



This postprint was originally published by Springer as:
Garrido, D., Petrova, D., Cokely, E., Carballo, G., & García-Retamero, R. (2021). **Parental risk literacy is related to quality of life in Spanish families of children with autism spectrum disorder.** *Journal of Autism and Developmental Disorders*, 51, 2475–2484.
<https://doi.org/10.1007/s10803-020-04733-8>

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Running head: Risk literacy in Autism Spectrum Disorder

Parental Risk Literacy Predicts Family Quality of Life in Spanish Families of Children with
Autism Spectrum Disorder

Abstract

Families of children with Autism Spectrum Disorder (ASD) often experience much more negative perceptions of their family quality of life (FQoL). To investigate key factors that may shape these experiences, we conducted a case-control study of sixty-one Spanish families (29 with a child with ASD) using a broad psychosocial assessment (e.g., ASD severity, social support, demographics), including the first direct test of the relationship between FQoL and parental risk literacy (i.e., the ability to evaluate and understand risk, as measured by numeracy). Results revealed that numeracy predicted differences in perceived FQoL among families of children with ASD ($R^2 = .10$), a finding that held across a wide range models statistically controlling for the influence of all assessed variables. Findings suggest that parental risk literacy skills may generally be associated with differences in decision making vulnerabilities (e.g., risk evaluation and interpretation) that influence many family outcomes including FQoL.

Keywords: Autism Spectrum Disorder; Quality of Life; Numeracy; Risk Literacy; Social Support

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Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is generally classified as a complex neurodevelopmental disorder characterized by social-communication challenges and restricted and repetitive behaviors (APA 2013). Among other outcomes, parents of children with this disorder often express higher levels of anxiety and stress compared to parents of children with typical development (TD) (see Vasilopoulou & Nisbet 2016 for a recent systematic review). Families of children with ASD are also at higher risk for experiencing physical and psychological distress, and tend to report significantly lower levels of family quality of life on standardized psychometric assessments (FQoL) (Allik et al. 2006; Garrido et al. 2015). Most of the relevant research on factors that affect FQoL in children with disabilities such as ASD has focused on negative experiences and perceptions (Hastings & Taunt 2002). However, an emerging and potentially valuable research trend has begun to examine the roles and implications of protective factors (Vasilopoulou & Nisbet 2016). For example, some research suggests that social support may meaningfully enhance FQoL in families of children with ASD (Khanna et al. 2011; McStay et al. 2014). Theoretically, among many benefits, social support may promote better mental health and more positive perceptions because it may help parents evaluate and cope with complex decision making (Khanna et al. 2011). Could other factors that also facilitate complex decision making, such as risk literacy skills (e.g., the ability to evaluate and understand risk), provide similar benefits to families with a child with ASD?

It is well-established that ASD includes heterogeneous symptoms. As such, families of children with ASD often receive a wide-range of information and must make many decisions based on complex information available from physicians, websites, support groups, professional societies, research articles, and clinical recommendations, to name a few

(Romancyk & Gillis 2005). In addition, parents often have to process and integrate this information to make health-relevant decisions for their children or themselves, and often need to assess potential risks and consequences of even routine policies and choices (e.g., risks of changing a bedtime routine, breakfast cereal, or after-school routine). Unfortunately, this information can be overwhelming, unclear, and contradictory (Webster et al. 2016), which is likely to be confusing and may complicate decisions regardless of the availability of other protective factors (e.g., social support).

The potential for misunderstanding and information overload among families with a child with ASD may be higher than for most other families (e.g., new behavioral interventions, psychopharmaceutical interventions, and educational options). As such, it seems likely that there may be many potential benefits for parents who become more fluent in the language of risk and decision making. A large and growing literature suggests that individual differences in acquired cognitive skills related to risk literacy (e.g., skills that promote accurate evaluation and understanding of risk; see RiskLiteracy.org) often predict skilled and adaptive decision making among diverse individuals, including those facing the complex, emotional, and stressful demands of high-stakes health decision making (e.g., when to seek emergency treatments, what kinds of treatments to trust, how to manage complex medical treatment compliance protocols) (Cokely et al. 2018; Garcia-Retamero et al. 2019). However, there do not appear to be any studies available in the peer-reviewed literature that have investigated the role of parental risk literacy skills among families with a child with ASD.

Although it is a complex and multiply-determined theoretical construct, research suggests that the single strongest predictor of risk literacy tends to be assessments of statistical numeracy, which may be broadly defined as tests of people's practical probabilistic reasoning ability (e.g., evaluating and interpreting numerical information about

risk, trade-offs, quantities, relations involving concepts such as probabilities, fractions, or ratios; Cokely et al. 2012, 2018; Peters et al. 2006; Reyna et al. 2009). Standardized and adaptive brief tests of statistical numeracy such as the Berlin Numeracy Test have also been found to be among the strongest individual predictors general decision making skill, often doubling the predictive power of other basic cognitive ability tests (e.g., working memory, intelligence; Cokely et al. 2012, 2018). These findings hold for decision making on problems involving numerical and non-numerical information, which has frequently been investigated in the context of health decisions and outcomes, including investigations of diverse samples from more than 50 countries (Garcia-Retamero et al. 2015; Petrova et al. 2018). Accordingly, in the current research, we aimed to provide the first investigation of the relations between parents' levels of practical statistical numeracy skills, as measured by the Berlin Numeracy Test, and FQoL in families of a child with ASD. Specifically, we compared perceptions of FQoL in these families with those of families with a child with typical development (TD), and we investigated the effect of both objective numeracy (i.e., actual differences in test scores) and subjective numeracy (e.g., self-reported or subjective skills), which in turn allowed us to develop an integrated statistical model comparing the potential predictive power of these skills in concert with other factors that are known to confer essential benefits to families of a child with ASD (i.e., social support).

