

Understanding the Quality of Life Among Caregivers of Children with Autism Spectrum Disorder Using the Risk and Resistance Model of Adjustment

Gloria K. Lee^{1*}, Fabienne Bain², Sarah Curtiss¹, Martin A Volker¹, Christopher Lopata³, Marcus L. Thomeer³, Jonathan D. Rodgers³, Jennifer A. Toomey⁴

¹Department of Counseling, Educational Psychology & Special Education, Michigan State University, USA

²Department of Psychiatry, University of Rochester Medical Center, USA

³Institute for Autism Research, Canisius College, USA

⁴The Summit Center, USA

*Corresponding author: Gloria K. Lee, Department of Counseling, Educational Psychology & Special Education, Michigan State University, USA. Email: leekalai@msu.edu

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Abstract

Background: There is a wide range of outcomes for children with Autism Spectrum Disorder (ASD). From a family systems perspective, one factor that affects child outcomes is caregiver well-being. In this study, we seek to understand the quality of life (QOL) among caregivers of children with ASD by examining the complex interplay between child and caregiver variables that are considered either risk or resistance variables, as postulated by the Risk and Resistance Model of Adjustment.

Method: Caregivers' stress, coping/appraisal, and support, as well as children's cognitive skills, language skills, adaptive functioning, and social functioning, were assessed, using cross-sectional survey data from 125 caregivers of children with ASD. Caregivers' physical and mental health outcomes were examined and predicted using hierarchical regression analyses to determine the amount of variance accounted for by these risk and resistance variables.

Results: No risk or resistance variables significantly predicted caregivers' physical health. However, a child's risk variable (functional impairments of adaptive and social functioning) and caregiver's ecological variable (resources) explained a significant amount of the variance associated with caregivers' mental health QOL.

Conclusions: Although child characteristics and caregiver risk variables were significant predictors of mental health outcomes, caregivers may be able to buffer these risks with factors, such as coping mechanisms, that they are able to control.

Keywords: Autism Spectrum Disorder; Caregivers; Resistance; Risk; Quality of Life

Introduction

Autism Spectrum Disorder (ASD) is characterized by pervasive impairments in social communication skills as well as restrictive, repetitive, and stereotyped patterns of behavior, interests, and activities [1]. Thus, ASD affects children in terms of how they socialize, communicate, and behave and can have long-

term effects on a child's psychological, adaptive, interpersonal, and educational functioning [2]. Caregivers play an imperative role in providing care and support for these children, who pose both anticipated and unanticipated changes and challenges. Parents of children with ASD have reported high level of stress e.g [3], poor quality of life (QOL) e.g [4], depression and anxiety e.g [5], high parenting burden and caregiving demands [6], and poor overall family dynamics [7]. Negative caregiver outcomes also have a direct impact on the quality of care and support for their

children, which, in turn, affect their child's success. To alleviate the detrimental outcomes for caregivers and the entire family, these negative impacts must be addressed.

Child Characteristics and Caregiver Well-Being

Child and caregiver characteristics as well as ecological factors have been associated with caregiver well-being. Specifically, the stress and challenges associated with a child's ASD (i.e., risk factors) have been shown to affect the caregiver's well-being e.g [8,9]. These risk factors include the severity of the child's ASD, as conceptualized by the basic level of cognitive and language skills, and functional impairments, such as delayed/reduced self-help or adaptive skills, maladaptive behaviors, and impaired social functioning [10]. The severity of ASD has received much empirical attention in terms of how it relates to caregiver adjustment e.g [11], caregiver stress and anxiety e.g [12], the parent-child relationship [13], caregiving demands and pessimism [14], and parental stress proliferation [15]. As noted, the level of language deficit plays a significant role in caregiver well-being. For instance, Beurkens et al. reported that a child's communication skills contribute to 41% of parent-child interactions, and when caregivers have difficulty communicating with their child, they are more likely to report fewer pleasurable or fulfilling interactions. Similarly, Hines, Balandin, and [16] reported that higher-quality communications between caregivers and their children with ASD were associated with more gratifying parent-child relationships.

Caregiver Characteristics and Well-being

When caregivers are faced with stress, coping can be a mediating factor for their well-being and can, thus, serve as a resistance variable. Coping is defined as the strategies utilized by an individual to manage stressful situations [17]. For example, problem solving behaviors have been correlated with less psychological distress in mothers of adolescents with ASD [18] and with better relationships with their children [19]. Information-seeking behaviors and the use of community services also are associated with better adjustment in caregivers [20]. Lee et al. (2012) [21] reported that emotion-focused coping (being optimistic) explained a significant amount of the variance in both health and mental health QOL, while problem-focused coping (seeking social support) explained a significant amount of the variance in mental health QOL only. Dardas and Ahmad (2015) [22] indicated that a positive approach to handling stress by caregivers mediated the relationship between stress and QOL. In addition, social-support coping strategies were found to correlate with better QOL. When it is used as a long-term coping strategy, avoidance increases the caregivers' stress and anxiety levels, thereby adversely affecting caregivers' mental health [23].

