

Families with autistic children^{*}

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The specific aspects of autistic persons' communication and interaction require responses based on the parents' personal capacities for coping, but also on the characteristics of the family system. The aims of the study were to analyze the relations between the perceptions of the parental couple about the styles of functioning of the family, and the competencies of their autistic children. It was hypothesized that the presence or absence of Intellectual Disability comorbid with the autism could influence these relations. Participants were 20 children, 85% males, age range 4-7 years, with a diagnosis of Autism Spectrum Disorder, 50% with Intellectual Disability, and both their parents. PEP3 to assess the performances of autistic persons, and FACES-IV to assess family functioning were used as instruments. The results demonstrated that cohesion, communication and satisfaction in the family system are higher when Intellectual Disability is not associated with autism. Higher cognitive skills in the child are associated with cohesion and flexibility, and with the communication level of the family system, while deficits in expressive and receptive language and affective expression are linked with the unbalanced dimensions of family functioning. Less maladaptive behaviors in the children were found in balanced types of families. The inverse correlation between child's visual-motor imitation and family cohesion may be attributed to the difficulty of the autistic person to articulate and detect appropriately the cues for an effective imitation in a highly cohesive system. The need of longitudinal studies to explain better causes and effects in these relations is underlined.

Keywords: autism, ADS, intellectual disability, family system, Faces IV.

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According to socio-cognitive theory, the autistic persons are less able to perceive the emotional expression and the inner states of mind of the caregivers, with a deficit in the fundamental capacities of imitation and of understanding the intentionality of the communication, that allow the construction of the interpersonal relations (Hobson, 1993). The deficit in the recognition of what the others think and feel (i.e., the “theory of the mind”) was hypothesized as the core problem in autism (Baron-Cohen, Leslie, & Frith, 1985; Baron-Cohen, 1997; Surian, 2002; Senju, Southgate, White, & Frith, 2009) and some recent neurophysiologic findings, e.g. on the mirror neurons system, seem to confirm this hypothesis (Oberman, Hubbard, McCleery, Altschuler, Ramachandran, & Pineda, 2005; Dapretto, Davies, Pfeifer, Scott, Sigman, Bookheimer, & Iacoboni 2006; Ramachandran & Oberman, 2006).

Based on the misperception and misunderstanding of the others’ mind the autistic children imitate not only the intentional actions but also those accidental and not pertinent to the task and/or to the situation (Vivanti, Nadig, Ozonoff, & Rogers, 2008).

What happens when the parents get in touch with these communicational and relational characteristics of their autistic children? Frustration, stress, ambivalence, perhaps guilt and shame, impotence, sometimes refusal, have been described in the literature in the families of autistic children. But to have a child with special needs is not necessarily a disrupting experience. The family is requested to acquire new competencies, and the presence of the autistic child stimulates dynamics existing – although latent – in the family system (Moderato, 2001).

As the *Family Stress and Coping Theory* (McCubbin & Patterson 1981) underlined, a cohesive, flexible and stable system should be more able to cope successfully with the stress provoked by the special needs of a member, considered as a critical event based on unforeseeable factors.

The model was named ABCX: A (the stressful event) interacts with B (the family resources) and with C (definition of the event) to produce X (the crisis). The “Double ABCX” model, an expansion of the early ABCX model, describes how families and other caregivers respond to stressors associated with caring for a disabled child under a long-term perspective, and it is therefore better applicable to autistic conditions (Pakenham, Samios, & Sofronoff, 2005).

The potential crisis (Xx) depends not only on the demands and burdens, cumulating in the time (Aa) but also on moderator variables, including the long-term evolution of caregivers’ psychological, social and material resources (Bb), the changing interpretation of stressors and demands (Cc), and the coping efforts which result from both (BbCc).

Based on the model, the relevance and the management of the crisis originate from the interaction between the stressful event, the perception and the meaning the couple attributes to the event itself, the resources present and

available and those which could be acquired. The stressors can be differently perceived in relation to their normative, internal/external, ambiguous, unwanted, chronic, cumulative aspects.

The resources are attributes, skills or ways of functioning that individuals and families have at their disposal when adapting to stressor events. When life events impacting upon the family unit produce, or are perceived as producing, changes in the family system, the efforts to achieve a new level of balance can be successful and lead to an adaptive outcome when members are able to restore balance, reducing demands, increasing capabilities, and changing meanings.

The vulnerability to stress (i. e., the lack of present resources for coping) can be overcome by “regenerative power” (Burr, 1973): the stage of disorganization of the homeostasis will be succeeded by a phase of active search for a new organizational level, with different modalities of functioning and a new equilibrium in the family system (McCubbin & Figley, 1983).