Methods

Participants

Participants were recruited at two schools (controls) and two associations of parents of children with ASD (cases) in Granada, (Spain). Sixty-five parents were approached to participate in our study. Informed consent was obtained from all parent participants included in the study, in accord with our approved human participant research protocols (i.e., approved by the Ethics Committee of the University of Granada). The inclusion criterion for

participants in the ASD group was to have a child with ASD according to (1) the DSM-TR-IV (APA 2000) or DSM-5 (APA 2013) and (2) ADI-R (Le Couteur et al. 2003) or ADOS-G (Lord et al. 2002). The inclusion criterion for participants in the TD group was that children did not have any diagnosed medical or psychological condition (e.g., Attention-Deficit/Hyperactivity Disorder, Down syndrome, or cerebral palsy) nor did they have a previous family history of ASD.

Measures

Participants completed a demographic survey developed for the current study, which included child and parents' ages, genders, levels of education, employment statuses, and family composition. Additional specific measures related to severity of ASD, social support, numeracy skills, and FQoL were also collected, as described below.

Severity of ASD. Parents completed the Gilliam Autism Rating Scale (GARS; Gilliam 2004). This scale is a norm referenced screening instrument designed to support professional identification of ASD. This scale gathers information about specific characteristics typically noted in ASD (stereotyped behaviors, communication, and social interaction). We used this measure as an indicator of severity of ASD.

Social support. We evaluated social support with the Social Network Index (SNI; Berkman & Syme 1979). This scale assesses the different types of support, including emotional, instrument, and structural support. For the porpoise of this study, we included the structural support measure (i.e., including parents' number of friends, perceptions of quality of their relationship with relatives, and number of weekly contacts that parents have with their relatives and friends). We computed the average of parents' answers in these items. This questionnaire showed good internal consistency, with a Cronbach's alpha score of 0.71.

Objective Numeracy. Objective numeracy was measured with a scale of 13 items, consisting of 9 items developed by Lipkus et al. (2001) as well as the 4 items of the Berlin Numeracy Test (Cokely et al. 2012). The scale assesses the ability to compare risk magnitudes, convert percentages to proportions, convert proportions to percentages, convert probabilities to proportions, and compute probabilities. The scale showed adequate internal consistency, with Cronbach's alpha score of 0.85. Tests of criterion validity have indicated that scores in the questionnaire are highly correlated with correct answers to ecologically valid decision quality and risk evaluation (Cokely et al. 2018; Garcia-Retamero et al. 2016).

Subjective numeracy. We used the Subjective Numeracy Scale (SNS) developed by Fagerlin et al. (2007), which is an 8-item self-report measure of the perceived ability to perform various mathematical tasks and preferences for use of numerical versus prose information. The scale demonstrates good reliability (Cronbach's alpha = 0.82) and tends to be reliably correlated with the objective numeracy scale ($r = 0.63$ – 0.6856 ; Galesic & Garcia-Retamero 2010).

Family quality of life. Participants completed the Family Quality of Life of People Survey (Spanish version, FQoLS; Verdugo et al. 2009). This questionnaire is adapted from the Family Quality of Life Survey, which was developed in the Beach Center on Disability, Kansas (USA) (Hoffman et al. 2006). This instrument evaluates FQoL in two domains (importance and satisfaction), and it includes two global scores (i.e., importance of FQoL and satisfaction with FQoL) derived from five factors related to FQoL: emotional wellbeing, family interaction, financial resources, the role as father/mother, and physical wellbeing. Both domains (importance and satisfaction) showed good reliability (Cronbach's alpha score of 0.88 and 0.85 respectively).

Data Analysis

All statistical analyses were performed using IBM SPSS statistics version 22.0, and in the R statistical environment. We computed descriptive statistics to characterize the sample of participants. We constructed a linear regression model, to estimate the extent to which group (family with a child with ASD vs. TD), levels of objective and subjective numeracy, and social support uniquely and jointly predict FQoL, while statistically controlling for the effect of two variables that are known to often influence FQoL (i.e., severity of ASD and level of education). Before developing the regression analysis, possible multicollinearity among the potential predictors was checked using the tolerance and the variance inflation factors (VIF). VIF values between 1-10 are typically used to indicate the absence of multicollinearity (Cohen et al. 2003). To investigate whether the relationships of numeracy and social support with FQoL varied as a function of group, we also tested the moderation effect of numeracy and social support, including their interaction with group using the PROCESS macro, embedded and operated in SPSS (Hayes 2013). For the current analysis, we selected PROCESS Model 1 for moderation. Given the limited sample size, and to reduce risks associated with violation of normal distribution assumptions, 5,000 bootstrap simulation samples were drawn to enhance the robustness of the estimation of direct model effects. To further understand any potential moderation effects we estimated effects at the sample mean, and plus/minus one standard deviation of the value of the moderator. A sensitivity analysis (using G*Power calculator; Faul et al. 2007) showed that given seven predictors (6 main effects and one interaction), power = .80, and alpha = .05, the minimum effect size that could be detected with the obtained sample size of $n = 61$ is $f = .104$ —i.e., indicating the analytical approach would be sensitive even for small to modest size effects (Cohen's $d = .25$).

