotional states, family functioning, personal characteristics and social support.
Conclusions: A thorough review of the literature combined with clinical experience showed that in clinical studies the focus on individual constructs is very strong and the subject, in this case the parent, is not viewed as a larger part of a social context, which can be a resource in stress management.

Keywords: *Parenting stress; Quality of Life; Outcomes, Autism Spectrum Disorders*

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Introduction

The family has long been a subject of scientific interest: many social sciences, including psychology, studied and investigated the structure and functioning of the family system.

The family presents itself as the most important and most enduring support in a child's development: it is within the family environment, in fact, that children receive the basis for learning, experience development, engage in early activities and participate in shared routines (Kuhaneck, Madonna, Novak, & Pearson, 2015). "Children's outcomes - their physical and emotional health and their cognitive and social functioning - are strongly influenced by the way their families function" (Schor, 2003, p. 1542).

The family-centred care model is therefore considered best practice in health care (Kuo et al., 2012); an important aspect of clinical practice to promote positive outcomes for children with special needs should be intervention to support and promote a healthy and functioning family system (Dunst, Hamby, & Brookfield, 2007; Pisula & Porębowicz-Dörsmann, 2017). Within the family dynamics, there are many reasons that can lead to dissatisfaction in the life of the couple: among these, the birth of a child with disabilities is certainly of particular importance. In this case, in fact, the couple encounters not only the complexities experienced by all new parents in reconciling responsibilities and commitments related to the new family dynamic, but also faces an additional burden of difficulties, of an emotional nature (Larcan, Oliva, & Sorrenti, 2008).

Numerous family surveys have shown that parents of children with disabilities tend to experience higher levels of stress than of typically developed children’s parents (Brei, Schwar, & Klein-Tasman, 2015; Craig et al., 2016; Hayes & Watson, 2013). Furthermore, other research, conducted within families of individuals with disabilities, has remarked that the poor adaptive skills of young people with disabilities have direct effects on parental stress (Estes et al., 2009; Hou, Stewart, Iao, & Wu, 2018; Pisula & Porębowicz-Dörsmann, 2017; Zaidman-Zait et al., 2014).

High stress indices appear to be related to both children's behavioural characteristics (Yorke et al., 2018) and parents' ability to access appropriate and functional coping strategies (Dardas & Ahmad, 2015; Hall & Graff, 2012; Seymour, Wood, Giallo, & Jellett, 2013). Specifically, it emerges that stress related to behavioural and personal aspects of the child, has a greater impact on mothers' vulnerability to stress (Hou et al., 2018; Reed, Sejunaite, & Osborne, 2016). They show significantly higher levels of fatigue than those reported by parents of typically developing children. In addition, mothers who reported high levels of fatigue also reported higher levels of depression, anxiety and stress (Dardas & Ahmad, 2015). A number of demographic, child and parental factors have been associated with maternal fatigue, including low educational attainment (high school certificate or commercial), more problematic child behaviour, poor quality diet, exercise and sleep, and high social support needs (Giallo, Wood, Jellett, & Porter, 2013).

Parental stress is a complex set of non-specific, persistent and significant challenges associated with one of the most important roles of parents, namely caring for their child. The theoretical framework adopted in many studies is the transactional model of stress and coping by Lazarus & Folkman (1984). In this approach, stress is a particular type of relationship between the person and the environment, in which the individual as exceeding his or her resources and endangering his or her well-being (Lazarus & Folkman, 1984) assesses the situation.

Parental stress is associated with the type of disability present in the child (Gupta, 2007). Several authors have reported higher levels of stress in mothers of children with autism spectrum disorder than mothers of children with other neurodevelopmental disorders, such as Down syndrome, fragile X syndrome, intellectual disability (Abbeduto et al., 2004; Craig et al., 2016; Weiss, 2002; White & Hastings, 2004).

Autism spectrum disorders (ASD) are considered persistent deficits in social communication and social interaction in multiple contexts, with restricted and repetitive patterns of behaviour, interests or activities (American Psychiatric Association, 2013). Individuals with autism may have various forms of impairment in their cognitive functioning and symptoms of varying intensity; symptoms should be present from the early period of development and continue to develop into adulthood (National Institute of Child Health & Human Development, NICHD, 2011).