Ecological Factors and Caregiver Well-being

Ecological factors can be a source of either risk or resilience.

Stigma, misdiagnoses, need for numerous referrals, and long waitlists for interventions have been found to cause caregivers stress [24] and, thus, are risk variables. In contrast, financial support and help from family members, friends, and community all contribute to better QOL and well-being [25,26,27]. Further, professionals who provide expert information and interventions and who link families to additional services and to other caregivers who may experience similar struggles also benefit caregivers of children with ASD [28].

Better quality of social support and spousal relationships increase the likelihood that caregivers successfully manage the stressors associated with caregiving, particularly in regard to instrumental (e.g., daily living activities, respite) and functioning [27] as well as flexibility in accessing support and intervention [29]. These characteristics thus serve as resistance variables.

Aim of the Study

In this study, we seek to understand the QOL among caregivers of children with ASD by examining the complex interplay between child and caregiver factors that are considered either risk or resistance variables, as postulated by the Risk and Resistance Model of Adjustment [30]. The model identifies risk factors that may hinder a caregiver's adjustment: the disability of the care-recipient, the functional impairment level of the care-recipient, and the psychosocial stressors of the caregivers. The model also identifies resistance factors that can contribute to resilience: stress appraisal, intrapersonal factors, and social-ecological variables. Specifically, we addressed two research questions:

- To what extent do child, caregiver, and ecological risk and resistance variables contribute to caregivers' physical health quality of life?
- To what extent do child, caregiver, and ecological risk and resistance variables contribute to caregivers' mental health quality of life?

Methodology

Participants

A total of 125 caregivers whose children had a primary diagnosis of ASD and whose ages were between 6 and 13 years participated in this study. These children were part of a larger social skills intervention study that took place from 2006 to 2014 through two autism and developmental disabilities centers on the east coast of the United States. The demographic information of parents (caregivers) and children with ASD is presented in (Table 1). Among the 125 caregivers, 118 were female and 7 were male. Their mean age was 41.0 years (SD = 6.8), 82.4% were married, and 89.6% identified as White. The average years of formal education was 15.9 (SD = 2.5), 56.0% reported having a joint family income of >US\$70,000, and 58.4% reported their perceived Socioeconomic

Status (SES) as middle class. For children with ASD, the mean age was 9 years (SD = 1.7). In terms of perceived severity of their child’s ASD, 36.8% rated it as “moderately severe,” followed by 20% as “somewhat severe,” 19.5% as a “little severe,” 15.4% as “quite severe,” and 7.3% as “very severe.”

Variable	Caregivers		Children	
	n	%	n	%
Gender				
Female	118	94.4	14	11.2
Male	7	5.6	111	88.8
Child’s formal diagnosis				
Asperger’s syndrome			70	56.0
PDD-NOS			34	27.2
High-functioning autism			11	8.8
Autism spectrum disorder			10	8.0
Marital status				
Married	103	82.4		
Never married	6	4.8		
Divorced	5	4.0		
Cohabiting	4	3.2		
Separated	4	3.2		
Engaged	2	1.6		
Widowed	1	0.8		
Ethnicity				
White	112	89.6		
Black	3	2.4		
Asian	2	1.6		
Hispanic	2	1.6		
Other	6	4.8		
Family income				
<\$20,000	4	3.2		
\$20,001-30,000	8	6.4		
\$30,001-40,000	6	4.8		
\$40,001-50,000	13	10.4		
\$50,001-60,000	9	7.2		
\$60,001-70,000	15	12.0		
\$70,001+	70	56.0		
Perceived SES				
Below poverty	7	5.6		
Lower middle	20	16.0		
Middle	73	58.4		
Upper middle	24	19.2		
Affluent	1	0.8		
Having a health disability	20	16.0		
Having a psychological disability	61	48.8		

Table 1: Demographics of Caregivers and Children with ASD (N = 250).

Power

An a priori power analysis was conducted, using G*Power 3.1.3 software [31], to estimate the sample size, with the criteria of an alpha of .05 (2-tailed), r² of .09 (i.e., multiple correlations of r=.30) of medium effect size, and seven predictors. The targeted sample size was 181; thus, the current study was underpowered. A post hoc power analysis was conducted which estimated power of the current study was 58% [32].