Results

From all parents ($n = 65$) who were invited, 61 (94%) participated in the study. This final sample included 29 parents of a child with ASD and 32 parents of a child with TD. Most

participants were mothers (93%) with an average age of 41.5 years (ranging from 31 to 58 years). We conducted preliminary analyses to examine socio-demographic characteristics and equivalences in our variables of interest in the groups of parents with a child with ASD and TD, respectively. Independent t-test and chi square analyses were computed for all measures, potential moderators, and socio-demographic characteristics (see Table 1). Analyses revealed two significant differences between groups, namely the levels of satisfaction with their FQoL ($p < .001$), and severity of ASD symptoms ($p < .001$), suggesting that the groups did not otherwise differ to any significant degree by level of education, objective numeracy, and subjective numeracy, or availability of social support (i.e., number of friends, and number of relatives with whom participants frequently contacted).

Table 1. Descriptive analysis of ASD and TD groups.

	Group		Analysis			
	ASD (N=29)	TD (N=32)	Coeff	<i>p</i>	Effect size	
Age	43.00 (6.53)	40.28 (4.74)	3.51	.066	.06	
Gender	3:26	1:31	1.29	.255	.29	
Level of education	8:10:10:1	7:17:8:0	4.25	.374	.23	
Marital status	1:23:5:0	3:29:0:0	6.56	.087	.45	
Employment status	11:9:9	7:6:19	7.61	.055	.51	
Severity of ASD	33.59 (8.36)	11.66 (8.53)	102.53**	<.001	.64	
Social support	6.44 (1.41)	7.47 (2.19)	3.09	.084	.05	
Numeracy	Subjective	7.10 (3.74)	7.84 (2.84)	.58	.449	.01
	Objective	25.07 (7.82)	23.41 (9.09)	.77	.385	.01
FQoL	Importance	18.69 (2.04)	19.34 (1.29)	2.29	.135	.04
	Satisfaction	13.45 (3.49)	18.34 (2.19)	443.87**	<.001	.43

Note: Cohen's *d* and eta squared were calculated as measures of effect size (categorical and continuous variables respectively).

Gender = Male: Female; Educational level = Basic level: Upper secondary level: Bachelor's degree: Doctorate degree; Marital status = Single: Married: Divorced: Widowed;

Employment status: Full-time: Part-time: Unemployed

* = $p < .05$

** = $p < .001$

We conducted a Pearson's correlation to examine the relation between subjective and objective numeracy. Results revealed a moderated correlation ($r = .38$). To avoid potential multicollinearity in multiple regression analyses, we conducted and report two separate regressions in order to identify which of these variables was a stronger predictor of satisfaction with FQoL. The resulting models indicated that objective numeracy had a predictive value for FQoL ($F(1, 59) = 6.67, p = .01, R^2 = .10, R^2 \text{ adjusted} = .09$) but subjective numeracy did not ($F(1, 59) = .20, p = .660, R^2 = .003, R^2 \text{ adjusted} = .01$). Additionally, no multicollinearity was evident among all other tested predictors, as evidenced by the VIF for the predictors, which ranged between 1.12 and 9.41, with tolerance values ranged between .11 and .89 (Cohen et al. 2003).

The multiple linear regression analysis indicated that only objective numeracy ($\beta = .24, p < .05$) and group ($\beta = -.67, p < .001$) had a significant main effect on FQoL, such that higher FQoL was associated with both numeracy and ASD family status. We further tested whether the relationship between objective numeracy and FQoL varied as a function of group by evaluating their interaction. The test of moderation including the interaction between objective numeracy and group is presented in Table 2, including standardized regression coefficients (β s) for each predictor. Results indicated that the interaction between group and objective numeracy was strong and significant ($\beta = .59, p < .05$). Overall, the statistical model indicates that in the context of all variables, these two factors (and the interaction thereof) may generally explain the majority of the observed variation in reported FQoL (54% of the total variance, $F(7, 53) = 8.958, p < .001$).

Despite the lack of significant effects of subjective numeracy and social support in the multiple regression model, we also tested other interactions between group and these variables on FQoL. Model testing included tests of interactions between group and subjective numeracy, and between group and social support, all of which failed to detect unique reliable

associations. While there are many potential factors that can obscure possible relations, the available evidence suggest that in the broader population these other variables are unlikely to robustly explain unique differences in FQoL responses, beyond their potential association with the direct effects of ASD status and numeracy ($\beta = -.49, p = .154$, and $\beta = .35, p = .411$ respectively).

Table 2. Linear regression model. Dependent variables: Satisfaction with FQoL.