The exact cause of ASD is unknown; however, it is highly likely that genetic and environmental factors are involved (National Institute of Neurological Disorders and Stroke, NINDS, 2012).

Children with autism spectrum disorder demonstrate, with varying degrees of impairment, communication deficits, inappropriate social engagement, as well as impairments in cognitive and adaptive functioning to the environment (Davis & Carter, 2014; Derguy, Loyal, Devouche, & Cappe, 2020). Their developmental abilities are often inconsistent, responses to intervention can have very different outcomes, affecting differently on prognosis (Roberts et al., 2011), and self-injurious, aggressive, or rigid behaviours can occur, affecting the functioning of the entire family (Meadan, Halle, & Ebata, 2010). Even in the face of therapies appropriately individualized to specific rehabilitation needs, children with ASD exhibit symptom-related performance difficulties and these difficulties can affect family well-being and routines (Kuhaneck et al., 2016).

Parents of children with autism soon discover that their child's maladaptive behaviours lead to long-term undesirable consequences. Behaviour management therapies, such as those proposed by Applied Behavior Analysis (ABA), are often used to reduce the symptoms of autism and moderate maladaptive behaviour. These therapies focus on behaviour management and the promotion of desired behaviours and the reduction of undesired ones (NICHD, 2011).

Raising a child with an autism spectrum disorder can be exhausting; with the potential impact, this has on parents' health and well-being (Derguy, Loyal, Devouche, e Cappe, 2020; Seymour et al., 2012). In addition, it is an established fact that the number of ASD diagnoses is steadily increasing (Kim et al., 2011), and this increase affects the social welfare system: as the number of diagnoses increases, so do the monetary costs for families (Hall & Graff, 2012).

The following analysis aims to investigate how much scientific research has focused on the assessment of stress and quality of life in parents of children with ASD, as well as the analysis of risk factors and strengths that can support them in the problems they face on a daily basis.

The starting point is the analysis of assessment systems aimed at parents, in order to investigate the impact of autism spectrum disorders from a broader perspective, which takes into account the fallout that they entail not only at an individual level, but also at a family level.

Specifically, this review analyses studies that have investigated the impact on life and psychological well-being of the daily difficulties faced by parents of children with autism spectrum disorder. Particular attention has been paid to the definition of the elements that present themselves as risk factors and those that present themselves as protective factors in the management of family and personal life: the parent is in fact considered an active subject who can influence the impact of a stressful event through cognitive, emotional and behavioural strategies (Lazarus & Folkman, 1984).

Method

Search procedures

The search strategy used was through consultation of the Library System of the University of Modena and Reggio Emilia. The following databases were analyzed in order to search for works relevant to the topic: Psychology and Behavioral Sciences Collection, PsycInfo, Education Research Complete, E-Journals and MEDLINE. In a first step, the author used the following terms to identify potential studies for consideration: autism, stress, family outcomes, parental stress, mental health, and assessment and perception of family well-being (referring to psychological concepts such as coping, adjustment, self-efficacy, and quality of life).

Among the various combinations, the terms used and identified as most relevant for data collection were: 'parenting stress', 'quality of life', 'outcomes' and 'autism spectrum disorders'. Searches were conducted on 31 July 2019, 3 August 2019 and 4 September 2019. After the initial search, the selected articles were reviewed manually.

Inclusion criteria

This review includes academic articles published in English in the last ten years; articles published from 2009 to the present were therefore considered.

Descriptive and correlational studies were selected for analysis; the choice to exclude experimental research is justified by the author's interest: it is not the purpose of this work to define the causal relationship between the variables considered.

A further inclusion criterion concerned the characteristics of the sample: among the limitations placed on databases, it was decided to select those studies applied to families with children aged 0-6 years (pre-school age). Accordingly, studies with an average sample age within 7 years were considered in the research phase, applying the following limitations per setting: “infancy”, “pre-school age” and “childhood”. This choice was determined by the will of the authors to collect the most used measurements in the literature in a specific reference population that is the parents of children with disabilities in pre-school age. The search conducted within the PsycInfo database allowed to refine the selection, in order to include studies aimed at assessing also the emotional components in caregivers, with the chance to select directly the instruments.

