

SIBLINGS' PERCEPTIONS IN AUTISM SPECTRUM DISORDER COMPARED WITH INTELLECTUAL DISABILITY AND TYPICAL DEVELOPMENT

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Abstract

Objective: Differences between the self-image of persons with typical development and the image they have of their brother or sister with disabilities have been hypothesized in literature, but no specific patterns have been detected with reference to intellectual disability associated or not with Autism Spectrum Disorder (ASD). The aim of the study was to address this specific issue.

Method: Two Semantic Differentials on self-image vs brother/sister's image were administered to 93 individuals with typical development divided into three groups, matched by age, according to the sibling's condition: Autism with Intellectual Disability, Intellectual Disability without Autism, Typical Development. Severity of impairment and levels of adaptation of disabled brothers/sisters were also taken into account.

Results and conclusions: Siblings of individuals with disability perceived the disabled brother/sister as less active and less emotionally stable than themselves, but not demonstrating any significant difference in showing affects and feelings. In future research, specific behaviors associated with ASD need to be controlled in order to better address the differences between the aforementioned groups.

Key words: siblings, autism spectrum disorder, intellectual disability, self-perception

Declaration of interest: nothing to declare

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Introduction

In recent decades, researchers and clinicians have focused on the adjustment, problems and coping strategies of siblings of children with Autism Spectrum Disorder (ASD). Literature shows that the experiences of life and the kind of relationship between siblings when one child has ASD may determine different outcomes, varying from the enrichment of human values to definitely pathological signs, passing through adaptive intermediate stages which result more or less successful (Orsmond and Seltzer 2000, Kaminsky and Dewey 2001, Pilowsky et al. 2003, Scheuer 2005, Constantino et al. 2006, Pilowsky et al. 2007, Toth et al. 2007, Hodapp and Urbano 2007, Orsmond and Seltzer 2007, Neely-Barnes and Graff 2011, Hastings and Petalas 2014).

Theories on family systems point out that the psychosocial adjustment of both parents and siblings can be influenced, directly or indirectly, by the presence of a child with autism (Cox and Paley 1997). According to several studies, the presence of a brother or a sister with ASD has negative effects on siblings (Marciano and Scheuer 2005, Orsmond and Seltzer 2009, Yoder

et al. 2009). Some studies have found more behavioral and emotional problems, higher levels of anxiety, and lower pro-social skills compared to control groups (Fisman et al. 1996, Fisman et al. 2000, Hastings 2003, Verte' et al. 2003, Constantino et al. 2006, Giallo and Gavidia-Payne 2006, Ross and Cuskelly 2006). Not every scholar agrees that the presence of individuals with ASD in the family leads inevitably to maladaptive outcomes. Having a brother or a sister with autism can be stressful but at the same time rewarding (Squillaci and Lanners 2005, Benson and Karlof 2008, Walton and Ingersoll 2015). Moreover, the literature shows that the siblings of people with autism, display different and peculiar reactions compared to those of the siblings of people with other kinds of disabilities (Orsmond and Seltzer 2007, Hastings and Petalas 2014).

Marciano and Scheuer (2005) investigated the quality of life of siblings of individuals with autism, by comparing its effects in a control group with language disorder. The results showed a lower quality of life among the siblings of subjects with autism. Vieira and Fernandes (2013) studied the quality of life in siblings of children with ASD using the World Health Organization Quality of Life-BREF (WHOQOL-

BREF) questionnaire. Further research has also studied the relationship between siblings of people with autism and people with Down Syndrome. The results indicated that the relationships established with brothers or sisters who have autism are characterized by lower intimacy and prosocial behaviors (Kaminsky and Dewey 2001). In another study, the authors examined the psychosocial adjustment in siblings of children with autism by comparing it to the one in siblings of children with Down syndrome and with typically development. They analyzed the relationship between feelings of loneliness, social support, psychosocial adjustment, influence of gender and family size in order to understand whether these factors affected psychosocial adaptation. The results revealed differences in the three groups. Siblings of children with ASD experienced low levels of loneliness and received more social support (for example by peers). Large family size appears to facilitate healthy adjustment in siblings of children with autism (Kaminsky and Dewey 2002, Mandlenco and Mason Webb 2015). Other authors have reported higher levels of social competence and self-concept, and higher levels of acceptance and warmth in social relations among siblings of persons with autism compared to the control groups (Fisman et al. 1996, Verte' et al. 2003).