	β	t	p	95% CI	
				LLCI	ULCI
$R^2 = .49, MSE = 2.75$					
Group	-.63	-6.60	<.001	-6.11	-3.27
Objective numeracy	.25	2.62	.011	.07	.50
$R^2 = .53, MSE = 2.64$					
Group	-1.14	-4.85	<.001	15.75	21.33
Objective numeracy	-.02	-.15	.881	-12.04	-5.00
Group x Objective Numeracy	.59	2.37	.021	.08	.94
$R^2 = .54, MSE = 2.72$					
Group	-1.22	-4.28	<.001	-13.54	-4.87
Level of education	.04	.45	.656	-.49	.77
Social support	.07	.66	.514	-.27	.54
Severity of ASD	.05	.32	.752	-.07	.10
Objective numeracy	-.08	-.49	.627	-.48	.29
Subjective numeracy	.06	.56	.577	-.07	.12
Group x Objective Numeracy	.65	2.39	.020	.09	1.03

Plots of interactions comparing the effect of objective and subjective numeracy on FQoL are shown in Figure 1. Results indicate that FQoL was particularly low in families with a child with ASD whose parents had relatively low objective numeracy. In contrast, FQoL was higher in families with a child with ASD whose parents have relatively high objective numeracy. FQoL was also relatively high in families with a child with TD regardless of their parents' levels of objective numeracy. In addition, there was a main effect of group such that FQoL was lower on average for families with a child with ASD, regardless of their level of objective numeracy. In other words, among families of children with ASD, parents with

lower numeracy (< 33th percentile) showed 3 times greater reduction in FQoL as compared to parents with high numeracy (> 65th percentile). This finding differs considerably from results among families of a child with TD, which typically do not vary substantially on FQoL as a function of numeracy (see Figure 1). To further contextualize and interpret these results, we compared differences between groups in FQoL as a function of level of numeracy.

Calculation of simple slopes (see Table 3) indicated that the effect of group on FQoL was statistically different both at the mean [$F(1, 57) = 47.696, p < .001$], and minus one standard deviation from the mean [$F(1, 57) = 41.542, p < .001$] on objective numeracy (a medium effect size of $d = .66$, and $d = .68$, respectively). Although the effects of group on FQoL was statistically different at plus one standard deviation from the mean [$F(1, 57) = 9.825, p = .003$], the effect size was nominally reduced by roughly 30% ($d = .46$).

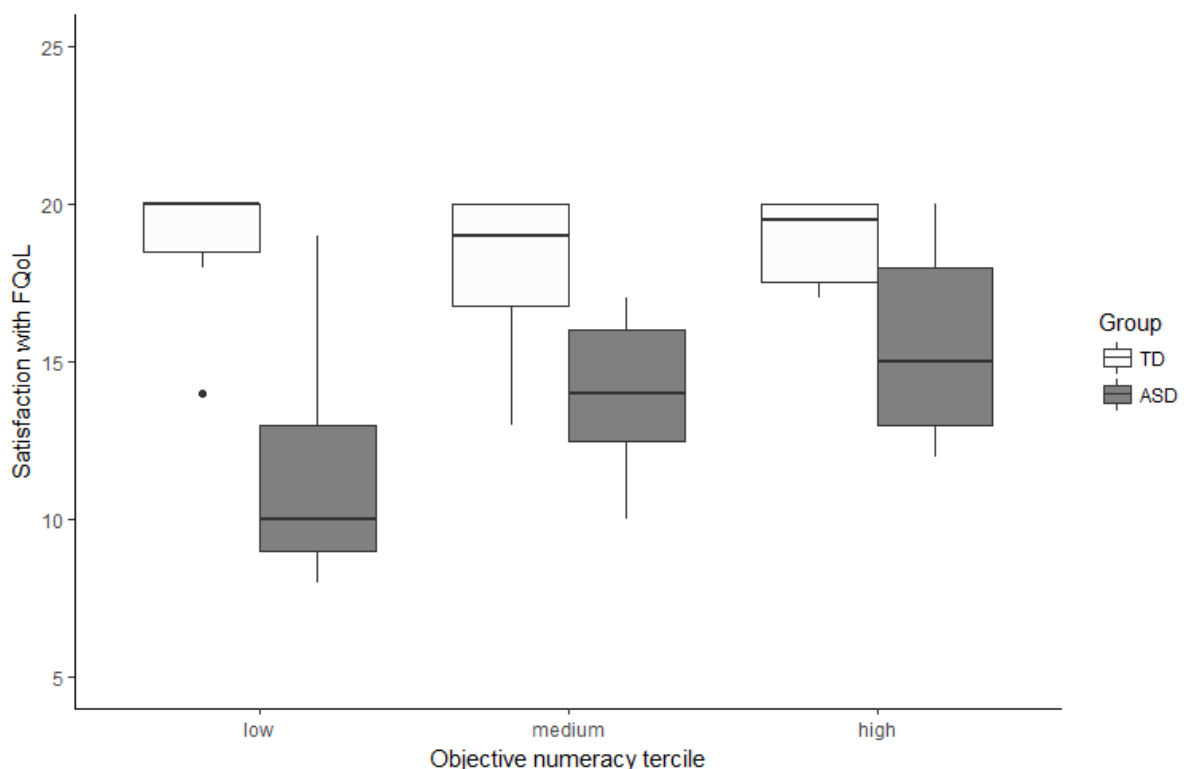


Figure 1. A visual representation of the moderation effect of numeracy (based on terciles) on satisfaction with FQoL by group.