In the *Family Adjustment and Adaptation Response (FAAR)* Model (Patterson, 1988, 2002) families engage in active processes to balance demands with capabilities and meanings, to reach a level of family adjustment or adaptation. In this model, family meanings consist in definitions of demands (primary appraisal) and capabilities (secondary appraisal), definition of family identity (how members see themselves as a unit), and world view, i.e. how members see the family system in relationship to outside systems. When *risk* factors (i.e., stressors and demands on the family system) and *protective* factors, including resources and coping strategies, are balanced, strengths for resilience are acquired.

Olson and Stewart (1990) proposed the *Multisystem Assessment of Stress and Health (MASH)* approach, aimed to assess the levels of stress, coping resources and (re)adaptation, both of the members, the couple, and the family system as a whole. More recently, the relation between coping, sense of coherence, and social support has been studied (Antonovsky & Souriani, 1988).

The *Developmental Approach* integrates the resources needed to cope with external events with those necessary to manage the normative, internal and predictable events in the family lifespan, to deal by means of conjoint developmental tasks. The developmental tasks needed to cope with disabled children have been described (e.g., Marsh, 1992; Dyson, 1993; Beresford, 1994; Floyd, Singer, Powers, & Costigan 1996; Saviolo Negrin & Cristante 1996, Costigan, Harter, & McClintock 1997; Valtolina, 2000; Di Nuovo e Buono, 2004), referring also to the support from the social networks (Ianes, 1991). Some authors (e.g., Goldfarb e al. 1990) presented data demonstrating an enhancement in the cohesion of the parents' couple after a long-lasting critical breakdown.

The study of the specific characteristics of the family system coping with a problematic child (e.g., disabled, autistic) has to be implemented to understand better the use of the resources to manage the problems.

The characteristics of the families with autistic children have been studied in relation to coping over time (Gray, 2006), the strategies specifically used (Troy, Connolly, & Novak 2007). Possible positive effects of dealing with a child with autism have been underlined: e.g., according to Marcus, Kuncze, & Schopler (2005), some parents of children with autism describe benefits of having a child with autism, such as enjoyment about small steps of developmental progress or finding a new meaning in their lives.

Some predictors of resilience have been described, as open and predictable patterns of communication, hardiness, commitment and flexibility, internal and external coping strategies, and positive belief systems about life (Greef & van der Walt, 2010). Recently, Siman-Toy & Kaniel (2011) found that sense of coherence, internal locus of control, social support and quality of marriage increase the ability to cope with the stress of parenting an autistic child. The need to study the association of family stress with child characteristics has been pointed out (Fong & Wilgosh, 1992; Davis & Carter, 2008); more effort has to be addressed to the structural features of the functioning of the family, according to MASH and Developmental Approach.

These approaches allow to go further the model claiming that a subjective deficit in recognition of what other thinks – although relevant in many cases - is the *core* problem of people with autism. A wider problem lies in the family system development and reorganization, including reciprocal recognition in communication, but involving also other cognitive, emotional, relational factors (Johnson & Myers, 2007; Montes & Halterman 2007; Kelly, Garnett, Attwood, Peterson, 2008; Kogan, Strickland, Blumberg, Singh, Perrin, & van Dyck 2008; Hall & Graff, 2011).

To verify the hypothesis of the “regenerative power” of the crisis in families with an autistic child, and to predict the resources for resilience, an accurate assessment of the characteristics of the family system is needed first.

Empirical Study

Objectives and research hypotheses

In our research study families with autistic children, with or without intellectual disability, were studied in order to assess differences among these conditions.

The relationships between the family variables perceived by their parents and the psycho-educational profile of the children were the focus of the

analysis. The main hypothesis was that these relations are relevant but are mediated by the intellectual level of the child and by his/her developmental competencies.

The assessment of the family system as perceived by the parents refers to the Circumplex model proposed by Olson, Sprenkle, and Russell (1979, 1989). Some dimensions are positive (cohesion, flexibility, communication, satisfaction) and represent the *balanced* aspect of functioning, while some others (disengaged, enmeshed, chaotic, rigid) are pertinent to the *unbalanced* modes of functioning. The extremes of the dimensions are typical of a non-adaptive homeostasis of the system.