In order to guarantee the reproducibility of the research, the selected instruments were:

- *Parenting Stress Index;*
- *Parenting Sense of Competence Scale;*
- *Center for Epidemiological Studies Depression Scale;*
- *Resource and Stress Questionnaire;*
- *Family Empowerment Scale;*
- *Parenting Scale;*
- *Positive and negative Affect Scale;*
- *Brief Cope Inventory;*
- *Hospital anxiety and depression scale;*
- *Multidimensional scale of perceived social support;*
- *Life satisfaction scale;*
- *Beck Anxiety Inventory;*
- *Caregiver Strain Questionnaire;*
- *Family Impact Questionnaire*
- *Family Support Scale*
- *General health questionnaire;*
- *Beck Depression Inventory;*
- *Family environment scale*.

Figure 1 represents the overall selection that guided the analysis of the studies.

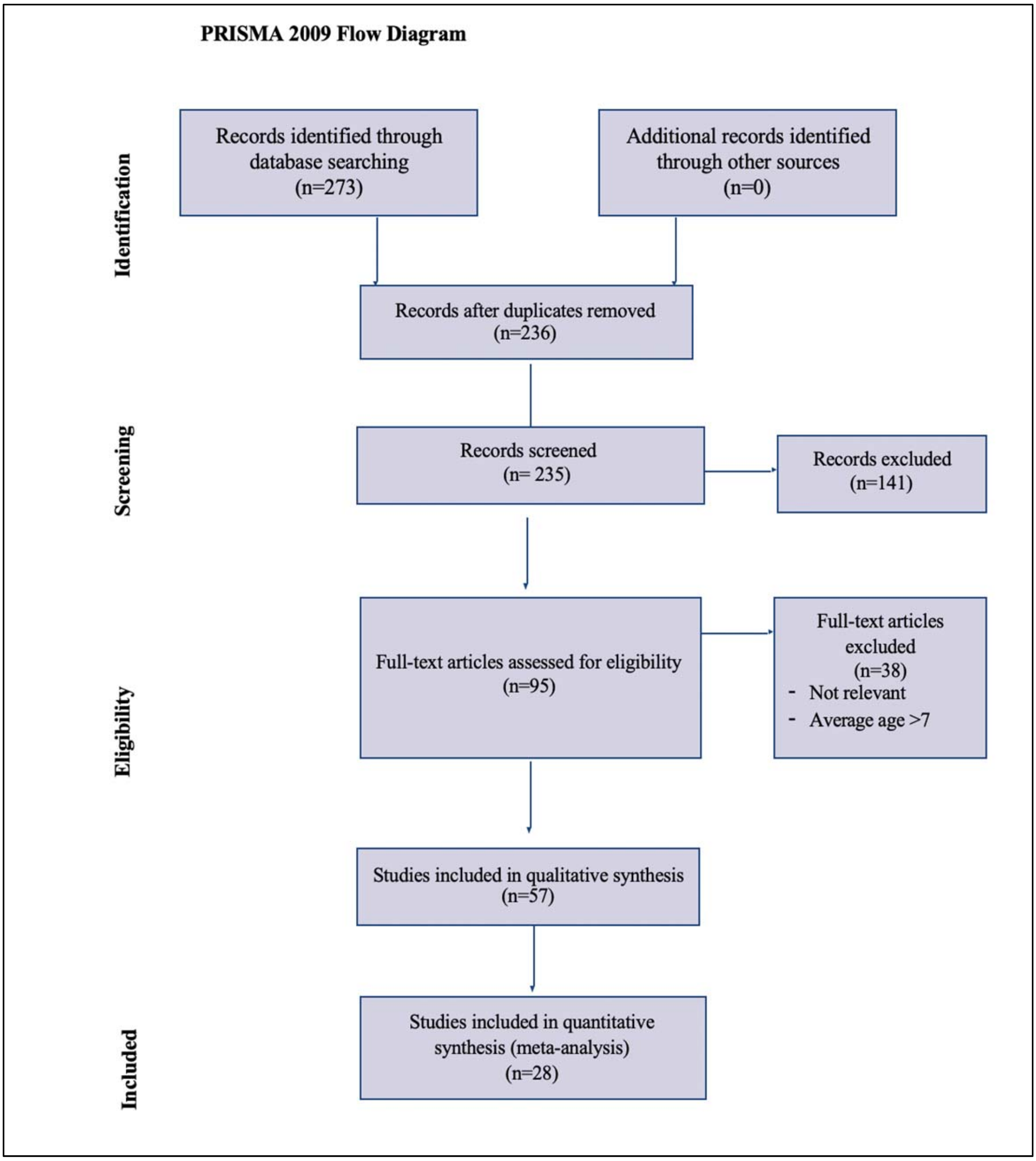

Figure 1. Flow Diagram

Screening process

This review includes academic articles published in English from 2009 to today, which meet the following criteria: (1) Most of the children included in the sample had an ASD diagnosis (Autism Spectrum Disorder, DMS-5); (2) most of the children included were aged within 18 years (in the final analysis were considered only studies in which average age of the children was within 7 years); (3) Authors focused on assessment of family well-being linked to the management of children with autism.

With the aim of summarizing most used tools to analyse emotional well-being of parents, it has been excluded works whose primary interest was to assess the effect of a specific rehabilitative intervention (aimed at children and/or parents), without considering it a secondary analysis variable, depending on a rehabilitative intervention.

Author conducted an initial literature search, focusing on identifying the most relevant keywords. After identifying the keywords, 273 articles pertinent to the topic were identified and analysed, drawing on the databases concerned above. Then, eliminated the duplicates, author analysed the titles and abstracts of these articles.