Procedures

All caregiver participants were recruited from the social skills intervention programs in which their children participated. Prior to the initiation of the intervention, caregivers were approached and presented with an opportunity to participate. Participants signed informed consent forms and were given packets of surveys to complete two weeks prior to the initiation of the child’s intervention program. The accuracy of the children’s diagnosis was confirmed via a multiple-gate procedure [33]. All participants received a \$20 gift card as compensation for completing the packet. Participants who returned packets with missing data were contacted to complete the data set.

Measures

Mos 36-Item Short-Form Health Survey (SF 36): The SF 36 is a 36-item, self-reported inventory that assesses health-related QOL [34]. The measure comprises Likert-type scales with a variety of descriptors and contains two higher-order summary scores (Physical Health Summary and Mental Health Summary). For this study, both summary scores were used to conceptualize the well-being of caregivers.

Wechsler Intelligence Scale for Children-Fourth Edition, Short-Form (WISC-IV SF): The WISC-IV is a measure of the intelligence of children from 6 to 16 years of age [35]. For this study, the total short-form composite was used to conceptualize children’s basic cognitive skills. The methods provided by [36] were used to calculate the deviation quotient, based on standardization information in the WISC-IV technical manual [35].

Comprehensive Assessment of Spoken Language (CASL): The CASL assesses oral language knowledge and processing skills for children from 3 to 21 years of age [37]. The CASL battery of 15 tests assesses comprehension, expression, and retrieval in four language categories. The total score is used to conceptualize children’s basic language skill.

The Social Responsiveness Scale (SRS): The 65-item SRS assesses ASD-related social functioning of children from 4 to 18 years of age as rated by caregivers and teachers [38]. Each item is rated on a Likert scale (1 = not true, 2 = sometimes true, 3 = often true, and 4 = almost always true). The total score is used to conceptualize the impairment of children’s social functioning.

Behavioral Assessment System for Children-Second Edition-Parent Rating Scale-Child Form (BASC-2-PRS-C): The 160-item BASC-2-PRS-C contains items that provide a description of the behaviors of the child. Each item is rated on a 4-point Likert scale (0 = never, 1 = sometimes, 2 = often, 3 = always) by the child’s parent [39]. For the adaptive scales, scores between 31 and 40 are considered in the “at-risk” range, while scores of 30 and below are in the “clinically significant” range. The adaptive skills composite is used to conceptualize children’s adaptive functioning.

Parenting Stress Inventory-Short-Form (PSI-SF): The PSI-SF [40] is a 36-item self-report inventory that assesses an individual’s perceived level of parenting-related stress. Each item is rated on a 5-point Likert scale (1 = strongly disagree, 2 = disagree, 3 = not sure, 4 = agree, and 5 = strongly agree). The total score is used to conceptualize the stress level of caregivers.

Family Crisis Oriented Personal Evaluation Scale (FCOPES). The FCOPES [41] is a 30-item, self-report inventory that assesses the problem-solving attitudes and behaviors developed by families in response to problems or difficulties. Each item is rated based on a 5-point Likert scale (1 = strongly disagree, 2 = moderately disagree, 3 = neither disagree nor agree, 4 = moderately agree, and 5 = strongly agree). The total score is used to conceptualize caregivers’ level of coping.

Family Inventory of Resources for Management (FIRM): The FIRM is a 69-item, self-report measure that assesses the social, psychological, community, and financial resources that are recognized by families as available resources to help them with their family lives [42]. Each item is rated on a 4-point Likert scale (0 = not at all, 1 = minimally; 2 = moderately, and 3 = very well). The total score is used to conceptualize caregivers’ level of support.

Data Analysis

Data analyses were conducted with SPSS, Version 21. Each measure was checked for missing data by a research assistant, and clarification with the parents was performed if missing data existed. As a result, there were no missing data. Two hierarchical regression analyses (one for health QOL and one for mental health QOL) were conducted to determine the relationship between risk and resistance factors and QOL. Total R², and total R² adjusted for the complete regression model with all predictor variables included were assessed, using simultaneous regressions. To determine the incremental variance contributed by risk and resistance factors, the theoretically-ordered variables were entered in separate steps and assessed using hierarchical regression. Step 1 involved significant caregiver demographics (age, ethnicity, years of education, household income, presence of health and/or psychological disability).

Step 2 used children’s basic cognitive and language skills. Step 3 involved child’s level of adaptive and social functioning. Step

4 used caregiver stress, appraisal/coping, and ecological variable resources/support. The R² change was assessed at each step to examine the significance of additional variance accounted by each variable above and beyond the sets of variables entered earlier.

Results

Descriptive Statistics

Descriptive statistics include the means and standard deviations for caregivers and children. These are presented for each scale in (Table 2).