As regards the autistic child variables, the model proposed by Schopler, Reichler & Lansing (1991) to assess and plan the educational intervention was followed, with the aim of pointing out the strength and weakness in the different cognitive, emotional and interpersonal variables and to provide a global developmental level score, useful to locate the subject along the continuum of the diagnostic profile of Autistic Spectrum Disorder.

Methodology

Participants. Twenty children, 17 males and 3 females, age range 4-7 years (mean 6.01 yrs, standard deviation 1.08), with a diagnosis of Autism Spectrum Disorder (ASD) participated in the study along with both their parents.

An half of them had a double diagnosis of comorbid Intellectual Disability of Mild/Moderate level, assessed preliminary by the neuropsychological équipe by means of the Wechsler Intelligence Scale (WISC-III) and of clinical evaluation according to DSM criteria.

The group of fathers has age range 36-60 years, mean age 44.30, standard deviation 5.42. Mothers have age range 34-54 years, mean age 41.50, standard deviation 5.09.

Instruments

(a) *Psycho-Educational Profile* 3rd edition (PEP-3, It. ed. Schopler, Lansing, Reichler, & Marcus 2005), a specific test to assess the performances of autistic persons, yielding three composite scores (Communication, Motor, and Maladaptive Behaviors) and subscores in ten Performance Subtests: Cognitive Verbal/Preverbal; Expressive Language; Receptive Language; Fine Motor; Gross Motor; Visual-Motor Imitation; Affective Expression; Social Reciprocity; Characteristic; Motor Behaviors; Characteristic Verbal Behaviors.

Six of the 10 subtests are related to broad performance across a variety of tasks, while the remaining four are concerned with adaptive behaviors demonstrated during the testing session. The PEP-3 test kit consists of attractive toys and learning materials presented to the child within the context of structured play activities. Chen, Chiang, Tseng, Fu, & Hsieh (2011) suggest

using the raw scores and developmental ages of the PEP-3 to detect developmental aspects of children with ASD.

(b) *Family Adaptability and Cohesion Evaluation Scales, 4th version (FACES-IV)*, a self-report Likert-type instrument that assesses family functioning based on the Olson's curvilinear or "Circumplex" model. The basic constructs of the model are cohesion, adaptability (i. e., flexibility), and communication; families who function best are balanced between two extremes on the dimensions of cohesion and adaptability. Open and clear communication also helps families function well. The FACES test measures *Cohesion* defined as the emotional bonding among family members, and *Adaptability* or *Flexibility* referring to the ability of a family system to change its roles, rules, and power structure in response to developmental changes or situational stressors. Families too cohesive (*enmeshed*) or too distant (*disengaged*), and those that change too much (*chaotic*), or do not change enough (*rigid*), are less functional. In the last version of the test, the scales measuring *Communication* and *Satisfaction* were added to further implement the model. The Italian version, adapted and standardized by Lorigo, Vesani, and Di Nuovo (2009) was used for the present study. Examples of items are: "In our family, when some rule is not respected there are serious consequences."; "We feel excessively involved with one another."; "Each of us is able to ask the other relatives about what they want."

Procedure. The tests were administered in the Association "A future for the Autism", promoted by parents of autistic persons to provide appropriate services for the specific children's pathologies.

The parents, once informed about the scientific aims of the study, gave their consent. Parents answered to the *FACES-IV*, while children were administered PEP-3 in a one-to-one setting; the examiner (a psychologist with experience in the field, G.A.) observed, recorded and evaluated the child's responses and behaviour during the activities stimulated by the test items, giving individual feedbacks when appropriate.

Results

The differences in mean raw couple scores in relation to the absence or presence of Intellectual Disability in the autistic children were calculated. The table 1 shows the *t* values and the associated probabilities. Significant differences were found in the *cohesion*, *communication* and *satisfaction* scales, confirming the hypothesis that a better functioning of the family system is linked with the condition of autism with a normal level of intelligence.

It is interesting to point out that mean scores falling in the 1st quartile for each variable (evidenced in Table 1) are present only in the ASD+ID group, in flexibility and satisfaction, confirming that Mental Retardation is a important

mediator in the relation between the autistic person's characteristics of the and family functioning.

Table 1. Comparison of mean couple raw scores in the FACES-IV scales in the subgroups divided according to the absence / presence of Intellectual Disability in the autistic child.