Table 3. Conditional effect of group on FQoL at different values (mean, and plus/minus one standard deviation from mean) of objective numeracy.

Objective numeracy value	Coeff	SE	t	p	95% CI	
					LLCI	ULCI
4.202	-6.39	.99	-6.45	<.001	-8.37	-4.40
7.492	-4.72	.68	-6.91	<.001	-6.08	-3.35
10.781	-3.05	.97	-3.14	.003	-4.99	-1.10

Discussion

The current results provide the first direct test of the relations between general decision making skills (i.e., risk literacy and statistical numeracy) and reported quality of life among families of children with ASD. Independent of other potentially relevant variables (e.g., social support, demographics), analyses suggest that risk literacy skills as measured by statistical numeracy tests are likely to be robustly linked to expressed quality of life among most families of children with ASD (e.g., within industrialized countries). Statistical analyses of our case-control study also reveal that the strength of the association between risk literacy and ASD-related FQoL is generally likely to be substantial: Among families of children with ASD, the estimated magnitude of the reduction in FQoL reported by parents with low versus high risk literacy (e.g., upper vs. lower numeracy quartile) appears similar to the overall reduction in FQoL that is associated with having a child with ASD, as compared to FQoL reported by families of a child with TD. Additionally, the current findings suggest that risk literacy may generally be a unique predictor of differences in FQoL among families of children with ASD, such that differences in risk literacy may help explain some relatively large differences in FQoL that are not directly attributable to other influential factors such as the severity of ASD, the level of parental education, and the availability of social support.

Risk Literacy and General Adaptive Decision Making. As in other research on risk literacy, the association between risk literacy and FQoL in families of a child with ASD is

likely multiply determined, reflecting the cumulative influence of many cognitive and socio-emotional factors related to skilled and adaptive decision making (e.g., fewer biases and errors). Unfortunately, because many people have relatively low-levels of practical statistical numeracy skills (and thus have limited risk literacy), they often struggle with evaluation and interpretation of numeric and non-numeric information about risks, decisions, trade-offs, and options (e.g., misinterpreting or misunderstanding the magnitude, frequency, or sources of potential costs, benefits, and decision trade-offs) (Cokely et al. 2012, 2018; Reyna et al. 2009). For example, less risk literate individuals appear to be generally less sensitive or consistent when evaluating the potential value or stakes of risky prospects, and thus they may often tend to accrue costs and take risks that are unjustifiable given the potential consequences or payoffs (Cokely & Kelley, 2009; Traczyk et al. 2018). Moreover, when faced with higher-stakes decisions or risk communications, it is simply easier for more risk literate individuals to “read” or interpret and comprehend—and thus learn and remember—the specific information about various risks. Because more risk literate individuals can more quickly and easily learn about decision-relevant information, and because they tend to do so with fewer errors, high risk literacy skills also tend to be associated with more precise, nuanced, and accurate mental models of trade-offs, costs, and benefits.

Ironically, perhaps in efforts to simplify overwhelmingly complex decision information, less risk literate individuals are generally less likely to thoroughly consider personally relevant implications of their decisions, as compared to more risk literate individuals (e.g., “yeah, I just hope that doesn’t happen” versus “it’s very unlikely, but, if so I don’t know how I would explain it to others and I’m not sure how long it would take to forgive myself...”) (Cokely et al. 2018). It is well-established that the more one elaborates about a decision in a personally relevant way, the more likely that information is to be encoded in a durable long-term memory representation. By moving information into long-

term memory, decision makers can build much more complex cognitive representations by circumventing the need to rely primarily on limited attentional and working memory capacities during complex reasoning (e.g., similar to the benefits that follow from reasoning about a familiar topic or reading something in one's native language—the more familiar and knowledgeable one is, the easier it is generate and process complex mental simulations). Moreover, less risk literate individuals often rely on simplifying decision heuristics and strategies that enable consistent yet naive and insensitive decisions making processes (e.g., “I always just try to avoid risks”).

Overall, more risk literate decision makers tend to enjoy many decision making benefits because more risk literate individuals deliberately invest their time on higher value decisions, because they work to understand these decisions using personally relevant and well-organized mental models, and because they have more of the basic skills and knowledge that supports faster, more accurate, and more consistent risk comprehension and evaluation (Cokely et al. 2018). Over time, these factors are also likely to promote and accelerate the acquisition of specific types of specialized knowledge and decision making expertise (e.g., detailed knowledge about ASD and durable memory for previous ASD decisions, risks, and outcomes.). In turn, the acquisition of more ASD specific knowledge should further promote skilled, confident, and successful ASD decision making (e.g., less time worrying, less confusion, less uncertainty, more successes and more free resources for other important family and health related activities).

