This version of the article has been accepted for publication, after peer review and is subject to Springer Nature's AM terms of use, but is not the Version of Record and does not reflect post-acceptance improvements, or any corrections. The Version of Record is available online at: <u>https://link.springer.com/article/10.1007/</u>

<u>s11136-020-02429-1</u>

Siblings of Children with Autism Spectrum Disorders: Social Support and Family

Quality of Life

Dunia Garrido^a

Gloria Carballo^a

Rocio Garcia-Retamero^{a,b}

^a University of Granada, Mind, Brain, and Behavior Research Center, Spain

^bMax Planck Institute for Human Development, Germany

Correspondence author at: Dunia Garrido, Mind, Brain, and Behavior Research Center,

University of Granada, Spain. CP: 18071.

E-mail address: duniag@ugr.es

Quality of Life

Abstract

Purpose: Autism spectrum disorder (ASD) often has a significant impact on all family members, including parents and siblings of the person who suffers the disorder. This case-control study explores potential factors that help explain the impact of having an older sibling with ASD on several developmental domains, and to test whether these factors could explain their satisfaction on family quality of life (FQoL).

Methods: A total of 78 unaffected siblings of children with ASD (Sibs-ASD) and siblings of children with typical development (Sibs-TD) from 6 to 12 years old were evaluated.

Results: Our analyses show significant differences between groups in motor skills, severity of autistic traits, satisfaction on FQoL, and social support (ps < .05). Moreover, social support acts as positive factor protecting from the negative effect of having a sibling with ASD on satisfaction of FQoL (R^2 = .32).

Conclusions: Our findings highlight the variability in the developmental abilities of the unaffected school-age children with familiar risk factors and emphasize the need for supervising development of all Sibs-ASD over different time points. Social support may be a critical aspect to consider in interventions for improving the satisfaction on FQoL.

Keywords: autism spectrum disorders; siblings; social support; family quality of life

Siblings of Children with Autism Spectrum Disorders: Social Support and Quality of Life

Autism spectrum disorder (ASD) is a neurodevelopmental disorder defined by social-communication challenges and restricted and repetitive behaviors [1]. Because of these characteristics, ASD might be expected to have an impact on the experiences in families [2]. For example, parents of children with ASD reported significant levels of stress and depression, lower happiness, and lower family support compared to those parents of children with typical development or other disabilities [3, 4]. These levels of stress and depression could have a negative impact on their family quality of life (FQoL), which is a global construct that reflects family well-being, and has emerged as a good outcome to define the global life situation of families [5].

To understand the complex experience of families of children with ASD, not only the unidirectional impact on parents and children with ASD should be considered. Assuming the influence of ASD on the whole family system, parents and siblings (Sibs-ASD) might be affected. Thus, this study has focused on the family as a unit of analysis. Specifically, we have followed the model of Poston, Turnbull, Park, Hasheem, Janet, and Mian [6], which guides the exploration of family functioning and the level of satisfaction of each member with regard their FQoL. Although research reveals an impact on family members, not all the members have a similar experience as a result of having a relative with ASD in the family [7]. For instance, Lovell and Wetherell [8] found that Sibs-ASD reported more emotional problems and depressive symptoms than siblings of children with typical development (Sibs-TD). In addition, Meadan, Stoner and Angell [9] stated that some characteristics of Sibs-ASD (e.g., social support) might have an influence over FQoL.

Additionally to the experience of having a sibling with ASD, it is important to consider potential factors that could have an impact on Sibs-ASD. In particular, research estimates that 25% of Sibs-ASD show subclinical symptoms of ASD [10, 11]. Drumm and Brian [12] found that Sibs-ASD are at an increased risk for developmental differences, especially in those domains that are compromised in ASD. Receptive and expressive language, social communication, and fine and gross motor difficulties are some of these features that have been found among Sibs-ASD from first years of life [10, 11, 13, 14).

However, there is a dearth of published research on how these deficits in schoolage Sibs-ASD are related to other domains of functioning. Motor, language, and social communication skills in school-age Sibs-ASD are investigated less frequently because most of the research focused on these abilities in Sibs-ASD have been undertaken with young children [13, 15]. Therefore, it becomes necessary to evaluate these abilities in older Sibs-ASD, and evaluate if these differences in motor, language, and sociocommunication abilities continue or dissipate over time. Some follow-up studies have described different developmental trajectories in Sibs-ASD [16, 17], such as social communication difficulties. However, other studies found that non-ASD Sibs-ASD showed average/above average expressive, receptive and socio communicative abilities compared to Sibs-TD [18, 19].

Despite language, motor development, and social communication, other abilities should be considered in school-age children. As children become older other variables impact over siblings' adjustment such as coping, stress, and social support [20].

Unfortunately, less attention has been given to the role of these other domains in Sibs-ASD [21]. Indeed, investigation that evaluates the idea that autistic traits affect sibling adjustment reported mixed results.

At the moment, most studies investigating factors that affect FQoL in families of children with ASD have focused on negative experiences and perceptions [22], although some researchers have begun to examine protective factors [23]. One such line of research has revealed that social support may improve FQoL in families of children with ASD [24, 25]. In that sense, social support has been found to be beneficial to familiar well-being [21, 26, 27]. Both informal (e.g., support from friends, extended members and partners) and formal (e.g., professional support) social support have been widely studied in children with ASD and their parents, but not in Sibs-ASD [20].