Mean couple score	ASD without ID		ASD with ID		d.f.=18	
	Mean	s.d.	Mean	s.d.	t	p
<i>Cohesion</i>	26.00	4.32	21.60	4.05	2.35	.03
Flexibility	21.10	4.98	17.75	5.50	1.43	.17
Disengagement	13.65	3.78	16.50	4.08	-1.62	.12
Enmeshment	19.60	3.20	19.20	3.30	.28	.79
Rigidity	17.50	3.57	16.55	3.32	.62	.55
Chaotic	16.05	3.20	16.35	4.77	-.17	.87
<i>Communication</i>	36.55	8.42	29.30	6.79	2.12	.05
<i>Satisfaction</i>	34.40	7.48	25.65	8.27	2.48	.02

Legenda: (a) Variables with significant differences between groups are evidenced in *Italics*. (b) Mean scores below the 1st quartile cut-off for each specific variable are evidenced in **bold**.

The relations between the dimensions of the family system, as perceived by the parental couple, and the psychological and adaptive variables of the autistic child were explored by means of multiple regression analyses, considering as predictors the variables of the PEP-3 and the scales of FACES-IV as effects. The Table 2 summarizes the results, evidencing as relevant the predictors > .50.

Table 2. Results of the analyses of multiple regression (the variables of the PEP-3 are considered as predictors, the scales of FACES-IV as effects).

Predictors	Effects in multiple regressions analyses							
	<i>Cohes</i>	<i>Flexib</i>	<i>Diseng</i>	<i>Enmesh</i>	<i>Rigid</i>	<i>Chaot</i>	<i>Comm</i>	<i>Satisf</i>
<i>Cognitive Verbal/Preverbal</i>	0.66	0.68	1.04	-0.23	0.08	-0.22	0.66	0.33
<i>Expressive Language</i>	-0.25	-0.32	-0.53	0.44	-0.51	0.25	-0.12	0.20
<i>Receptive Language</i>	0.71	0.08	-0.64	0.01	0.09	-0.50	0.53	0.35
<i>Fine Motor</i>	0.34	0.59	-0.35	0.06	0.40	0.06	0.40	-0.11
<i>Gross Motor</i>	-0.11	-0.37	-0.18	0.45	-0.42	0.06	-0.26	-0.10
<i>Visual-Motor Imitation</i>	-0.51	0.11	0.28	0.03	-0.36	-0.15	-0.42	-0.20
<i>Affective Expression</i>	-0.07	0.11	-0.14	-0.67	-0.34	-0.02	-0.04	-0.02
<i>Social Reciprocity</i>	-0.15	-0.29	-0.24	0.18	0.18	0.13	0.08	0.20

In **bold** the predictors > 0.50

Cohesion and *Flexibility* are positively connected with the preverbal and verbal cognitive development, while *Cohesion* is inversely linked with the visual-motor imitation (the same tendency is shown with the level of *Communication*). While the connection between the child's cognitive skills and the main positively balancing dimension of the family system confirms our hypotheses, the other result was quite unexpected. It could be explained with the difficulty of a child with the characteristics of autism, described in literature, to follow the cues for an effective imitation in a highly cohesive family system with members communicating more to each others. In fact, the visual-motor imitation results as not connected with *Enmeshment* but rather with a positive, although minor, relation with *Disengagement*.

Flexibility is linked with better child's motor skills.

The *Disengagement* in the family system is related to deficits in expressive and receptive language, *Enmeshment* in affective expression.

A *Rigid* family system is related to less competencies in expressive language, while *Chaotic* in receptive language. This receptive aspect of the language is fostered by a better *Communication* level.

Communication is linked also to the child's acquisition of better cognitive skills.

Satisfaction perceived by the couple is related – but at a non significant level – with cognitive abilities and receptive language.

Using the PEP-3 scaled scores – i.e. developmental ages – significant correlations were found as shown in Table 3. Developmental age for communication skills in the child is significantly and positively related with cohesion, flexibility, communication and satisfaction, inversely with disengagement. Developmental ages for motor skills is significantly correlated only with parent's perception of Flexibility.