Once the inclusion criteria were defined and applied, author read the full 95 selected articles. At the end of this first analysis, 28 articles were deemed eligible to the inclusion criteria. Ethical approval was not required to conduct this study, considering no experimental tests were performed and the aim is to summarize the different types of assessments conducted with parents of children with disabilities, based on the previously published works.

Considering the used keywords ("Parenting stress", "Quality of Life", "outcomes" and "autism spectrum disorders"), author acknowledges that research conducted in this way is subject to a bias: definition of stress in the search leads to the risk of excluding articles centered on proactive resources for managing the difficulties associated with taking care of a child with disabilities.

Study selection

During final synthesis, author reviewed all the articles using a constant comparison approach to organize themes. Through this synthesis, five macro-variables about measurement of well-being in parents of children with disabilities in preschool age have been identified: stress, emotional states, family functioning, personal characteristics and social support. It's been considered stress studies (n=20), intended as general terms and in relation to parenting, articles related to emotional states (n=14) experienced by this sample of parents, defined as the experienced level of anxiety and depression, worries about the future, physical and emotional fatigue. In addition, were analyzed works about family functioning (n=8), defined in terms of couple relationship, family cohesion, quality of the family environment and parenting skills, other than studies (n=5) which have focused on the analysis of social support, as a possible resource for families of children with autism.

Finally, author consider those researches (n=14) focused on personal characteristics of the parents, in terms of physical well-being, personal and general satisfaction, quality of life, sense of competence, self-efficacy, other than coping and resilience strategies. The classification of the studies analysed will be presented in the next table (Table 1), concerning the participants included in the different studies and the survey variables with the corresponding instruments used (stress, emotional states, family functioning, personal characteristics, social support).