A formal social support has shown a positive outcome in siblings' adjustment [28]. Hastings [22] found that higher formal social support was related to fewer adjustment problems in Sibs-ASD. Indeed, a successful adjustment may be moderated by this social support and by the severity of the Sibs-ASD's autism traits. Sibs-ASD also need social support from other relatives and friends [29]. Lowell and Wetherell [8] examined the psychophysiological impact of ASD on Sibs-ASD, finding that informal social support in Sibs-ASD (especially from parents and close friends) predicted total depressive symptoms. Moreover, Kaminsky and Dewey [30] found that higher informal social support was associated with better adjustment at school age. Unfortunately, the relationship between social support in Sibs-ASD and FQoL has not been studied widely in relatives of children with ASD.

In sum, studies of unaffected Sibs-ASD, have found difficulties into mildchildhood [19], and variability in linguistic, and motor areas, social communication,

traits of ASD, and social support [see 16, 17, 19, 21, 31] Although previous research shows that Sibs-ASD are at higher risk for autistic traits and other developmental difficulties than the general population, others seems to not provide a strong indication for developmental difficulties in school-age unaffected Sibs-ASD [12, 32]. However, we are still interested in these domains due to the potential impact of developmental skills on their adjustment and might influenced their family, which would have an impact on their FQoL [9, 33].

Therefore, our main goal is to evaluate several developmental domains in school-age Sibs-ASD versus Sibs-TD, and to test whether either developmental domains or social support could predict family quality of life (FQoL). The current study, which is focused on school-age unaffected Sibs-ASD and Sibs-TD, has three aims: (a) to evaluate several developmental domains (i.e., receptive and expressive language, motor skills, intelligence, and social communication), social support, and traits of ASD in Sibs-ASD and Sibs-TD, (b) to determine differences between having or not a sibling with ASD in their FQoL, and (c) to determine whether FQoL might be explained by differences in social support and/or any developmental domain.

2. Method

2.1. Participants

A sample of 78 unaffected siblings of children with ASD (Sibs-ASD, N = 41), siblings of children with no family history of ASD (Sibs-TD, N = 37) between 6 and 12 years, and their families was recruited from several associations of families with children with ASD, and several public schools from Granada, Spain. All parents signed the informed written consent before participation, and The Ethics Committee of the

University of Granada approved the methodology of this study. The inclusion criterion for families in the Sibs-ASD group was to have another child with ASD according to the DSM-TR-IV [34] or DSM-5 [1] and ADI-R [35] or ADOS-G [36]. Moreover, both group of siblings had to show a typical development. Families in both groups were excluded if siblings received special education, related services (e.g. speech therapy), or had an identified emotional, behavioral o developmental disability (e.g. attentiondeficit/hyperactivity disorder, learning disability, speech delay, Down syndrome, language impairment, or cerebral palsy). Additional criteria for participants in the Sibs-TD group were that participants did not have a previously family history of ASD, should be matched in ages with Sibs-ASD, and sibling status (i.e., having an older sibling). Moreover, parents in both groups were excluded if they had any psychological disorder (e.g., depression or stress).

Demographic characteristics of participants are presented in Table 1. All families were considered middle-class families (based on their level of education and place of residence). No significant differences between groups were found in parental demographic variables (i.e., age, gender, level of education, and marital status) or demographic variables of children and siblings (i.e., age, and gender).

INSERT TABLE 1 ABOUT HERE

2.2. Measures

We use different assessment measures: direct measures and indirect measures (parental reports). Parents completed a demographic survey developed for the current study, which included child age, gender, family composition (including marital status), parental education level, parental age, and gender. Additional specific measures related

to receptive and expressive language, motor skills, intelligence, social communication,

traits of ASD, social support, and FQoL were also collected, as described below.

Receptive language

The comprehension test of grammatical structures (CEG [37]) evaluates 20 different grammatical structures with different levels of complexity. This test provides a general score in children from 4 to 12 years.

The Peabody Picture Vocabulary Test (PPVT–III [38]) is a test that provides an estimation of the receptive vocabulary ability in children older than two years old. *Expressive language*

The Clinical Evaluation of Language Fundamentals –Fourth Edition (CELF-4 [39]) is a test for determining if a child (from 5 to 21 years) has a language disorder or delay. We included the expressive language index (normative mean of 100 and SD of 15), which is an overall measure of expressive language skills.

Motor skills

The Movement Assessment Battery for Children –Second Edition (MABC-2

[40]) identifies children (from 3 to 16 years) who have motor function impairment. We evaluated 3 areas: manual dexterity, ball skills, and static and dynamic balance.
Moreover, this test provides an overall score of total motor skills. A total score below the 5th percentile is considered indicative of a conclusive motor problem, and scores between the 5th and 15th percentile range suggest a degree of difficulty [40]. *Intelligence*

The Wechsler Intelligence Scale for Children (WISC-IV [41]) provides a composite score in children from 6 to 16 years. Because we were interested in measuring general intelligence quotient (IQ), we included the full scale IQ.

Parents completed the *Social Communication Questionnaire* (SCQ [42]) is a screening for ASD validated for children older than 4 years. This measure offers a cutoff score (15 points or more) than provides a dimensional measure of symptoms of ASD, and can be used to indicate the likelihood that a child has ASD.

Severity of ASD

Parents completed the *Gilliam Autism Rating Scale* (GARS [43]). This scale is a norm referenced screening instrument that helps professionals identify ASD. Moreover, it gathers information about specific characteristics typically noted in ASD (stereotyped behaviors, communication, social interaction, and developmental disturbances, which yield an overall autism quotient). We used the autism quotient as severity of traits related to ASD (cutoff score of 69 or less indicate a child is "unlikely" to have autism, 70-84 indicate a child "possibly" has autism, or 85 and higher indicate child is "likely" to have autism [44]).

Social support

We evaluated social support with the *Structural Social Support* [45]. This scale was completed by parents and allowed us to know the social support in terms of interactions face to face: the number of friends, the quality of their relatives' relationship, and the number of weekly contacts they have with their relatives and friends. The final score is a sum of all items and ranges from 3 to 30, where higher scores indicate more perceived social support. This scale showed a good internal consistency (Cronbach's = .94).