Orsmond and Seltzer (2007) reviewed literature on the siblings of people with ASD, from childhood to adulthood, focusing on their welfare. The authors conclude that, during childhood, the siblings have an atypical development in the domain of social communication, whereas, during adolescence, they experience both positive and negative aspects of their fraternal relationship. Furthermore, there is some evidence that siblings of children with ASD may be prone to increased risks during the development of social adaptation and consequent behavioral problems.

A study by Bagenholm and Gillberg (1991) noted no major differences in self-concept between siblings of individuals with ASD compared with both siblings of people with typical development and with intellectual disabilities; nevertheless, siblings of people with disabilities, especially with autism, appeared more concerned about their future development and showed behavioral problems with peers.

Studies currently available in literature still have a nuanced picture of the impact of autism on siblings and cannot be considered exhaustive. Frequently, all the increased attention of the family focuses on the difficulties encountered in the education of the autistic child, and takes away attention from the other children who, once grown up and become of adult age, should often assume the role of caregiver (Heller and Arnold 2010, Burke et al. 2012, Burke et al. 2015). The consideration of these aspects, grounded on evidence-based studies, could help to determine appropriate treatment guidelines useful for increasing the quality of life in families where a member is diagnosed as ASD (Passanisi and Di Nuovo 2015).

Objective

This study aims to explore, in groups of normal individuals, the perception of themselves and their brothers/sisters with ASD and / or intellectual disability of different degrees, by comparing the same perceptions in siblings of individuals with typical development (TD).

In particular, despite the contrasting evidence on this topic accumulated so far, we expected significant differences not only between siblings of individuals

with TD and siblings of subjects with disability in general, but also among the group with pathologically affected brothers or sisters, i.e. between siblings of a brother or a sister with ASD and siblings of individuals with only intellectual disability (ID).

Method

Participants

The sample consisted of 93 individuals with TD, divided into three groups, matched by chronological age:

The first group was composed of 31 individuals with a mean age of 21 years (range: 12-42), sisters (n=17) and brothers (n=14) of persons with ASD associated with ID.

The second group consisted of 31 individuals, mean age 23 years (range: 13-42), sisters (n=15) and brothers (n=16) of persons with ID but without ASD.

Both these groups were composed of siblings of persons with disability (31 for each group, F=29, M=33; mean age 19, range 5-44), that went to the Institute for Research on Mental Retardation and Brain Ageing "Oasi Maria SS" (Troina) for the services of diagnosis, psycho-educational training and rehabilitation cycles. For both groups, the level of ID of the disabled brothers/sisters (either mild, moderate, or severe) had been diagnosed by the specialized équipe of the Institution, using the ICD-10 (World Health Organization 1993) criteria, based on intellectual test (i.e., *Leiter International Performance Scale* – LIPS: Leiter 1979) and adaptation test (i.e., *Vineland Adaptive Behavior Scales* - VABS: Sparrow et al. 2005). The diagnosis of ASD was made by the specialized équipe of the Institution, using to the pertinent ICD-10 criteria (World Health Organization 1993) and according to the results of the *Autism Diagnostic Observation Schedule* (ADOS, Lord et al., 1999).

The third group was formed by 31 individuals (mean age 22 years, range: 10-35), 20 sisters and 11 brothers of persons with TD having mean age 22 (F=19, M=12, range 9-43).

Measures

All participants were administered two Semantic Differentials (SD) in order to both evaluate differences in some dimensions of the Self-image and the image they had of their brother/sister.

The SD, derived by the psycholinguistic studies of Osgood et al. (1957), refers to the 'connotative' use of language, consisting in the associated or secondary meaning of a word or an expression in addition to its literal meaning as defined by the context (Hampton et al. 2011). Based on the relevance of non-cognitive aspects, Osgood et al. (1975) defined connotative language as source of 'affective meanings'. Therefore, SD appears to be a useful instrument for evaluating differences in self and other perceptions, more effective for this purpose than using explicit questionnaires.