Scale	Caregivers		Children	
	Mean	SD	Mean	SD
PSI-SF Total	100.73	20.02		
FCOPES Total	93.70	14.55		
FIRM Total	203.12	41.00		
SF 36 Physical Summary Score	76.80	16.80		
SF 36 Mental Summary Score	65.85	20.12		
WISC-IV Short Form IQ Total			105.75	14.21
CASL Total			101.97	15.66
SRS Composite			83.74	12.24
BASC-2 Adaptive Skills Composite			32.70	7.46

Table 2: Means and Standard Deviations of Studied Variables (N = 125).

Note: PSI-SF = Parenting Stress Inventory-Short Form; FCOPES = Family Crisis Oriented Personal Evaluation Scale; FIRM = Family Inventory of Resources for Management; SF 36 = MOS 36 Short-Form Health Survey; WISC-IV SF = Wechsler Intelligence Scale for Children, Fourth Edition-Short Form; CASL = Comprehensive Assessment of Spoken Language; SRS = Social Responsiveness Scale; BASC-2 = Behavior Assessment System for Children-Second Edition.

Correlations among demographic, caregiver-, and child-related variables are reported in (Table 3). Caregivers who have more support are more likely to be married, White, and have a higher income and perceived SES. They are less likely to have a health disability and more likely to perceive their child’s ASD symptoms as less severe. The higher amount of support reported, the more positive the caregiver appraisal and coping skills. The higher the child’s social skills impairment, the more severe the child’s ASD and lower adaptive skills; this also was related to caregivers’ having a psychological disability, higher levels of

stress, and lower levels of support. Children's having a higher level of adaptive functioning was related to less severe ASD symptoms, as well as caregivers' reporting having less psychological disability, a lower level of stress, and a higher level of support.

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	
1 Child age																								
2 Child gender	.025																							
3 Child ethnicity	-.082	.142																						
4 Caregiver gender	.097	.086	-.050																					
5 Caregiver age	.265**	.080	-.031	-.180*																				
6 Marital status	.108	-.135	-.030	.093	-.119																			
7 Caregiver ethnicity	-.018	-.081	.757**	-.125	-.088	.063																		
8 Caregiver education (years)	.050	-.119	-.099	.039	.005	-.132	-.038																	
9 Household income	-.012	-.049	-.171	-.077	.277**	-.429**	-.122	.269**																
10 Perceived SES	-.039	-.049	-.206*	-.065	.205	-.339**	-.195*	.293**	.707**															
11 Health disability	.039	-.086	.081	-.178*	.155	.148	.184*	-.219*	-.159	-.189*														
12 Psychol. disability	-.058	.110	-.029	.099	-.079	.090	.47	.007	-.135	-.126	.098													
13 No. of children	-.020	.010	.113	.064	.239**	-.144	.049	-.212*	.021	-.019	.156	-.043												
14 No. of Children w/disability	-.034	-.081	-.025	.033	.013	-.077	.034	-.100	.102	.026	.226*	-.044	.292**											
15 Severity of ASD	-.075	.069	.174	.028	.029	.042	.113	.061	-.112	-.173	-.040	.188*	-.011	-.178*										
16 WISC-IV SF	.025	.051	.188*	-.039	-.119	-.115	.176	.019	.066	.014	-.101	-.088	-.023	-.025	-.103									
17 CASL Total	.035	-.002	.150	-.116	-.167	-.032	.094	.060	.019	-.055	-.059	-.066	-.100	-.059	-.066	.739**								
18 SRS Composite	-.076	.153	.097	-.051	.040	-.061	.063	-.009	-.016	-.028	-.032	.191*	-.034	.077	.415**	-.207*	-.099							
19 BASC-2 adaptive skills composite	.081	.134	-.117	.051	-.006	.064	-.132	-.089	-.003	.060	-.030	-.176*	-.068	-.077	-.426**	.076	.018	-.670**						
20 PSI-SF Total	.064	.032	-.197*	-.127	.066	-.045	-.015	.120	-.012	-.071	.057	.190*	.086	-.078	.068	-.118	-.099	.247**	-.283**					
21 FCOPES Total	-.019	.051	-.090	.002	.020	.170	-.158	-.089	.113	.096	.033	.043	-.176	.006	-.092	.012	.040	-.019	.152	-.095				
22 FIRM Total	.002	.081	-.267**	-.073	.105	-.187*	-.374**	.164	.493**	.511**	-.222*	-.168	.030	.012	-.235**	-.009	-.086	-.197*	.274**	-.093	.374**			
23 SF 36 Physical QOL	-.054	-.061	-.095	.069	-.196*	-.184*	-.176*	.209*	.193*	.129	-.310**	-.248**	-.219*	-.105	-.129	.146	.104	-.158	.167	-.046	.050	.240**		
24 SF 36 Mental QOL	.084	.062	-.064	.053	.004	-.025	-.169	.027	.175	.189*	-.239**	-.332**	-.229	-.229*	-.203*	.069	.059	-.287**	.324**	-.120	.173	.423**	.593**	

Note: CASL = Comprehensive Assessment of Spoken Language; WISC-IV SF = Wechsler Intelligence Scale for Children, Fourth Edition-Short Form; SRS = Social Responsiveness Scale; BASC-2 = Behavior Assessment System for Children-Second Edition; PSI-SF = Parenting Stress Inventory-Short Form; FCOPES = Family Crisis Oriented Personal Evaluation Scale; FIRM = Family Inventory of Resources for Management; SF 36 = MOS 36-Item Short-Form Health Survey.