Family quality of life

FQoLS [46]). This instrument is adapted from the Family Quality of Life Survey, which was developed in the Beach Center on Disability, Kansas (USA) [47]. It consists of 25 questions which evaluate FQoL in two domains (importance and satisfaction), and it includes five factors related to FQoL: emotional well-being (4 items), family interaction (6 items), disability-related support (4 items), parenting (6 items), and physical wellbeing (5 items). The overall score was also calculated by averaging all factors ratings, and ranges from 5 to 25, where higher scores indicate more perceived importance and satisfaction. In our study, this scale showed a good internal consistency in both domains: importance and satisfaction (Cronbach's = .87, and .76 respectively). Moreover, this survey has been adapted to other countries, such as Colombia, where it has shown an excellent internal consistency (Cronbach's = .96, and .95 in importance and satisfaction respectively) [48]. Because our main interest was to describe the satisfaction on FQoL as a comprehensive measure, we included in our analyses the global score related to satisfaction.

Parents completed the Family Quality of Life of People Survey (Spanish version,

2.3. Data analyses

All statistical analyses were performed using SPSS statistics version 22.0. Descriptive statistics were calculated to characterize the sample, including means, and standard deviations. Independent t-test and chi square analyses were used to compare groups on expressive language, motor skills, intelligence, social communication, severity of traits of ASD, social support, and FQoL. Cohen's d was calculated as measure of effect size (considering 0.2, 0.5, and >0.8 as small, medium, and large effect size) [49]. Pearson correlations were conducted to test for associations between the outcome (i.e., global score of satisfaction on FQoL) and the five potential predictor

variables (i.e., language, motor skills, social communication, severity of traits of ASD, and social support). To determine the unique influence of each potential predictor (i.e., those variables that showed significant correlations with satisfaction on FQoL), we conducted multiple regressions. Intelligence, age, and gender were entered as covariates in all analyses. To investigate whether the relationships of the potential predictor with FQoL varied as a function of group, we tested the moderation effect of this predictor and their interaction with group using the PROCESS macro, embedded and operated in SPSS [50]. For the current analysis, we selected PROCESS Model 5 for moderation. Given the limited sample size, and to prevent violation of normal distribution assumptions, 5.000 bootstrap samples were drawn to provide a robust estimation of direct effects. To further understand the moderation effects, we estimated conditional effects at the sample mean plus/minus one standard deviation of the value of the moderator.

Before performing the regression analysis, we tested several assumptions of linear regression models. First, possible multicollinerarity among the potential predictors was checked using the tolerance and the variance inflation factors (VIF). VIF values between 1-10 indicate the absence of multicollinerarity [51]. Moreover, we tested the normality of the error distribution and homoscedasticity of the errors. A sensitivity analysis (using G*Power calculator [52]) showed that given six predictors, power = .95, and alpha = .05, the minimum effect size that could be detected with the obtained sample size of n = 78 is f = .14 (Cohen's d = .28).

3. Results

From the whole sample (n = 78), 58% (n = 45) were male, with a mean age of 8.75 years (range from 6.00 to 12.00 years). Descriptive statistics for all variables are

shown in Table 2. Results showed that there were significant differences between groups in autistic traits (p = .025), social support (p < .001), and satisfaction on FQoL (p < .001). However, there were no differences between groups in vocabulary (p = .469), receptive language (p = .509), expressive language (p = .154), motor skills (p = .055), intelligence (p = .324), social communication (p = .124), or importance on FQoL (p = .513). Although there were no differences between groups, we conduced bivariate Pearson's correlations to examine the relationship between potential predictors and the global score in satisfaction on FQoL (see Table 3). Additionally, no multicollinerarity was evident among all predictors, since the VIF for the predictors ranged between 1.10 and 1.29, and tolerance values ranged between .79 and .90 [51].

INSERT TABLE 2 ABOUT HERE

INSERT TABLE 3 ABOUT HERE

We conducted a multiple linear regression analysis with satisfaction on FQoL as outcome variable. Social support, which was highly correlated with satisfaction on FQoL, and the group were included as potential predictors. Vocabulary, receptive language, expressive language, motor skills, social communication, and autistic traits were not included in the analysis because these variables were not related to the outcome (see Table 3). The multiple linear regression analysis showed that only social support ($\beta = .46$, p = .002) had a significant main effect on satisfaction on FQoL. We tested whether the relationship between social support and FQoL varied as a function of group by adding their interaction. The test of moderation including the interaction between social support and group are presented in Table 4, including standardized regression coefficients (β s) for each predictor. Results showed that the variable group

SIBLINGS OF CHILDREN WITH ASD: SOCIAL SUPPORT was significant ($\beta = -7.92$, p = .021) as well as the interaction between group and social support ($\beta = .93$, p = .032). The completed model accounted for 32% of the total variance [F(6, 71) = 5.483, p < .001].

INSERT TABLE 4 ABOUT HERE

Calculation of simple slopes (see Table 5) indicated that the effect of group on satisfaction on FQoL was statistically different at minus one standard deviation from the mean (p = .024) on social support (with a medium effect size of d = .52). However, the effects of group on satisfaction on FQoL was not statistically different at mean plus one standard deviation from the mean on social support (both with p > .05).

INSERT TABLE 5 ABOUT HERE

Plot of interactions of the effect of social support on FQoL are shown in Figure 1. Results indicate that FQoL was particularly low in Sibs-ASD who had relatively low social support. In contrast, FQoL was higher in Sibs-ASD who have relatively high social support and in Sibs-TD, regardless of their levels of social support. In addition, there was a main effect of group such that FQoL was lower on average for Sibs-ASD, regardless of their level of social support. Sibs-ASD with lower social support (minus one standard deviation) showed a greater reduction in FQoL than those with high social support (plus one standard deviation) –a result that is in contrast with results from Sibs-TD, who did not show differences in FQoL as a function of social support (see Figure 1).