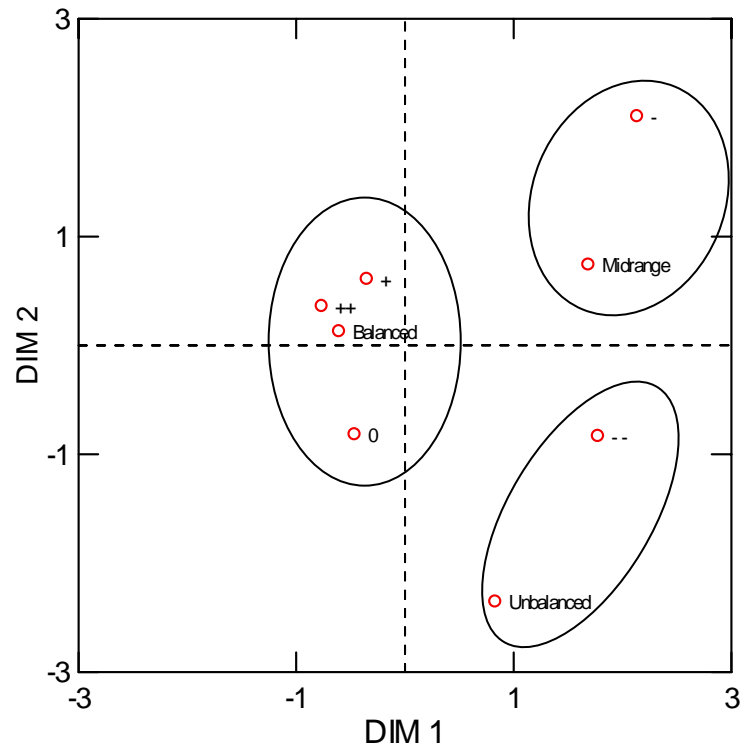
Table 3. Pearson correlations between the scaled variables of the PEP-3 (developmental ages) and the scales of FACES-IV.

	COHES	FLEXIB	DISENG	ENMESH	RIGID	CHAOT	COMMUN	SATISF
<i>Developm.age Communication</i>	0.48**	0.66***	-0.54*	0.06	-0.01	-0.26	0.62***	0.62***
<i>Developm.age Motor</i>	0.25	0.51*	-0.32	0.17	0.01	-0.08	0.39	0.36

* $p < .05$; ** $p < .01$; *** $p < .001$

A further analysis tried to explore the relations between the family system and maladaptive behavior. A Multiple Correspondence Analysis was performed joining the types of family (balanced, midrange and unbalanced according to the Olson's criteria for the test FACES-IV) and the level of child's maladaptive behavior. The analysis yielded a total inertia = 3.00, and the coordinates in the two main factors are shown in Figure 1.

Figure 1. Correspondence plot for the relations between the family types and the child's maladaptive behavior.



Legend:

Types of family: Balanced, Midrange, Unbalanced

Levels of child's maladaptive behavior: -- Very severe, - Severe, 0 Moderate, + Mild, ++ Very mild

The graph shown in Figure 1 clearly illustrates the link between the balanced type of family and the child's more adaptive levels of behavior, while midrange and unbalanced families are closer respectively to the severe and very severe levels of maladjustment.

Discussion and conclusions

The parents' response to the specific aspects of autistic children's communication and interaction depends on their personal capacities for coping, but also on the characteristics of the family system, as perceived by themselves.

Our study aimed to analyze the associations between the perceptions of the parental couple regarding the styles of the family functioning and the competencies of their autistic children. The results, within the limits due to small samples, were interpreted according the socio-cognitive and developmental theoretical framework presented in the introduction, with reference to the family

system. They demonstrated that the sense of mutuality and the levels of communication and overall satisfaction in the family system are higher when the autistic child has not comorbidity of Intellectual Disability.

Higher cognitive skills in the child are associated with cohesion and flexibility, and with the communication level of the family system, while deficits in expressive and receptive language and affective expression are linked with the unbalanced dimensions of family functioning.

Also, the child's communication developmental age was found to be positively related to cohesion, flexibility, communication and satisfaction in the family system, while inversely with disengagement. Balanced types of families were associated with less maladaptive behaviors in the children.

A specific and quite unexpected result from our study was the inverse correlation between child's visual-motor imitation and family cohesion; as already said, it may be attributed to the difficulty of the autistic person to articulate and detect appropriately the cues and the stimuli coming from a highly cohesive system, characterized by a strict emotional and communicational bond among the members of the family.

We are aware that in a not-experimental design causes and effects in these relations are difficult to explain, and the explanation of the found differences can be pertinent to child as well as family characteristics.

Perhaps this issue cannot be solved in absence of a longitudinal study assessing very early the variables both in the parents and in the children, and retesting the same variables some years later. This is an aim we would pursue in future research, with the cooperation of the "Association for the Future of Autism". We think that the future of the persons affected with autism – apart from the progress made in the research about the genetic and neuropsychological causes – may be improved by the increasing knowledge about the variables that connect the family system with the cognitive and adaptive behavior of the phenotype, and by appropriate interventions aimed at enhancing these relations as well.

A proper assessment of the variables, by means of reliable and validated instruments, is the needed preliminary condition of the interventions that should be implemented in the services offered to the autistic persons and to their families.

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