*p < .05, **p < .01

Table 3: Correlations of Child-related Variables and Caregiver-related Variables (N = 250).

The caregivers' health QOL correlated with various caregiver demographic variables, suggesting that caregivers are more likely to report having better physical health if they are younger, married, and White; have fewer children, more years of education, and higher income; and do not have any physical or mental health disabilities. Caregivers were more likely to report having better mental health if they had higher SES, fewer health or psychological disabilities, fewer children, and fewer children with a disability; and perceived their

child’s overall ASD symptoms to be less severe. Caregivers have better mental health when they have better physical health and more support and their children have better social and adaptive skills.

Research Question 1: Health QOL

In Step 1, caregiver demographics (age, ethnicity, years of education, household income, presence of health, and psychological disability) accounted for 24.8% of the variance for health QOL [F (6,118) = 6.486; p = .000] (Table 4). Among those variables, age ($\beta = -.243, p < .01$), psychological disability ($\beta = -.228, p < .01$), and ethnicity ($\beta = .184, p < .05$) were significant individual predictors. These results suggested that caregivers were more likely to have a poorer health QOL when they were older, are a minority, or have psychological disabilities. In Step 2, the child’s cognitive and language skills was found to contribute to an additional but nonsignificant 1.1% of the variance [F (2,116) = .824; p = .441] of caregivers’ health QOL. In Step 3, the child’s functioning levels, in terms of adaptive and social functioning, contributed to an additional but nonsignificant amount of variance (1.4%); [F (2,114) = 1.105; p = .335] of their health QOL. In Step 4, caregiver-related psychosocial variables (stress, coping, and support) contributed to an additional but nonsignificant .4% of the variance [F (3,111) = .187; p = .905] of caregivers’ health QOL.

Step	Variable Set	R ²	Adjusted R ²	ΔR^2	F change (df)	Δ p-value
1	Caregiver demographics	.248	.210	.248	6.486 (6,118)	.000**
	Individual variables	β	SE _b	β	T	p-value
	Age	-.597	.210	-.243	-2.842	.005**
	Ethnicity	12.598	5.997	.184	2.101	.038*
	Years of education	.901	.588	.131	1.532	.128
	Household income	1.023	.806	.115	1.270	.207
	Health issues	-6.456	4.052	-.141	-1.593	.114
	Psychological issues	-7.641	2.721	-.228	-2.808	.006**
	Variable Set	R ²	Adjusted R ²	ΔR^2	F change (df)	Δ p-value
2	Child’s basic skills	.259	.207	.011	.824 (2,116)	.441
	Individual variables	β	SE _b	β	T	p-value
	WISC	.165	.143	.140	1.154	.251
	CASL	-.059	.129	-.055	-.462	.645
	Variable set	R ²	Adjusted R ²	ΔR^2	F change (df)	Δ p-value
3	Child’s functions	.273	.209	.014	1.103 (2, 114)	.333
	Individual variables	β	SE _b	β	T	p-value
	WISC	.144	.147	.122	.982	.328
	CASL	-.048	.129	-.044	-.368	.714
	SRS	-.099	.155	-.006	-.057	.954
	BASC-2	.265	.248	.118	1.070	.287
	Variable set	R ²	Adjusted R ²	ΔR^2	F change (df)	Δ p-value
4	Caregivers’ psychosocial issues	.276	.192	.004	.187 (3, 111)	.905
	Individual variables	β	SE _b	β	T	p-value
	WISC	1.147	.149	.124	.988	.325
	CASL	-.048	.133	-.045	-.366	.715
	SRS	-.023	.158	-.017	-.145	.885
	BASC-2	.274	.261	.122	1.049	.297

	PSI	.048	.073	.057	.662	.509
	FCOPES	.041	.105	.035	.387	.700
	FIRM	-.003	.047	-.008	-.072	.942

Note: CASL = Comprehensive Assessment of Spoken Language; WISC-IV SF = Wechsler Intelligence Scale for Children, Fourth Edition-Short Form; SRS = Social Responsiveness Scale; BASC-2 = Behavior Assessment System for Children-Second Edition; PSI-SF = Parenting Stress Inventory-Short Form; FCOPES = Family Crisis Oriented Personal Evaluation Scale; FIRM = Family Inventory of Resources for Management; SF 36 = MOS 36-Item Short-Form Health Survey. b = unstandardized estimate, SE_b = standard error, β = standardized.
*p < 0.05 (one-tailed), **p < 0.01 (one-tailed)

Table 4: Hierarchical Regression Analyses of Physical Health QOL (N = 250).