Previous psychometric analyses on SD as instrument for measuring self-perception have confirmed its reliability and factorial validity (e.g. Coglisier and Schriesheim 1994, Piotrowski and Dunham 1984, Sherry and Piotrowski 1986, Zhikun and Fungfai 2008).

The SD used in our study consisted of 36 opposite qualifiers through which participants had to evaluate the Self-image and the image of their brother/sister on a 7-point scale (e.g., *strong... weak; calm... agitated;*

tender... hard; efficient... inefficient). The procedures to generate the 36 couples of qualifiers constituting the questionnaire are described in Di Nuovo and Magnano (2013).

The factor analysis showed three principal factors, named *Energy*, *Positive affect*, and *Emotional stability* (i.e., three out of the “big five factors”) and the total scores for each subscale corresponding to the factors have a good reliability: in the preliminary study Cronbach’s α was 0.80 for the 1st, 0.79 for the 2nd and 0.87 for the 3rd factor. Moreover, a confirmatory analysis was computed to verify the factorial structure;

Procedure

The tests were administered by psychologists trained in psychometric assessment, in the Institute where the brothers/sisters with disability were assessed and (for TD participants) in public schools or professional courses of the same town where the Institute is located.

At the Institute for Research on Mental Retardation and Brain Ageing an Ethics Committee evaluates the acceptability of the studies planned to be performed. Prior to the participation to the study, all participants gave a written informed consent.

Table 1. SD factors scores in the subgroups of the sample (ASD, ID, TD), reporting the participants’ perceptions of themselves and of the brother/sister

	ASD n=31		ID n=31		TD n=31		ANOVA
	M	SE	M	SE	M	SE	p (F)
Participants’ evaluation of themselves							
<i>Energy (E)</i>	5.59	.11	5.82	.13	5.70	.14	0.41
<i>Positive Affect (A)</i>	5.41	.08	5.41	.11	5.32	.08	0.74
<i>Emotional stability (S)</i>	4.77	.18	5.24*	.17	4.46	.21	0.01
Participants’ evaluation of their brother/sister							
<i>Energy (E)</i>	4.79	.18	4.37	.21	5.63*	.15	<.001
<i>Positive Affect (A)</i>	4.82	.15	4.84	.11	4.97	.18	0.77
<i>Emotional stability (S)</i>	3.90	.26	4.14	.18	4.50	.19	0.13

* Significant post-hoc analysis (Scheffé test, $p < .05$)

the indices were satisfying: *CFI* near to 0.90; *RMSR* <.05; *RMSEA* not higher than 0.08.

The factors detected allow obtaining three separate factor scores.

Energy (E): Self-perception as a person substantially active in the orientation toward life, with good capacity to sustain this orientation with strength and decision. The person with a high score in this factor has self-confidence and presents him/herself as vivacious, exuberant and attractive for his/her assertiveness and expansiveness. Lower scores characterize a person unsure and passive, with a reduced trust in his/her own resources.

Positive Affect (A): High scores in this factor express self-perception as a person able to show feelings and affects, fostering a satisfying interpersonal relationship: tolerance, open mindedness, altruism, warmth, sincerity are the main traits that allow good intimacy in relationships. Lower scores, on the contrary, characterize aggressive, complicated, self-centred persons, with difficulties in expressing affective openness.

Emotional stability (S): Perception of an emotional state characterized – in the higher scores – by calm, peacefulness, inner order and reflexivity; at the opposite pole of the factor lower scores indicate a person who is aware to be unstable, emotionally disordered, easy to lose inner tranquillity and to express his/her emotions in an uncontrolled way.

The factor scores derived from the SD allow comparing different dimensions of self-perception with perception of other significant objects: in our study, the perception of the brother/sister.

Statistics

The statistical analyses included the computation of means and standard errors for each group, *t-test* for evaluating gender differences, *ANOVAs* with Scheffé’s post hoc evaluations, and Analysis of covariance (*ANCOVA*). The statistical package SYSTAT 12 was used for the analyses.

Results

Firstly, the participants’ perceptions of themselves and of their brother/sister were evaluated computing the mean SD factor scores.

Some statistically significant differences emerged from data reported in **table 1**: in the participants’ evaluation of themselves the dimension *Emotional stability* was significantly higher in the siblings of ID persons, while siblings’ *Energy* was evaluated higher in the group composed of normal individuals. No other significant difference was detected among the three groups.