		PARTICIPANTS	***STRESS***	***EMOTIONAL STATES***	***FAMILY FUNCTIONING***	***PERSONAL CHARACTERISTICS***	***SOCIAL SUPPORT***
1	Lu et al. (2018)	479 parents	*PSI-SF*			*SWLS*	*MSPS-S*
2	Seymour, Wood, Giallo, & Jellett (2013)	65 mothers		*DASS-21* *FAS*		*Brief COPE*	
3	Zaidman-Zait et al. (2011)	411 parents	*PSI-SF*				
4	Estes et al. (2009)	51 mothers	*QRS*	*BSI*			
5	Estes et al. (2013)	46 mothers	*QRS*	*BSI*			
6	Hayes, & Watson (2013)	/	*PSI* *QRS* *FIQ*				
7	Osborne, & Reed (2010)	138 parents	*QRS*		*PCRI*		
8	Brei, Schwarz, & Klein-Tasman (2015)	40 parents	*PSI-SF*				
9	Davis, & Neece (2017)	72 parents	*PSI-SF*				
10	Zaidman-Zait et al. (2014)	184 mothers	*PSI-SF*				
11	Mian, Soto, Briggs-Gowan, & Carter (2018)	174 mothers	*PSI-SF*	*CES-D*		*FLIS*	
12	Pastor-Cerezuela, Fernández-Andrés, Tárraga-Mínguez, & Navarro-Peña (2016)	42 families	*PSI*			*RS*	
13	Hsieh, & Lo (2013)	40 mothers		*PANAS*		*SWLS*	
14	Carter, Martínez-Pedraza, & Gray (2009)	143 mothers		*CES-D* *BAI* *POMS*	*FES* *MES*	*COPE*	*MOS-SSS*
15	Lindsey & Barry (2018)	157 caregivers		*DASS*	*FRS*	*PSOC*	*MSPSS*
16	Weitlauf, Vehorn, Taylor, & Warren (2014)	70 mothers	*PSI-SF*	*CES-D*	*DAS*		
17	Ben-Sasson, Soto, Martínez-Pedraza, & Carter (2013)	174 mothers	*PSI*	*CES-D* *BAI* *FLIS*			
18	Schlebusch, Dada, & Samuels (2017)	180 families				*FQOL*	
19	Derguy, Roux, Portex,& M'bailara (2018)	115 parents				*WHOQOL BREF*	
20	Wang et al. (2013)	165 mothers	*PSI-SF*	*SAS* *CES-D*		*SCSQ*	
21	Zaidman-Zait et al. (2017)	283 mothers	*PSI-SF*		*FAD*	*WoC*	*SSS*
22	Hou, Stewart, Iao, & Wu (2018)	51 mothers	*PSI*	*BDI-II*			
23	Giallo, Wood, Jellett,& Porter (2013)	50 mothers		*DASS-21* *Adapted FAS*		*Health Behaviour scale* *PSOC*	*Parent Social Support Index*
24	Suzumura (2015)	60 mothers				*SF-36*	
25	Karp, Ibañez, Warren,& Stone (2017)	54 parents	*PSI- SF*	*PCF*	*MES*		
26	Sim, Cordier, Vaz, Parsons, & Falkmer (2017)	127 parents	*The Parental Stress Scale*		*CSI-32* *DCI*		
27	Samadi, McConkey, & Bunting (2014)	103 parents	*PSI- SF*		*Family functioning*	*GHQ* *- Satisfaction with caring*	

TABLE 1. *Summary of main characteristics about academic articles analyzed*

Results

All the selected articles allowed collecting a range of useful tools to define the critical points and potential resources to consider in the assessment of the well-being of parents of children with disabilities of preschool age.

Referring to survey sample, the most used tools in literature will be reported below, divided into variable:

About stress, the most used tools were resulted the following:

Parenting Stress Index-Short Form (PSI-SF)
Parenting Stress Index (PSI)
Questionnaire on Resources and Stress (QRS)
Family Impact Questionnaire (FIQ)

In case of emotional states, assessments are mainly conducted through:

The depression, anxiety and stress scale-21 (DASS-21)
The Brief Symptom Inventory (BSI)
Center for Epidemiologic Studies Depression Inventory (CES-D)
The Brief Symptom Inventory (BSI)
Beck Anxiety Inventory (BAI)
The Depression, Anxiety and Stress Scale (DASS)
Self-Rating Anxiety Scale (SAS)
The Beck Depression Inventory-II (BDI-II)
Positive and Negative Affect Scale (PANAS)
Parent Concerns Form (PCF)
Fatigue assessment scale (FAS)
Family Life Impairment Scale (FLIS)

At family functioning level, the most relevant measurements are made through:

Parent-Child Relationship Inventory (PCRI)
Family Environment Scale (FES)
Maternal Efficacy Scale (MES)
The Family Resource Scale (FRS)
Dyadic Adjustment Scale (DAS)
The Mc Master Family Assessment Device (FAD)
Dyadic Coping Inventory (DCI)
Couple Satisfaction Index-32 (CSI-32)
Family functioning

About personal characteristics the evaluation tools most successful were result:

Satisfaction with Life Scale (SWLS)
Satisfaction with caring
Health Behaviour scale
Short Form 36 Health Survey Questionnaire, version 2 (SF-36)
General Health Questionnaire (GHQ)
The Parenting Sense of Competence Scale (PSOC)
Family Quality of Life Scale (FQOL)
The World Health Organization Quality of Life Bref (WHOQOL-BREF)

Resilience Scale (RS)
Coping Orientations to Problems Experienced (COPE)
Brief COPE
Simplified Coping Style Questionnaire (SCSQ)
Ways of Coping Questionnaire (WoC)

Finally, social support measurement tests are mainly made through:
Multi-Dimensional Scale of Perceived Social Support (MSPSS)
Medical Outcomes Study Social Support Survey (MOS-SSS)
Social Support Scale (SSS)
Parent Social Support Index

Discussion

The data analysed regarding the assessment of quality of life and perceived parental stress refer to a total reference sample of 3474 caregivers. Specifically, half of the studies considered in this review (54%) directly involved mothers as primary caregivers in the care of their child with autism spectrum disorder; 1556 mothers were interviewed, with an average age of 33.13 years.