Research Question 2: Mental Health QOL

In Step 1, caregivers' demographics (perceived SES, presence of a health or psychological disability, number of children in the family, number of children with a disability, and the caregivers' perceived level of their child's ASD severity) accounted for a significant amount of variance (26.4%) associated with the caregivers' mental health QOL [F (6,118) = 7.040; p = .000] (Table 5).

Four of the variables were significant: psychological disability (β = -.289, p < .001), number of children with a disability (β = -.202, p < .05), perceived severity of child's ASD (β = -.173, p < .05), and number of children in the family (β = -.164, p < .05). Thus, caregivers had poorer mental health QOL when they experienced a psychological disability, had more children, had more children with a disability, and when they perceived their child's ASD as more severe. In Step 2, the children's basic skills (cognitive and language skills) [F (2,116) = .003; p = .0.997] contributed no further variance and, thus, do not contribute to the caregiver's mental health QOL. In Step 3, children's level of impaired functioning (social and adaptive functioning) contributed to a small but significant additional 4.1% of the variance [F (2, 114) = 3.352; p = .039], suggesting that, when caregivers' demographic variables and children's ASD severity were controlled for, their level of adaptive and social functioning contributed significantly to caregivers' mental health QOL. In Step 4, caregivers' psychosocial variables (stress, coping, and resources) contributed to a significant and additional 7.9% of the variance [F (3,111) = 4.745; p = .004] of mental health QOL, with social support as a significant variable, (β = .328, p < .01).

Step	Variable Set	R ²	Adjusted R ²	ΔR ²	F change (df)	Δ p-value
1	Caregiver demographics	.264	.226	.264	7.040 (6,118)	.000**
	Individual variables	B	SE _b	β	T	p-value
	Number of children	-2.695	1.362	-.164	-1.979	.050*
	Perceived SES	2.676	2.113	.104	1.267	.208
	Health issues	-7.094	4.573	-.130	-1.551	.124
	Psychological issues	-11.588	3.263	-.289	-3.552	.001**
	No. of children with a disability	-5.215	2.218	-.202	-2.351	.020*
	Perceived ASD severity	-3.009	1.445	-.173	-2.082	.040*
2	Child's basic skills	.264	.213	.000	.003 (2,116)	.997
	Individual variables	B	SE _b	β	T	p-value
	WISC	.013	.170	.009	.074	.941
	CASL	-.011	.154	-.009	-.074	.941
	Variable set	R ²	Adjusted R ²	ΔR ²	F change (df)	Δ p-value
3	Child's functions	.305	.244	.041	3.352 (2, 114)	.039*
	Individual variables	B	SE _b	β	T	p-value
	WISC	-.047	.170	-.033	-.275	.784

	CASL	.026	.152	.020	.169	.866
	SRS	-.189	.184	-.115	-1.028	.306
	BASC-2	.383	.295	.142	1.297	.197
	Variable set	R ²	Adjusted R ²	ΔR ²	F change (df)	Δ p-value
4	Caregivers' psychosocial	.384	.311	.079	4.745 (3, 111)	.004**
	Individual variables	B	SE _b	β	T	p-value
	WISC	-.042	.162	-.029	-.257	.798
	CASL	.054	.146	.042	.372	.711
	SRS	-.185	.178	-.113	-.104	.301
	BASC-2	.198	.292	.073	.679	.499
	PSI	.019	.082	.019	.237	.813
	FCOPES	.052	.116	.038	.450	.653
	FIRM	.161	.050	.328	3.248	.002**
<p>Note. CASL = Comprehensive Assessment of Spoken Language; WISC-IV SF = Wechsler Intelligence Scale for Children, Fourth Edition-Short Form; SRS = Social Responsiveness Scale; BASC-2 = Behavior Assessment System for Children, Second Edition; PSI-SF = Parenting Stress Inventory-Short Form; FCOPES = Family Crisis Oriented Personal Evaluation Scale; FIRM = Family Inventory of Resources for Management; SF 36 = MOS 36-Item Short-Form Health Survey. b = unstandardized estimate, SE_b = standard error, β = standardized. *p < 0.05 (one-tailed), **p < 0.01 (one-tailed)</p>						

Table 5: Hierarchical Regression Analyses of Mental QOL (N = 250).