INSERT FIGURE 1 ABOUT HERE

4. Discussion

Our results showed significant differences between groups in motor skills,

severity of autistic traits, satisfaction on FQoL, and social support between Sibs-TD and Sibs-ASD. However, there were no differences between groups in expressive language skills, intelligence, social communication, or importance on FQoL. Moreover, our results suggest that social support may act as a positive factor protecting the negative effect of having a sibling with ASD on perceptions on satisfaction of quality of life. These results are in line with previous research showing that siblings of children with ASD may show differences in cognitive, motor, language and/or social development. However, these results also suggest that these difficulties have not been shown in older Sibs-ASD [53, 54]. Our results indicated that there were no differences between groups in language abilities, as other authors have found [12, 31, 55, 56].

In contrast to other studies [57, 58] we did not find social communication and language deficits in Sibs-ASD. Our results indicated that the group of Sibs-ASD showed higher levels of traits of ASD but also similar levels of verbal and nonverbal skills than those in the Sibs-TD group. In addition, our data referring to the language in Sibs-ASD group did not agree with those obtained by Gamliel et al. [16]. In particular, they showed that school-age Sibs-ASD showed significantly more cognitive, linguistic, and parent-reported difficulties compared to Sibs-TD (performance of at least 1.5 SD below average). One explanation of this result is that we measured all developmental skills through directed measures, not parent-reported scales, which could have an impact on the results.

Regarding social communication, several authors have found deficits in Sibs-ASD (see [58] for a review). Other authors have found that young unaffected Sibs-ASD showed lower overall rates in social communication than Sibs-TD [59]. However, Pilowsky et al. [57] found no differences between groups in social communication, as we did. Some studies have not found differences in language between Sibs-ASD and Sibs-TD during the school years. This fact could be explained because only a subset of Sibs-ASD is characterized by lower scores [14].

Although social support is important for all members in families of children with ASD, the literature that relates FQoL, social support, and psychological and social adjustments in Sibs-ASD is still scarce and contradictory [60]. It is possible, as our results suggest, that a certain level of social support is required to achieve adaptive adjustment in Sibs-ASD, and their FQoL [28, 30]. Our research adds to this literature showing that siblings of children with ASD and social support deficiencies are also vulnerable and experience lower levels of quality of life. For instance, siblings of children with ASD might show positive results when they report higher levels of social support [61, 62]. One plausible explanation may be that siblings of children with ASD usually take on additional responsibilities, thus limiting chances for social and peer interaction, which could affect their social support [29].

4.1. Limitations of the study

Our research contributes to the growing literature on variables of Sibs-ASD that help families with children with ASD improve their FQoL as much as families with children with TD. Nevertheless, this study has several limitations. First, the small sample size does not allow us to generalize results. Second, the majority of participants in this study were mothers of Sibs-ASD. Therefore, the low participation of fathers can be considered as a limitation of the current work. However, Wang, Summers, Little, Trunbull, Poston, and Mannan [63] found similar patterns of responses among fathers and mothers using the Family Quality of Life Survey. Third, the Structural Social Support questionnaire may not be a complete measure of social support. Thus, the

effects of social support found in the present analysis may be considered by limitations of this measure. Finally, having a child with ASD could influence the information reported by parents. Thus, future studies could incorporate opinions from older Sibs-ASD related to FQoL and assess if there are discrepancies between parents and children's opinions.

4.2. Implications for research and practice

From our results, several clinical implications could be suggested. First, we support the importance of planning interventions focus on improving social support in Sibs-ASD. Second, perceived social support may serve as potential point of intervention for reducing distress and improving the satisfaction with their FQoL. Finally, differences found between Sibs-ASD and Sibs-TD should be taken into account when making decisions about how to support siblings and what kind of interventions is appropriate for each member of the family. In conclusion, these findings highlight the variability in the developmental abilities of the unaffected school-age children with familiar risk factors and emphasize the need for supervising development of all Sibs-ASD over different time points, as stated Szatmari et al. [35]; not only until the first 3 years of life, but along school years.

Acknowledgements

We are grateful to the families who participated in this study for their continued support of our research. This work was supported by the Ministerio de Economía y Competitividad (Spain) under Grant [PSI2014-51842-R]; and the Ministerio de

SIBLINGS OF CHILDREN WITH ASD: SOCIAL SUPPORT Educación, Cultura y Deporte (Spain) under Grant [FPU14/00723]. The authors have

declared that they have no competing or potential conflicts of interest.

References

1. American Psychiatric Association (2013) Diagnostic and statistical manual of

mental disorders (5th ed.). Washington, D.C: American Psychological Association.