Risk Literacy and ASD-Related Decision Making. To the extent that the general mechanisms of decision making skill help explain the observed relations between FQoL and numeracy, there appear to be many pathways by which benefits may manifest among more risk literate families of children with ASD. For example, it seems obvious that less risk literate families may generally have more subjective difficulty evaluating and understanding

the relatively large amount of (sometimes conflicting) information that is widely available from various sources about children with ASD (e.g., relevant ASD treatment outcomes and risks). These families are also likely at higher risk of other decision biases such as overconfidence, confirmation bias (e.g., looking for information that confirms your beliefs), and misunderstandings of essential decision relevant information (Cokely et al. 2012; Garcia-Retamero & Cokely 2017). Less risk literate families of children with ASD may also have more difficulty understanding or anticipating potential complications of their child's condition, the likelihood or magnitude of potential challenges, or the probabilistic role of genetics and environment factors related to ASD (Lea et al. 2011). These parents are also much more likely to be biased by persuasive advertising and special-interest communications that do not provide balanced or comprehensive information about novel medical or educational opportunities.

Predicting Decision Vulnerability. Beyond differences in underlying cognitive and decision making mechanisms, the current study also hints at opportunities to provide some practical guidance related to decision making vulnerabilities (e.g., how understandable is a risk communication for more v. less numerate people). For example, skill assessments such as the brief numeracy tests could potentially be used to estimate how much numeracy would be required in order to (likely) understand certain risk communication brochures. Similarly, each level of a numeracy scores could be directly linked to the probability of accurately interpreting specific brochures, advertisements, or other decision support artefacts (Cokely et al. 2012, 2018). Although it remains untested, it seems plausible that families with two parents who have relatively high levels of risk literacy are less likely to benefit as much as others from intensive and supportive interventions by professionals (e.g., they don't need much help evaluating the risks). However, it is unknown when and if it might be sufficient to have only one risk literate parent. With respect to buffering against threats to FQoL, it is also

unclear when and why risk literacy operates like a threshold variable (e.g., you have enough or not) as compared to operating more like an accumulator (e.g., more risk literacy = better outcomes even if benefits tend to taper off). While we find these practical and theoretical questions interesting, more data will be needed to go beyond speculation about the potential relative costs and benefits of using parental risk literacy assessments to anticipate and predict decision vulnerability and the relative benefits of existing risk communication and decision support technologies.

Transparent Risk Communication and Skill Development. In addition to using tests to identify and quantify risks and potential vulnerabilities of families, there may be opportunities develop specific skills and create more transparent and inclusive outreach and risk communications. A small but growing body of emerging research is now available on the potential benefits of risk literacy educational and training programs, which could confer additional benefits beyond programs designed to train specific ASD knowledge (Cokely et al. 2018). Perhaps even more actionable, is the large and impressive body of work showing the major potential benefits of simple risk communication tools that focus on “transparent” risk communication standards and technologies (i.e., promoting representative understanding for independent decision making) (Gaissmaier et al. 2012; Garcia-Retamero & Cokely 2013, 2017; Zikmund-Fisher et al. 2014). For example, simple visual aids that make part-to-whole relations visually available and comparable also tend to help orient information search and improve comprehension processes, thereby offering substantial benefits despite relatively minimal development costs. These kinds of visual aids have been found to be particularly useful when designed to serve vulnerable populations with limited numeracy (Garcia-Retamero & Cokely 2017).

To further illustrate, consider one set of risk communication applications that was used to depict various risks and decision-relevant information via icon arrays (i.e., transparent

graphical representations consisting of a number of circles symbolizing individuals at risk). In these studies, researchers found that the graphs consistently and dramatically improved risk understanding and reduced decision biases across diverse individuals, often equating the decision quality of high versus low numerate individuals (upper v lower quartile), while also matching the overall decision quality of highly persuasive messages as well as extensive training programs (e.g., 8 hours). Over the last two decades (and particularly in the last 10 years) these and similar results have been documented many times and in many different samples, countries, age groups, and across demographic differences and education levels, often with the largest benefits for the most vulnerable and at-risk individuals (Garcia-Retamero & Cokely 2017; Garcia-Retamero et al. 2016; Galesic & Garcia-Retamero 2010).

Potential Limitations & Future Directions. To our knowledge, the current research is the first case-control study examining the relationship between parental risk literacy and family quality of life in families of a child with ASD. Our research contributes to the growing literature suggesting that parental characteristics may promote psychological resilience, helping some families with children with ASD thrive in the face notable challenges. Although the rather large observed relation between numeracy and FQoL in families of children with ASD suggests there is good reason to expect the current findings will robustly generalize, as with all research there are potential limitations that should not be neglected. For instance, our sensitivity analysis indicated that with the obtained sample size, a moderate or large effect size would be readily detected (as evidenced by the interaction between numeracy, group, and FQoL). However, the current sample size was not sufficient to allow for a precise estimate of the overall relative influence of other less influential but still potentially significant variables in our analyses (e.g., parents' age, employment status, or family composition).