Discussion

The current study investigated how child-related risk variables (cognitive and language skills, adaptive and social functioning), and caregivers' and ecological risk and resistance variables (stress, coping/appraisal, resource/support) affect the health and mental health QOL of caregivers of children with ASD. The results of this study both supported and deviated from those seen in the literature. First, caregiving for a child with ASD may have differential effects on caregivers' health versus mental health QOL. Second, one ecological variable, i.e., social support/resources, remained a significant individual variable, underscoring the importance of resources. Third, children's severity of ASD, defined by their basic cognitive and language skills, did not affect caregivers' health or mental health QOL but the children's level of impaired functioning as defined by adaptive and social functioning significantly predicted caregivers' mental health.

Differential Effects on Health and Mental Health QOL

The results indicated that none of the studied variables predicted caregivers' health QOL but that a child's functional skills and caregivers' social support/resources predicted caregivers'

mental health QOL. The results of our study were similar to those of [26]. We found that social support accounted for a larger percentage of variance (39.9%) for caregivers' mental health QOL but only 4.3% of health QOL. There are several potential explanations for this finding. First, caregivers in our study tended to be young, with an average age of 41 years. Therefore, their physical health was affected less by aging as compared to older caregivers. Further, chronic exposure to stressors may have a long-term negative impact on the immune system, which ultimately affects one's health [43]. In this regard, longitudinal studies on the long-term impact of chronic stressors would be valuable.

Ecological Variables: Support/Resources

In this study, a high level of caregivers' support correlated significantly with a lower perception of their child's overall ASD severity as well as a higher level of adaptive functioning and social functioning. These results suggest that caregivers who had more support and resources tended to perceive their child with ASD to have less-severe manifestations. Better support and resources for caregivers of children with ASD may have made it easier for them to manage their child's ASD symptoms, which resulted in enhanced adaptive functioning and less social impairment [9].

Further, caregivers who perceived the symptoms of their child with ASD to be severe may experience more difficulty in finding support that would enable them to manage their family stressors and the child's ASD manifestations [9,26]. The results from the hierarchical regression analyses supported the hypotheses that resources and support accounted for a significant amount of variance in the caregivers' mental health QOL. The existing literature is conclusive in showing that caregivers of children with ASD who have access to additional support and resources are less likely to report a high stress level [44] and have better well-being [9,26]. Caregivers in this study were engaged in a parent support group while their children were receiving social skills intervention; thus, having an active intervention and an active support system may have buffered some of the stressors that could lead to mental health difficulties.

Child's Functional Abilities

Research has shown that more-severe ASD symptoms are associated with poorer caregiver outcomes. For instance, family QOL was found to be poorer when the child had lower cognitive functioning [27], while mothers were found to have better mental health when their child with ASD had better nonverbal and verbal communication skills [8]. The results of our study, however, did not support this trend. Perhaps our study was limited by the narrow variance in the children's cognitive and language skills, as 56% of the children were diagnosed with Asperger's syndrome and the full child sample had mean IQ and language scores of 105.75 and 101.97, respectively. More importantly, we contend that children's cognitive ability or ability to verbalize and communicate may not necessarily reflect how much these skills affect their actual functioning. Consistent with prior studies, we found that parental stress, depressive symptoms, and exhaustion were predicted by the child's level of functional impairment [3,9,45].

Rivard et al. reported that the adaptive skills of children with ASD were the strongest predictor of their parents' psychological difficulties but not the child's intellectual abilities or severity of their ASD symptoms. In this regard, the concept of "high functioning" for those with higher IQ and language skills can be misleading. Although these children may require less assistance with basic daily living skills, they may still face tremendous challenges, such as familial expectations for more sophisticated levels of pragmatic and social communicative abilities [3]. Therefore, the use of cognitive and language levels to conceptualize ASD severity is too simplistic; further investigations should determine how having certain cognitive and language skills affects the actual functioning of the child. In conclusion, our results demonstrated that the functional abilities of a child, rather than the severity of the child's ASD condition, played a more significant role in regard to affecting the caregivers, and support and resources continued to remain significant variables. Finally, caregivers' health and

mental health can be affected differently. Further, we found that stress and coping/appraisal did not predict caregivers' QOL. These results were unexpected and were inconsistent with the majority of findings in the literature. We speculate that caregivers' stressors were likely to be moderated by the caregivers' age or mediated by existing engagement in support groups; further, participants reported insignificant variability in the types of coping that they utilized. In addition, there may be other types of coping that may be more helpful for caregivers of children with ASD.