- Gardiner, E., & Iarocci, G. (2012). Unhappy (and happy) in their own way: A developmental psychopathology perspective on quality of life for families living with developmental disability with and without autism. *Research in Developmental Disabilities*, 33(6), 2177-2192, doi: 10.1016/j.ridd.2012.06.014
- Higgins, D. J., Bailey, S. R., & Pearce, J. C. (2005). Factors associated with functioning style and coping strategies of families with a child with an autism spectrum disorder. *Autism*, 9(2), 125-137, doi: 10.1 177/1362361305051403
- Kogan, M. D., Strickland, B. B., Blumberg, S. J., Singh, G. K., Perrin, J. M., & van Dyck, P. C. (2008). A national profile of the health care experiences and family impact of autism spectrum disorder among children in the United States, 2005– 2006. *Pediatrics*, *122*, 1149–1158, doi: 10.1542/peds.2008-1057
- Mannan, H., Summers, J. A., Turnbull, A. P., & Poston, D. J. (2006). A review of outcome measures in early childhood programs. *Journal of Policy and Practice in Intellectual Disabilities*, 3(4), 219-228, doi: 10.1111/j.1741-1130.2006.00083.x
- Poston, D., Turnbull, A., Park, J., Hasheem, M., Janet, M., & Mian, W. (2003).
 Calidad de Vida Familiar: Un estudio cualitativo. *Mental Retardation, 41, 5*, 313-328.
- Hastings, R. P., Kovshoff, H., Brown, T., Ward, N. J., Espinosa, F. D., & Remington, B. (2005). Coping strategies in mothers and fathers of preschool and school-age children with autism. *Autism*, *9*, 377–391, doi: 10.1177/ 1362361305056078
- Lovell, B., & Wetherell, M. A. (2016). The psychophysiological impact of childhood autism spectrum disorder on siblings. *Research in Developmental Disabilities, 49,* 226-234, doi: 10.1016/j.rldd.2015.11.023

- Meadan, H., Stoner, J. B., & Angell, M. E. (2010). Review of literature related to the social, emotional, and behavioral adjustment of siblings of individuals with autism spectrum disorder. *Journal of Developmental and Physical Disabilities, 22*, 83-100, doi: 10.1007/s10882-009-91 71-7.
- Georgiades, S., Szatmari, P., Zwaigenbaum, L., Bryson, S., Brian, J., Roberts, W., et al. (2013). A prospective study of autistic-like traits in unaffected siblings of probands with autism spectrum disorder. *JAMA Psychiatry*, *70*, 42–48, doi: 10.1001/2013.jamapsychiatry.1
- Messinger, D., Young, G. S., Ozonoff, S., Dobkins, K., Carter, A., Zwaigenbaum,
 L., et al. (2013). Beyond autism: a baby siblings research consortium study of highrisk children at three years of age. *Journal of the American Academy of Child & Adolescent Psychiatry*, 52(3), 300-308, doi: 10.1016/j.jaac.2012.12.011
- Drumm, E., & Brian, J. (2013). The developing language abilities and increased risks of 'unaffected' siblings of children with autism spectrum disorder. *Neuropsychiatry*, *3*, 513–524, doi: 10.22 17/npy.13.65
- Garrido, D., Petrova, D., Watson, L. R., Garcia-Retamero, R., & Carballo, G. (2017). Language and motor skills in siblings of children with autism spectrum disorder: A meta-analytic review. *Autism Research*, *10*(11), 1737-1750, doi: 10.1002 /aur.1829
- 14. Miller, M., Young, G. S., Hutman, T., Johnson, S., Schwichtenberg, A. J., & Ozonoff, S. (2015). Early pragmatic language difficulties in siblings of children with autism: implications for DSM-5 social communication disorder. *Journal of Child Psychology and Psychiatry*, 56(7), 774-781, doi: 10.1111/jcpp.12342
- 15. Gowen E, & Hamilton, A. (2013). Motor Abilities in Autism: A Review Using a

SIBLINGS OF CHILDREN WITH ASD: SOCIAL SUPPORT Computational Context. Journal of Autism and Developmental Disorders, 43,

323-344, doi: 10.1007/s10803-012-1574-0

- 16. Gamliel, I., Yirmiya, N., Jaffe, D. H., Manor, O., & Sigman, M. (2009).
 Developmental trajectories in siblings of children with autism: Cognition and language from 4 months to 7 years. *Journal of Autism and Developmental Disorders, 39*, 1131–1144, doi: 10.1007/s10803-009-0727-2
- Lai, M. C., Lombardo, M. V., & Baron-Cohen, S. (2014). Autism. *Lancet, 383,* 896-910, doi:10.1016/S0140-6736(13)61539-1
- Drumm, E., Bryson, S., Zwaigenbaum, L., & Brian, J. (2015). Language-related abilities in 'unaffected' school-aged siblings of children with ASD. *Research in Autism Spectrum Disorders, 18, 83-96, doi: 10.1016/j.rasd.2015.07.007*
- Shephard, E., Milosavljevic, B., Pasco, G., Jones, E.J.H., Gliga, T., Happé, F., et al. Mid-Childhood outcomes of infant siblings at familial high-risk of autism spectrum disorder. *Autism Research*, *10*(3), 546-557, doi: 10.1002/aur.1733
- 20. Tsai, H. W. J., Cebula, K., & Fletcher-Watson, S. (2017). The role of the broader autism phenotype and environmental stressors in the adjustment of siblings of children with autism spectrum disorders in Taiwan and the United Kingdom. *Journal of Autism and Developmental Disorders*, 47(8), 2363-2377, doi: 10.1007/s10803-017-31 34-0
- 21. Hastings, R. P. (2003). Behavioral adjustment of siblings of children with autism engaged in applied behavior analysis early intervention programs: The moderating role of social support. *Journal of Autism and Developmental Disorders*, *33*(2),
 141. 150. doi: 10.1022/A:1022082200004