The remaining studies considered (46%) involved the family unit, thus envisaging the involvement of both mothers and fathers in completing the proposed questionnaires. Also in these studies, the percentage of mothers involved appears higher (61%) than that of fathers, confirming the more significant impact in terms of psychological fatigue on mothers of the processes of caring for and managing children with disabilities (Hou et al., 2018).

Related to mentioned results, implications referred to tests will be discussed, according to different variables considered.

In most of the studies presented, authors have focused mainly on stress in parents, according to those studies which revealed parents of children with disabilities tend to experience higher levels of stress than parents of children with typical development (Brei, Schwarz, & Klein-Tasman, 2015; Hayes & Watson, 2013).

The global impact of a neuro developmental disorder in a family is linked to high levels of perceived stress that often appear not only as a reaction to the diagnosis, but last over time, causing a decrease in quality of life within the family and a increased problems within the parental couple.

It is therefore urgent to due attention at family functioning: in the analysis reported, less than a third of the data presented make a use of tools aimed at investigating family functioning. This is certainly a significant fact, which makes the authors think on encouraging family to consider their role, their expectations and giving them a space for active listening.

Analysis of expectations and needs expressed by caregivers offers a new way to think the complexity of offering a service aimed at children that at the same time it responds at the parents' need. As widely emphasized, it is essential to build not only a therapeutic alliance with the family, but also planning interventions focused on parental stress, family functioning and considering their health (Carter et al., 2009; Craig et al., 2016).

In half of the researches presented, psychological well-being of mothers and fathers were investigated. The attention paid to their personal needs must be strengthened; according to literature, these are families severely affected by their children's deficits who experience stress on an individual, marital, and parental level (Brei et al., 2015; Carter et al., 2009; Meadan et al., 2010; Weiss, 2002). It is therefore essential to help parents in increase awareness on themselves, on their individual and social needs (Zaidman-Zait et al, 2017).

Finally, social support appears to be the least considered in these studies: actually only five studies have considered the social network around the family of children with ASD as an element to be considered to support their well-being. Literature agrees in confirm the demand for these parents to create a space for discussion where they can give and get support for sharing emotional impact of the diagnosis and the complexity of daily efforts required (Sim et al., 2017; Weitlauf et al., 2014).

Premises of this paper have highlighted the strong attention paid to psychological constructs on the single; the part of social context in supporting these families is not properly considered and it shows up as an area to be study in deep in future researches.

Results and implications of this study must be considered according to some limits. First, it is not possible to determine causality relation in the constructs investigated for methodological reasons. A further limitation is about not providing clear results on the relationships between parental stress and child's behavioral characteristics, such as the severity of symptoms, which could significantly influence parental stress. Finally, research conducted with the selected keywords authors acknowledge could be subject to a risk of bias about the definition of stress: in these terms, there is possibility to exclude articles centered on proactive resources for managing difficulties related to caring for a child with disabilities.

According to clinical experience of the authors in the rehabilitation centre (TICE), in purely clinical studies the subject is not considered as a larger part of a social context. Starting from this point, future prospective should reflect on the importance of the contamination between clinical psychology, health psychology and the world of personal services in the design of increasingly effective and efficient rehabilitation services. It is important indeed keep doing research and studying parental well-being is important not only for the parents themselves, but for the development of their children with autism spectrum disorders.

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Authors' contribution:
All authors assisted with concept, study design, data analysis, manuscript preparation and manuscript editing; Monica Cattalini and Francesca Cavallini assisted with the generation of the initial draft of the whole manuscript, manuscript editing and data interpretation, assisted with manuscript editing and study concept; Monica Cattalini and Angela Saccà assisted with manuscript editing, data analysis, data interpretation, and study supervision. All authors contributed and approved the final manuscript.

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