In a second step of the analysis, the differences in the three factor scores on the SD test were computed for each respondent (self-perception vs brother/sister perception), to obtain a score representing the perceived distance on the considered variables.

The differences in these scores for gender, analyzed by means of *t test* for independent samples, were all non-significant ($p > .05$). Therefore, the subsequent analyses were conducted without taking into account gender.

In order to examine the effect of diagnosis (ASD, ID, TD) and of its severity (none, mild, moderate, severe) on the differences in self vs brother/sister perceptions in each SD factor, univariate ANOVAs and post hoc analyses with Scheffé test ($p < .05$) were conducted (see **table 2** and **3**).

differences in relation to Energy ($F_{(3,89)} = 6.35; p < .01$). In particular, post hoc test showed that the differences between the self and the brother/sister evaluation scores were lower in the no-severity group than the ones in the other three groups. Significant differences were also detected in relation to the factor Emotional

Table 2. Differences among groups divided according to brother/sister's diagnosis. Scores are differences in SD evaluating participants' self vs brother/sister perception in each factor

	Diagnosis of brother/sister						ANOVA <i>p</i> (F)
	ASD n=31		ID n=31		TD n=31		
	M	SE	M	SE	M	SE	
Energy (E)	.80*	.21	1.46*	.21	.07*	.21	<0.01
Positive Affect (A)	.59	.18	.57	.18	.35	.18	ns
Emotional stability (S)	.86	.29	1.10	.29	-.04*	.29	<0.05

* Significant post-hoc analysis (Scheffé test, $p < .05$)

Table 3. Differences among groups divided according to presence / severity of disabled brothers/sisters' ID. Scores are differences in SD evaluating participants' self vs brother/sister perception in each factor

	Diagnosis of brother/sister's ID severity								ANOVA <i>p</i> (F)
	none n=31		mild n=12		moderate n=18		severe n=32		
	M	SE	M	SE	M	SE	M	SE	
Energy (E)	.07*	.21	1.17	.34	.78	.28	1.31	.21	<.01
Positive Affect (A)	.35	.18	.84	.29	.32	.24	.62	.18	ns
Emotional stability (S)	-.04*	.29	1.14	.38	.41	.38	1.25	.28	<.05

* Significant post-hoc analysis (Scheffé test, $p < .05$)

Results reported in **table 2** showed that diagnosis groups differed significantly on Energy Factor ($F_{(2,90)} = 11.15; p < .001$). Post-hoc testing revealed that the differences between the three groups in relation to the difference in the self and the brother/sister evaluation score were all significant. In addition, the diagnosis groups differed significantly on Emotional Stability ($F_{(2,90)} = 4.39; p < .05$). Post-hoc test revealed that the difference between the self and the brother/sister evaluation was significantly lower in the normal group in comparison with the other two groups. With respect to the Affectivity factor no significant difference was found between the groups considered.

The ANOVA for the levels of severity (none, mild, moderate, severe) reported in **table 3** revealed significant

Stability ($F_{(3,89)} = 4.00; p < .05$). Post hoc test revealed that the differences between the self and the brother/sister evaluation scores were significantly lower in the no-severity group compared to the three groups with brothers/sisters with mild, moderate, or severe disorders. Again, no significant difference was found between the severity groups in relation to the factor of Positive Affect.

Moreover, an analysis of covariance (ANCOVA) assessed differences, exclusively in the groups with pathological brothers/sisters, in relation to the diagnosis (ASD vs ID) while controlling for severity and adjustment measured by the Leiter and VABS total score previously administered to the disabled brothers/sisters (**tables 4** and **5**).

Table 4. Analysis of covariance for SD factors with covariate severity (brother/sister' Leiter Scores), in siblings of disabled brothers/sisters (n=62)

	Diagnosis		covariate: Severity	
	F	P	F	p
Energy (E)	4.81	.03*	.67	.42
Positive Affect (A)	.08	.93	.09	.75
Emotional stability (S)	.42	.52	.52	.47

* $p < .05$

Table 5. Analysis of covariance for SD factors with covariate adjustment (sibling' VABS Scores), in siblings of disabled brothers/sisters (n=62)

	Diagnosis		covariate: VABS	
	F	P	F	p
Energy (E)	5.11	.03*	.47	.50
Positive Affect (A)	.01	.99	.03	.86
Emotional stability (S)	.76	.39	.79	.38

* $p < .05$

The effect of diagnosis remained significant only in relation to the factor of Energy after controlling both for severity and adjustment scores. None of the covariates (severity and adjustment level of the brother/sister) did affect any factor.