141-150, doi: 10.1023/A:1022983209004

22. Hastings, R. P., & Taunt, H. M. (2002). Positive perceptions in families of children

- SIBLINGS OF CHILDREN WITH ASD: SOCIAL SUPPORT with developmental disabilities. *American Journal on Mental Retardation, 107*(2), 116-127, doi: 10.1352/0895- 8017(20 02)107<0116:PPIFOC>2.0.CO;2
- Vasilopoulou, E., & Nisbet, J. (2016). The quality of life of parents of children with autism spectrum disorder: A systematic review. *Research in Autism Spectrum Disorders, 23,* 36-49, doi: 10.1016/j.rasd.2015.11.008
- 24. Khanna, R., Madhavan, S. S., Smith, M. J., Patrick, J. H., Tworek, C., & Becker-Cottrill, B. (2011). Assessment of health-related quality of life among primary caregivers of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 41*(9), 1214-1227, doi: 10.1007/s10803-010-1140-6.
- 25. McStay, R. L., Trembath, D., & Dissanayake, C. (2014). Stress and family quality of parents of children with autism spectrum disorder: parent gender and the double ABCX model. *Journal of Autism and Developmental Disorders, 44*(12), 3101-3118, doi: 10.1007/s10803-014- 2178-7.
- 26. Ekas, N. V., Lickenbrock, D. M., & Whitman, T. L. (2010). Optimism, social support, and well-being in mothers of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 40*, 1274-1284, doi: 10.1007/ s10803-010-0986-y
- 27. Lin, L. Y., Orsmond, G. I., Coster, W. J., & Cohn, E. S. (2011). Families of adolescents and adults with Autism Spectrum Disorders in Taiwan: The role of social support and coping in family adaptation and maternal well-being. *Research in Autism Spectrum Disorders*, 5(1), 144-156, doi: 10.1016/j.rasd.2010.03.004
- Tsao, L. L., Davenport, R., & Schmiege, C. (2012). Supporting siblings of children with Autism Spectrum Disorders. *Early Childhood Education Journal*, 40(1), 47-54, doi: 10.10 07/s10643-011-0488-3

- 29. Moyson, T., & Roeyers, H. (2011). The quality of life of siblings of children with autism spectrum disorder. *Exceptional Children*, 78(1), 41-55, doi: 10.1177/001440291107800103
- Kaminsky, L., & Dewey, D. (2002). Psychosocial adjustment in siblings of children with autism. *Journal of Child Psychology and Psychiatry*, 43(2), 225-232, doi: 10.1111/1469-7610.00015
- 31. Ben-Yizhak, N., Yirmiya, N., Seidman, I., Alon, R., Lord, C., & Sigman, M. (2011).
 Pragmatic language and school related linguistic abilities in siblings of children with autism. *Journal of Autism and Developmental disorders*, *41*(6), 750-760, doi: 10.1007/s10803-010-1096-6
- 32. Meyer, K. A., Ingersoll, B., & Hambrick, D. Z. (2011). Factors influencing adjustment in siblings of children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 5(4), 1413-1420, doi: 10.1016/j.rasd.2011.01.027
- 33. Szatmari, P., Chawarska, K., Dawson, G., Georgiades, S., Landa, R., Lord, C., et al. (2016). Prospective longitudinal studies of infant siblings of children with autism: Lessons learned and future directions. *Journal of the American Academy of Child and Adolescent Psychiatry*, 55(3), 179-187, doi: 10.1016/j.jaac.2015.12.014.
- 34. American Psychiatric Association (2000). Diagnostic and statistical manual of mental disorders (4th ed., text rev.). Washington, D.C: American Psychological Association.
- 35. Le Couteur, A., Lord, C., & Rutter, M. (2003). The autism diagnostic interviewrevised (ADI-R). Los Angeles, CA: Western Psychological Services.
- 36. Lord, C., Rutter, M., DiLavore, P. C., & Risi, S. (2002). Autism Diagnostic Observation Schedule-WPS (ADOS-WPS), Los Angeles, CA: Western

- SIBLINGS OF CHILDREN WITH ASD: SOCIAL SUPPORT Psychological Services.
- 37. Mendoza, E., Carballo, G., Muñoz, J., & Fresneda, M. D. (2005). CEG: Test de comprensión de estructuras gramaticales. Madrid: TEA Ediciones.
- 38. Dunn, L. M., Dunn, L. M., & Arribas, D. (2006). Picture Peabody Vocabulary Test, Third edition (PPVT-III). Madrid: TEA ediciones.
- Semel, E. M., Wiig, E. H., & Secord, W. (2006). CELF 4: Clinical Evaluation of Language Fundamentals 4: Spanish Edition. PsychCorp.
- 40. Henderson, S. E., Sugden, D. A., & Barnett, A. L. (2007). *Movement assessment* battery for children (2nd ed.) *MABC-2*, London: Harcourt Assessment.
- 41. Wechsler, D. (2012). *Wechsler Preschool and Primary Scale of Intelligence— Fourth Edition*. San Antonio, TX: Psychological Corporation.
- Rutter, M., Bailey, A., & Lord, C. (2005). SCQ. The Social Communication Questionnaire. Torrance, CA: Western Psychological Services.
- 43. Gilliam, J. E. (2004). Gilliam autism rating scale: Examiner's manual. Pro-ed.
- 44. Hampton, J., & Strand, P. S. (2015). A review of level 2 parent-report instruments used to screen children aged 1.5–5 for autism: A meta-analytic update. *Journal of Autism and Developmental Disorders*, 45(8), 2519-2530.
- 45. Berkman, L. F., & Syme, S. L. (1979). Social networks, host resistance, and mortality: a nine-year follow-up study of Alameda County residents. *American Journal of Epidemiology*, 109(2), 186-204, doi: 10.1093/ oxfordjournals.aje.a112674
- 46. Verdugo, M. A., Rodríguez, A., & Sainz, F. (2009). Escala de calidad de vida familiar. Salamanca: INICO (Spanish adaptation to the Family Quality of Life Survey, Beach Center on Disability, 2003).

47. Hoffman, L., Marquis, J., Poston, D., Summers, J. A., & Turnbull, A. (2006).

Assessing family outcomes: Psychometric evaluation of the beach center family quality of life scale. *Journal of Marriage and Family, 68*(4), 1069-1083.