Another potential concern to note is that, in contrast to other studies (e.g., Khanna et al. 2001; McStay et al. 2014), we did not find that social support was a robust predictor of

FQoL in our current sample. The finding of this difference is not easily attributable to the differences across groups of participants with a child with ASD. A further complication is that our results showed that individual differences in objective numeracy were more reliable predictors of FQoL even as compared to the well-established influence of structural social support. One possible explanation for both these findings may reflect the fact that the participants in our study were all enrolled in a respite care program. Respite care programs tend to provide families with a higher level of social support (as compared to those who don't have access to respite care programs). As such, it may be the case that the current sample is more representative of family dynamics among those families that have sufficient (or considerable) amounts of social support available. While it seems plausible that this support might have improved their mental health—as revealed in previous research (e.g., Yantzi et al. 2007)—if this is correct, it is more likely that the current study underestimates rather than overestimates the strength of the relations among a broader population for a simple mathematical reason related to restriction of range. However, although we think this is most likely given the available relation, given current limits more research will be needed before we can adequately address this hypothesis. Furthermore, we think it would be wise to also investigate the extent to which different types of social support might improve outcomes (e.g., perceived social support, general or context-specific social support) to also consider the psychometric qualities of various social support assessment instruments that may provide more or less (measurement) sensitivity for hypothesis testing and model evaluation.

Lastly, we think it is noteworthy that 93% of the current study sample consisted of mothers, which suggests there are some open questions that remain about the extent to which the current findings generalize to fathers as a group. While we think this relation is likely to be robust, we would caution against broad, confident generalizations across all parents until and unless research can address these and related additional assumptions using large and

diverse samples. In summary, our research suggests that adequate levels of objective numeracy may often be associated with large increases in FQoL in families of children with ASD. To the extent the current findings reflect the kinds of casual linkages between risk literacy skills and decision outcomes as observed in other behavioral studies, we see many novel, valuable opportunities to leverage lessons from other research to the benefit of many families of children with ASD (e.g., reducing the burden of information overload, predicting potential decision vulnerability, promoting greater transparency in risk communications, developing general decision making and risk literacy skills).

Ethical approval: “All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee (include name of committee + reference number) and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.”

References

- Allik, H., Larsson, J. O., & Smedje, H. (2006). Health-related quality of life in parents of school-age children with Asperger syndrome or high-functioning autism. *Health and Quality of Life Outcomes*, 4, 1, doi: 10.1186/1477-7525-4-1
- American Psychiatric Association (2000). *Diagnostic and statistical manual of mental disorders manual text revision (DSM-IV-TR)*, Washington, DC, American Psychiatric Association.
- American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders (5th ed.)*, Washington, DC, American Psychiatric Association.
- 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.
- Cohen, J., Cohen, P., West, S. G., & Aiken, L. S. (2003). *Applied multiple regressions/correlations analysis for the behavioral sciences*. Mahwah: Lawrence Erlbaum Associates.
- Cokely, E. T., Feltz, A., Ghazal, S., Allan, J. N., Petrova, D., & Garcia-Retamero, R. (2018). Skilled Decision Theory: From intelligence to numeracy and expertise. In K. A. Ericsson, R. R. Hoffman, A. Kozbelt, & A. M. Williams (Eds.), *Cambridge handbook of expertise and expert performance (2nd Ed.)* (pp. 476–505), New York, NY, Cambridge University Press.
- Cokely, E. T., Galesic, M., Schulz, E., Ghazal, S., & Garcia-Retamero, R. (2012). Measuring risk literacy: The Berlin numeracy test. *Judgment and Decision Making*, 7, 25-47.

- Cokely, E. T., & Kelley, C. M. (2009). Cognitive abilities and superior decision making under risk: A protocol analysis and process model evaluation. *Judgment and Decision Making*, 4(1), 20-33
- 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
- Fagerlin, A., Zikmund-Fisher, B. J., Ubel, P. A., Jankovic, A., Derry, H. A., & Smith, D. M. (2007). Measuring numeracy without a math test: Development of the Subjective Numeracy Scale. *Medical Decision Making*, 27, 672-680, doi: 10.1177/0272989X07304449
- Gaissmaier, W., Wegwarth, O., Skopec, D., Müller, A., Broschinski, S., & Politi, M. C. (2012). Numbers can be worth a thousand pictures: Individual differences in understanding graphical and numerical representations of health-related information. *Health Psychology*, 31, 286–296, doi: 10.1037/a0024850
- Galesic M., & Garcia-Retamero, R. (2010). Statistical numeracy for health: A cross-cultural comparison with probabilistic national samples. *Archives of Internal Medicine*, 170, 462–468, doi: 0.1001/archinternmed.2009.481.
- Garcia-Retamero, R., Andrade, A., Sharit, J., & Ruiz, J. G. (2015). Is patients' numeracy related to physical and mental health? *Medical Decision Making*, 35 (4), 501-511, doi: 10.1177/0272989X15578126
- Garcia-Retamero, R., & Cokely, E. T. (2013). Communicating health risks with visual aids. *Current Directions in Psychological Science*, 22, 392–399, doi: 10.1177/0963721413491570