Discussion and conclusions

The current study adds data to the literature on siblings' perception when one of their sister/brother has a disorder.

Sibling and, more broadly, family perceptions and interactions are often considered to be essential for the strongest relationships that human beings establish (Brody 2004). Depending on the family context, individuals will develop functional or dysfunctional personality traits responsible for their psychosocial adjustment and adaptive or maladaptive behavior (e.g. Schimmenti et al. 2014, Leanza et al. 2013, Di Blasi et al. 2015, Pace et al. 2014).

The purpose of the present study was to compare the difference in perceived self and brother/sister's image, among TD siblings of TD individuals or of disabled persons diagnosed with either an ID or an ASD associated with ID. The question addressed was: does the non disabled sibling perceive him/herself significantly different, on the same categories of assessment, with respect to the disabled sibling? How is this distance differentiated according to the specific condition of the sibling (normal, with ID, with ID plus ASD)?

Results showed that siblings of individuals either with or without a disorder perceive the sister/brother with disability as less active persons in the orientation toward life values than themselves, whereas, individuals with disabled siblings consider themselves and their disabled relatives equally able to show feelings and affects. Nevertheless they perceive the brother/sister with either an ID or an ASD associated with ID less emotionally stable than themselves.

In general, an increase in the severity of diagnosis leads to a greater difference between self- and brother/sister-image perception, particularly in the aspects regarding energy and activity; this form of psychological distancing is not apparent in affective and emotional variables.

Literature is controversial about the consequences of having a disabled brother/sister. According to some scholars, individuals with a disability do not cause specific maladaptation in TD siblings (e.g. Rodrigue et al. 1993, Stoneman 2005). Instead, siblings of children with disabilities grow up in a rich and complex set of roles, such as that of caregiver, teacher and confidant, which may promote positive developmental outcomes (Stoneman and Brody 1982, Squillaci and Lanners 2005, Petalas et al. 2012). This is congruent with the finding that families with a son with disability have normal or increased levels of cohesion, adaptability and communication (Gray 2006, Tzoy et al. 2007, Di Nuovo and Azzara 2011).

On the contrary, according to other authors TD individuals often regard their brother/sister with disability as a burden. In particular, having a brother or sister with ASD would lead to more concerns about the future, more intense feelings of loneliness and more behavior disturbances (e.g. Bagenholm and Gillberg 1991). Thus, we expected different outcomes not only between siblings of TD and disabled individuals, but also between subjects with a brother or a sister with ASD and siblings of individuals with only ID. In our

sample, no differences have been found with regard to affective parameters of self-evaluation; only energy and emotional stability (more linked to behavioral aspects) influenced the 'perception of distance' between self and the disabled sibling.

The different results obtained may be due to the fact that symptom presentation of ASD can vary greatly (Lord et al. 2000). For instance, being a sibling of a child showing strong aggressive behavior may lead to a greater difference between the self-perception and the brother/sister perception than being a sibling of a child with predominantly repetitive behaviors and scarce eye contact.

Therefore, further studies in this field are needed in order to better understand both personal background and personality characteristics, and to reduce the risk of failure while strengthening the family resources useful to cope with the disability of a member.

As a limitation of the present study, only adaptive factors – not specific behaviors associated with ASD – have been controlled as covariate in evaluating the difference between the self and the brother/sister image perceived by participants. This may also explain why the individuals in our sample perceived themselves and their brothers/sisters with disability as not significantly different in the domain of interpersonal relationships and why the current literature has so many contradictory findings. In future research, it should be useful to address these differences in the behaviors associated with ASD in order to get a better picture on the sibling dynamic in families with children with developmental disabilities by promoting the need for establishing more research and greater clinical evaluation in this area.

Moreover, it would be interesting to investigate the reciprocal perception that siblings with a disorder may have on their brothers and sisters with TD, and to better explore the gender differences in the self/other image perception often leading to different outcomes and symptoms.

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