- 48. Verdugo, M.A., Córdoba., L., & Gómez, J. (2005). Spanish adaptation and validation of the Family Quality of Life Survey. *Journal of Intellectual Disability Research*, 49(10), 794-798
- 49. Cohen, J. (1988). Statistical power analysis for the behavioral sciences (2nd ed.).Hillsdale, NJ: Lawrence Earlbaum Associates.
- 50. Hayes, A. F. (2013). *Introduction to mediation, moderation, and conditional process analysis: A regression-based approach*. New York, NY: Guilford Press.
- 51. Cohen, J., Cohen, P., West, S. G., & Aiken, L. S. (2003) Applied multiple regressions/correlations analysis for the behavioral sciences. Mahwah: Lawerence Erlbaum Associates.
- 52. Faul, F., Erdfelder, E., Lang, A. G., & Buchner, A. (2007). G*Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods*, 39, 175-191, doi: 10.3758/BF03193146
- 53. Bedford, R., Elsabbagh, M., Gliga, T., Pickles, A., Senju, A., Charman, T., et al. (2012). Precursors and communication difficulties in infants at-risk for autism: Gaze following and attentional engagement. *Journal of Autism and Developmental Disorders*, *42*(10), 2208-18, doi: 10.1007/s10803-012-1450-y
- 54. Ozonoff, S., Young, G. S., Belding, B. A., Hill, M., Hill, A., Hutman, T., et al.
 (2014). The broader autism phenotype in infancy: When does it emerge. *Journal of the American Academy of Child and Adolescent Psychiatry*, 53(4), 398-407, doi: 10.1016/j.jaac.2013.12.020

- 55. Hudry, K., Chandler, S., Bedford, R., Pasco, G., Gliga, T., Elsabbagh, M., et al. (2014). Early language profiles in infants at high-risk for autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *44*, 154-167, doi: 10.1007/s108 03-013-1861-4
- 56. Warren, Z. E., Foss-Feig, J., Malesa, E. E., Lee, E. B., Taylor, J. L., Newsom, C. R., et al. (2012). Neurocognitive and behavioral outcomes of younger siblings of children with autism spectrum disorder at age five. *Journal of Autism and Developmental Disorder*, 42(3), 409-418, doi: 10.1007/s10803-011-1263-4
- 57. Pilowsky, T., Yirmiya, N., Gross-Tsur V., & Shalev, R. S. (2007).

Neuropsychological functioning of siblings of children with Autism, siblings of children with Developmental Language Delay, and siblings of children with Mental Retardation of Unknown Genetic Etiology. *Journal of Autism and Developmental Disorders*, *37*(3) 537-552, doi: 10.1007/s10803-006-0185-z

- 58. Pisula, E., & Ziegart-Sadowska, K. (2015). Social communication and language deficits in parents and siblings of children with ASD. A short review. *In: M. Fitzgerald (Ed.), Autism Spectrum Disorder-Recent Advances,* pp.95-112. Rijeka: Intech., doi: 10.5772/59134
- 59. Bontinck, C., Warreyn, P., Van der Paelt, S., Demurie, E., & Roeyers, H. (2018).
 The early development of infant siblings of children with autism spectrum disorder: Characteristics of sibling interactions. *PloS one, 13*(3), e0193367, doi: 10.1371/
 journal.pone.0193367
- 60. Vieira, C. B. M., & Fernandes, F. D. M. (2013). Quality of life of siblings of children included in the autism spectrum. *CoDAS 25*(2), 120-127, doi: 10.1590/S2317-17822 013000200006

- 61. Cebula, K. R., (2012). Applied behavior analysis programs for autism: sibling psychosocial adjustment during and following intervention use. *Journal of Autism and Developmental Disorders*, *42*(5), 847-862, doi: 10.1007/s10803-011-1322-x
- 62. Tomeny, T. S., Barry, T. D., & Fair, E. C. (2017). Parentification of adult siblings of individuals with autism spectrum disorder: Distress, sibling relationship attitudes, and the role of social support. *Journal of Intellectual & Developmental Disability,* 42 (4), 320-331, doi: 10.3109/13668250. 2016.1248376
- 63. Wang, M., Summers, J. A., Little, T., Turnbull, A., Poston, D., & Mannan, H. (2006). Perspectives of fathers and mothers of children in early intervention programmes in assessing family quality of life. Journal of Intellectual Disability Research, 50(12), 977-988.

Table 1. Demographic characteristics

							G A	roups nalysis			
				Sibs-ASD (N=41) (N=37) Effect size							-TD f p
	М	SD	SE M	Ra nge	М	SD	SE M	Ra nge			
Pa ren											
ts	35. 02	5.4 1	.84 5	28- 50	35. 19	6.0 9	1.0 0	27- 55	.02	.90 0	.00
Δσ Gender	~	-	-		-/	-	č	~~	.26	.61	.06
Male	36	_	_	_	31	_	_	_			
Fe	5	_	_	_	6	—	_	_			
mal									2.0	.36	.06
e	28	_	_	_	28	_	_	_	0	8	
Some college	e 2	_	_	_	0	—	_	_			
Hig	11	_	-	_	9	_	_	_			
h									.05	.81	.03
sch	33	_	_	_	29	_	_	—		8	
ool											
Ma											
Divorced	8	_	-	_	8	_	_	_			
Sib lin	0.0	• •		~ •	6.4	1.0	•	<i>.</i> .			
gs	8.3 2	2.0 5	.32	6-1 2	9.1 8	1.8 1	.30	6-1 1.9	3.8 2	.05 4	.05
Gender									.58	.44	.09

Male	22	_	_	_	23	-	_	_			
Female	19	—	_	_	14	_	_	_			
Children with ASD											
Age	11. 85	2.3 7	.36	8-1 7	12. 82	1.9 9	.3 3	8.25- 16.5	3.85	.05 3	.05
Gender									2.12	.14	.16
Male	30	_	_	_	32	_	_	_			
Female	11	_	_	_	5	_	_	_			