Strengths and Limitations

There are several strengths of the present study. First, to the authors' knowledge, this is one of the few studies that utilized a validated theoretical framework to carefully select variables that affect the well-being outcomes of caregivers of children with ASD. This framework holds that a combination of both risk and resistance variables contribute to one's overall well-being, allowing a broader conceptualization of the complexity of social and behavioral science phenomenon. The second strength of this study was that QOL was operationalized as a multidimensional concept. By understanding caregivers' well-being from physical and mental health dimensions, it became evident that these dimensions can be affected differently by the unique experience of caring for a child with ASD. Several potential limitations should be noted when interpreting the results of the present study. First, the homogeneity of the sample considerably limited the generalizability of the results. The majority of caregivers were White, married females, relatively well educated, and from a relatively high SES. It is likely that caregivers in this study had more financial and social support and were more cognizant of accessing information and interventions for their children with ASD, as compared to those from a lower SES background. In addition, due to the overrepresentation of mothers in this sample, the experience of other caregivers (e.g., fathers, siblings, grandparents) was not captured. Second, the children had a higher level of cognitive and language skills than many children with ASD. As such, it is valuable to understand how the impact of lower-functioning children with ASD may have a different impact on their caregivers' QOL.

Another limitation in this study is related to the measures used. The measures of stress, coping/appraisal, and resources/support may not have exhaustively captured these constructs. As is evident from the literature and the results of our study, certain coping strategies and resources do not contribute significantly to caregivers' health and mental health QOL, and other types of coping and resources may affect their well-being differently. Further, although the current study was designed based on a well-validated adjustment model, there were unique variables that were not included in this study. For instance, other child and disability-related variables (e.g., onset of diagnosis, comorbidities), caregiving variables (e.g., caregiving duration, efficacy, resilience), and ecological variables

(e.g., availability of insurance and intervention, societal attitudes) may affect caregivers' well-being. The conceptualization of health and mental health QOL were only two aspects of an adjustment outcome, and other adjustment outcomes (e.g., psychopathology, marital adjustment, family dynamics and functioning) could be affected differently. In terms of statistical limitations, the sample size was small, given the number of variables included in this study. Further, this cross-sectional study provided only a snapshot of the psychosocial profiles of these caregivers. The use of regression analyses did not allow a causal interpretation of the risk and resistance variables to the adjustment outcomes. Based on these limitations, the results of this study must be interpreted with caution.

Future Research Directions

Future research should include a wider range of caregivers' demographic variables that better capture caregivers of different genders, ethnicities, SES, and incomes. Future studies should include children with more variable cognitive and language skills and adaptive and social functioning levels. This is particularly important, as individuals with "high functioning" ASD may be considered to have fewer issues; however, they still face unique challenges that can hinder their functioning and success in life. Future research should carefully consider the inclusion of other variables guided by the risk and resistance model that may not have been included in the current study. Such variables include other aspects of coping mechanisms; different types of resources and support; intrapersonal variables, such as self-efficacy and motivation; and other socio-ecological variables, such as availability of medical insurance and societal attitudes toward people with ASD. Adjustment outcomes also can be expanded beyond health and mental health QOL to include marital and family functioning. Further, the adjustment of other family members, such as fathers and siblings, and how caregiving may affect the family dynamics need to be examined. A larger sample size and a more heterogeneous sample are recommended to ensure greater variability and increased ability to detect significant effects, particularly because the current study may have shown insignificant results due to low power. A longitudinal design would provide additional insight into the long-term impact on caregivers of raising a child with ASD as well as whether temporal factors may have a differential impact on their physical health and mental health.

Clinical Implications

Based on the findings of this study, there are three overarching themes for working with caregivers of children with ASD. First, clinicians who work with these families should take into consideration the range of variables that could potentially affect caregivers' physical and mental health. Although the child with ASD is the person that requires services, caregivers also have needs. It is important to remember that parents' well-being

indirectly influences a child's well-being via the quality of care that they provide. Therefore, interventions should not only aim to reduce deficits and to improve the child's functioning but also focus on the needs of the caregivers, including the provision of a combination of direct services, such as counseling and skills, and indirect services, such as referral, respite care, and community resources. Second, it is imperative to acknowledge the interplay of challenges and positive attributes and how positive aspects, such as improved coping, better resources, and positive appraisal, can alleviate the stressors associated with caregiving. Clinicians also should be cognizant of the unique stressors and challenges that caregivers face when raising a child with ASD. Such unique stressors and challenges are based on the nature of the ASD condition in terms of basic skill levels and impairments of adaptive and social functioning that children across the spectrum exhibit. In this study, basic cognitive and language skills did not have an impact on the caregivers' QOL. Rather, deficits in adaptive and social skills that affect how the child functions pose stressors for caregivers.

Third, clinicians should understand the diverse and unique nature of coping, perceptions, and resources of caregivers. In this regard, different types of resources and support showed a relationship to different adjustment outcomes, and clinicians need to be aware of other potential factors that may have an impact on the caregivers' well-being.

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