- Garcia-Retamero, R., & Cokely, E. T. (2017). Designing visual aids that promote risk literacy: a systematic review of health research and evidence-based design heuristics. *Human Factors*, *59* (4), 582-627, doi: 10.1177/0018720817690634
- Garcia-Retamero, R., Cokely, E. T., Ghazal, S., & Joeris, A. (2016) Measuring graph literacy without a test: A brief subjective assessment. *Medical Decision Making*, *36*, 854–867, doi: 10.1177/0272989X16655334
- Garcia-Retamero, R., Sobkow, A., Petrova, D., Garrido, D., & Traczyk, J. (2019). Numeracy and Risk Literacy: What Have We Learned so Far? *The Spanish journal of psychology*, *22*. doi:10.1017/sjp.2019.16
- Garrido, D., Carballo, G., Franco, V., & Garcia-Retamero, R. (2015). Dificultades de comprensión del lenguaje en niños no verbales con trastornos del espectro autista y sus implicaciones en la calidad de vida familiar [Language comprehension disorders in non-verbal children with autism spectrum disorders and their implications in the family quality of life]. *Revista de Neurología*, *60*, 207-14.
- Gilliam, J. E. (2004). *Gilliam Autism Rating Scale*. Austin, TX, Pro-Ed.
- Hastings, R. P., & Taunt, H. M. (2002). Positive perceptions in families of children with developmental disabilities. *American Journal on Mental Retardation*, *107* (2), 116-127, doi: 10.1352/0895-8017(2002)107<0116:PPIFOC>2.0.CO;2
- Hayes, A. F. (2013). *Introduction to mediation, moderation, and conditional process analysis: A regression-based approach*. New York, NY: Guilford Press.
- 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, doi: 10.1111/j.1741-3737.2006.00314.x

- 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.
- Lea, D. H., Kaphingst, K. A., Bowen, D., Lipkus, I., & Hadley, D. W. (2011). Communicating genetic and genomic information: health literacy and numeracy considerations. *Public Health Genomics, 14* (4-5), 279-289, doi: 10.1159/000294191
- Le Couteur, A., Lord, C., & Rutter, M. (2003). *The autism diagnostic interview-revised (ADI-R)*. Los Angeles, CA, Western Psychological Services.
- Lipkus, I. M., Samsa, G., & Rimer, B. K. (2001). General performance on a numeracy scale among highly educated samples. *Medical Decision Making, 21* (1), 37-44, doi: 10.1177/0272989X0102100105
- Lord, C., Rutter, M., DiLavore, P. C., & Risi, S. (2002). *Autism Diagnostic Observation Schedule-WPS (ADOS-WPS)*. Los Angeles, CA, Western Psychological Services.
- McStay, R. L., Trembath, D., & Dissanayake, C. (2014). Stress and family quality of life in 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.
- Peters, E., Vastfjall, D., Slovic, P., Mertz, C. K., Mazzocco, K., & Dickert, S. (2006). Numeracy and Decision Making. *Psychological Science, 17*(5), 407-413, doi: [10.1111/j.1467-9280.2006.01720.x](https://doi.org/10.1111/j.1467-9280.2006.01720.x)
- Petrova, D., Kostopoulou, O., Delaney, B., Cokely, E. T., & Garcia-Retamero, R. (2018). Strengths and gaps in physicians' risk communication: A scenario study of the

- influence of numeracy on cancer screening communication. *Medical Decision Making*, 38, 355–365, doi: 10.1177/0272989X17729359.
- Reyna, V. F., Nelson, W. L., Han, P. K., & Dieckmann, N. F. (2009). How numeracy influences risk comprehension and medical decision making. *Psychological Bulletin*, 135, 943–973, doi: 10.1037/a0017327
- Romanczyk, R. G., & Gillis, J. M. (2005). Treatment approaches for autism: Evaluating options and making informed choices. In D. Zager (Ed.), *Autism spectrum disorders: Identification, education, and treatment* (3rd ed., pp. 515–535.). Mahwah, NJ, Lawrence Erlbaum.
- Traczyk, J., Sobkow, A., Fulawka, K., Kus, J., Petrova, D., & Garcia-Retamero, R. (2018). Numerate decision makers don't use more effortful strategies unless it pays: A process tracing investigation of skilled and adaptive strategy selection in risky decision making. *Judgment and Decision Making*, 13, 372–38
- 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).*
- Vasilopoulou, E., & Nisbet, J. (2016). The quality of life of parents of children with autism spectrum disorder: A systematic review. *Research in Autism Spectrum Disorder*, 23, 36-49, doi: 10.1016/j.rasd.2015.11.008
- Webster, A., Cumming, J., & Rowland, S. (2016). *Empowering Parents of Children with Autism Spectrum Disorder: Critical Decision-making for Quality Outcomes*. Springer.
- Yantzi, N. M., Rosenberg, M. W., & McKeever, P. (2007). Getting out of the house: the challenges mothers face when their children have long-term care needs. *Health & Social Care in the Community*, 15 (1), 45-55, doi: 10.1111/j.1365-2524.2006.00663.x

Zikmund-Fisher, B. J., Witteman, H. O., Dickson, M., Fuhrel-Forbis, A., Kahn, V. C., Exe, N. L., . . . Fagerlin, A. (2014). Blocks, ovals, or people? Icon type affects risk perceptions and recall of pictographs. *Medical Decision Making*, *34*, 443–453, doi: 10.1177/0272989X13511706