* = *p*<.05

SIBLINGS OF CHILDREN WITH ASD: SOCIAL SUPPORT Table 2. Descriptive analysis of Sib-ASD and Sib-TD groups

	Groups Analysis							roups nalysis			
				Sibs- (N=3) Effect	ASD (1 7) t size		Sibs Coe	s-TD ff <i>p</i>			
	М	SD	SE M	Ra nge	М	SD	SE M	Ra nge			
Receptive vocabulary	75. 37	26. 72	4.1 7	21- 121	70. 73	29. 53	4.8 6	10- 121	.53	.46 9	.20
Receptive language	44. 00	27. 84	4.3 5	2-9 7	48. 27	28. 92	4.7 5	1-9 0	.44	.50 9	.54
Expressive language	59. 05	28. 78	4.5 0	1-1 26	68. 05	26. 22	4.3 1	19- 116	2.0 7	.15 4	.35
Motor skills	48. 55	32. 94	5.1 4	.50 -98	61. 27	23. 32	3.8 3	9-9 5	3.8 0	.05 5	.46
Intelligence	11 0	13. 92	2.2 0	88- 128	107 .11	10. 78	1.8 2	76- 125	.99	.32 4	.20
Social	5.2	4.8	.76	0-1	3.7	2.7	.45	1-1	2.4	.12	.35
Severity of ASD	43. 95	25. 36	3.9 6	0-1 12	31. 92	20. 73	3.4 1	0-6 5	5.1 9*	.02 5	.51
Social support	6.2 9	1.4 5	.23	4-9	8.7 8	1.0 3	.17	7-1 0	74. 72*	<.0 01	2.00
FQoL importance	22. 66	2.6 1	.41	15- 25	22. 98	1.4 8	.24	19- 25	.43	.51 3	.20
Emotional well-being	16. 83	3.7 2	.58	6-2 1	16. 54	2.2 6	.37	12- 20	.17	.68 4	.00
Family interaction	28. 44	2.1 7	.34	21- 30	28. 78	1.9 3	.32	25- 30	.55	.46 3	.20
Disability- related support	18. 61	2.5 1	.39	9-2 0	18. 95	2.5 2	.41	9-2 0	.35	.55 7	.20
Parenting	27. 00	3.2 6	.51	18- 30	27. 30	2.2 0	.36	21- 30	.22	.64 2	.00
Physical well- being	22. 41	3.1 1	.49	13- 25	23. 32	1.9 7	.32	17- 25	2.3 2	.13 2	.35
FQoL satisfaction	18. 63	2.6 7	.42	14- 24	20. 65	1.9 8	.33	16- 25	14. 09*	<.0 01	.87

44

Emotional well-being	12. 20	2.5 2	.39	6-1 8	14. 97	2.2 .37 4	11- 20	26. 20*	<.0 01	1.19
Family	23.	3.6	.58	16-	25.	3.2 .52	20-	8.5	.00	.67
Disability-	15.	3.9	.62	8-2	15.	4.0 .67	8-2	.21	.64	.00
Parenting	22.	4.7	.75	10-	24.	2.6 .43	20.	4.7	.03	.51
Physical well- being	19. 85	3.6 0	.56	13- 25	22. 51	2.6 .43 4	16- 25	13. 57*	<.0 01	.84

Note: Receptive vocabulary, receptive language, expressive language, motor skills, and intelligence scores are presented in percentiles.

* = *p*<.05

	1	2	3	4	5	6	7	8
1. Vocabulary	_	.266 *	.418 *	.055	01 8	.191	06 1	.069
2. Receptive language	.266 *	-	.155	.123	.022	.061	.086	.113
3. Expressive language	.418 *	.163	-	.131	.024	156	.086	.207
4. Motor skills	.055	.123	.131	-	01 4	050	.126	.117
5. Social	01 8	.022	.024	01 4	-	.221 *	12 4	.021
6. Autistic traits	.191	.061	15 6	05 0	.220 *	_	15 1	21 7
7. Social support	06 1	.086	.086	.126	12 4	151	_	.419 *
8. Satisfaction on FQoL	.069	.113	.207	.117	.021	217	.419 *	_

Table 3. Correlations between potential predictors and satisfaction on FQoL

* *p*<.05

				95%	6 CI
	β	t	р	LLCI	ULCI
$R^2 = .32$, MSE = 4.803					
Group	.14	.19	.849	-1.34	1.62
Social Support	.66*	3.29	.002	.26	1.06
Gender	.85	1.68	.097	16	1.86
Age	.11	.85	.397	15	.37
Intelligence	03	-1.44	.155	08	.01
$R^2 = .32$, MSE = 4.859					
Group	-7.92 *	-2.36	.021	-14.62	-1.23
Social Support	21	62	.535	89	.47
Gender	.70	1.33	.188	35	1.75
Age	.20	1.62	.109	04	.44
Intelligence	03	-1.17	.244	07	.02
Group x Social Support	.93*	2.19	.032	.08	1.77

Table 4. Linear regression analyses to determine the influence of each predictor onsatisfaction on FQoL.

* = *p*<.05.

					95% CI		
Social Support	Coeff	SE	t	р	LLCI	ULCI	
5.689	-2.36*	1.02	-2.30	.024	-4.39	32	
7.439	50	.71	70	.487	-1.92	.92	
9.190	.43	.88	.49	.629	-1.33	2.19	
* <i>p</i> <.05							

Table 5. Conditional effect of group on FQoL at different values of social support.

Figure 1. A visual representation of the moderation effect of social support on

satisfaction with FQoL by group.



Note: Means are adjusted