

**Title: Resilience in Family Caregivers of Adults with Autism Spectrum Disorder (ASD)**  
*An Integrative Review of the Literature*

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**INTRO**

- ASD is a lifelong, pervasive, neurodevelopmental disorder
- Family caregivers (FCG) of adults with ASD:
  - Provide lifelong care
  - Are at risk for poor mental health and low quality of life
- Public costs for adults with ASD projected to be \$549 billion by 2025

**METHODS**

- Integrative review methodology (quantitative, qualitative, mixed-methods)
- Comprehensive database and hand search
- PRISMA statement guidelines
- Search end date October 13, 2020

**RESULTS**

- Significant, chronic stress reported by FCGs
- Challenging behaviors of adults with ASD impact social support, coping, and QOL

**DISCUSSION**

Identification of factors associated with and that predict resilience may aid in tailoring assessment tools and interventions

**FINANCIAL DISCLOSURE**

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**Factors positively associated with FCG resilience:**  
 FCG social support, leisure participation, and Care recipient community participation.

**Factors negatively associated with FCG resilience:**  
 FCG burden, depression, anxiety, stress, worry and Care recipient choice-making and external behaviors (lethargy, withdrawal, hyperactivity).

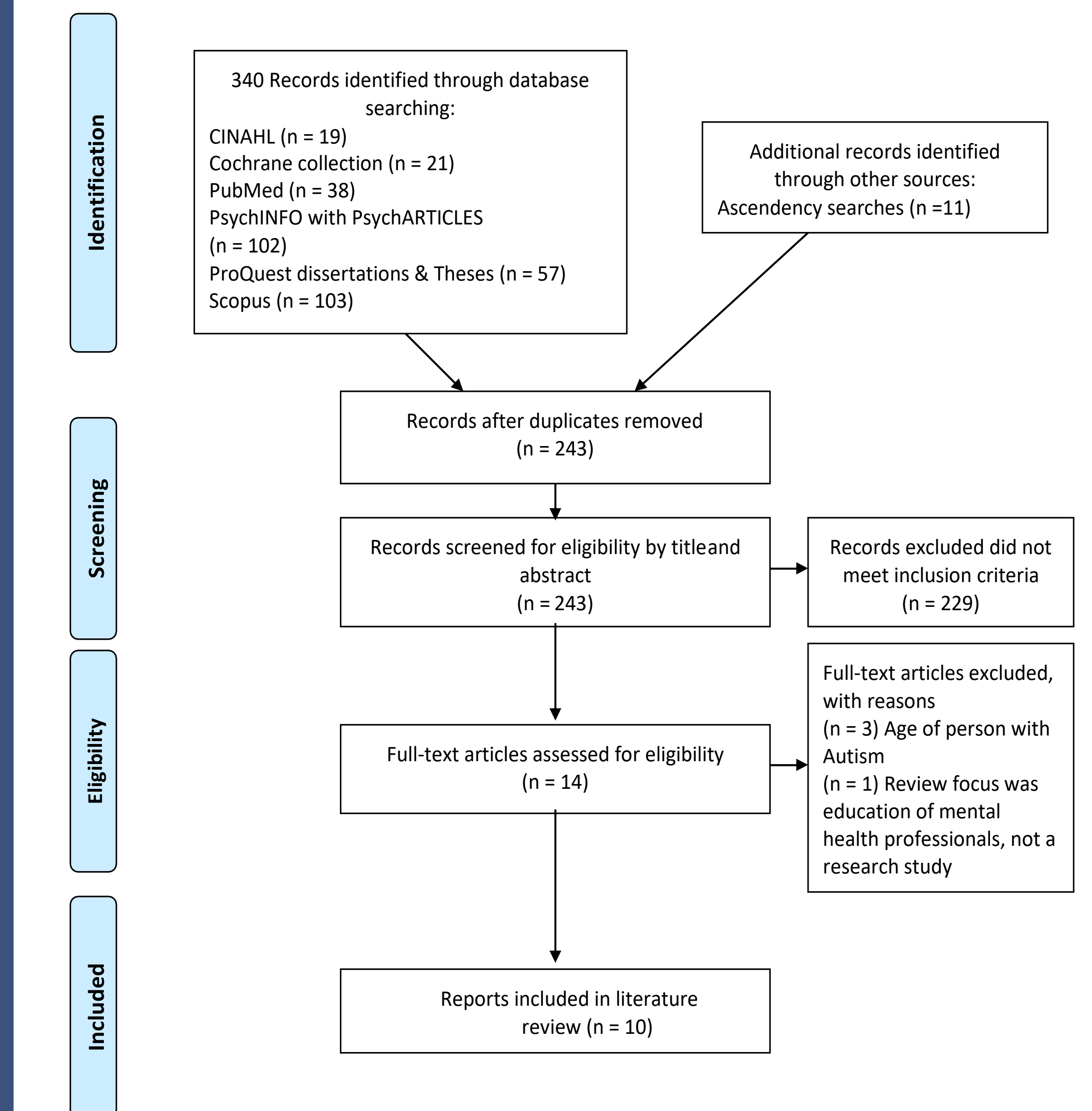
**Search string:** autism or autism spectrum disorder or autistic AND care giver or caregiver or carer or caregiving or care partner or parent or parental AND resilience or resilient or hardiness

References can be viewed at:  
<https://hdl.handle.net/10355/86941>

Figure 1



**PRISMA 2009 Flow Diagram**



Note: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

Factors Associated with and Predictive of Resilience			
Resilience Indicator	Quantitative Studies	Statistical Analysis of Quantitative Variables	Qualitative Studies
Quality of Life	correlates with FCG Depression	$r = -.659, p < .05$	1) FCGs reported positive appraisal of their QOL; 2) Increased leisure participation by accompanying their adult child
	correlates with FCG Anxiety	$r = -.466, p < .05$	
	correlates with FCG Stress	$r = -.518, p < .05$	
	correlates with FCG Worry	$r = -.461, p < .05$	
	FCG Developmental burden predicted QOL	$r^2 = .35, F(4, 315) = 42.05, p < .01, \beta = -.54$	
	FCG health predicted QOL	$r^2 = .17, p < .002; F(1, 309) = 58.14, \beta = .41, p < .001$	
	FCG burden predicted QOL	$r^2 = -.26, \beta = -.52, p < .002$	
Social Support (informal)	Adult with ASD behavior was highest predictor of QOL	lethargy/withdrawal, OR = 2.2, 95% CI 1.2 - 4.3; hyperactivity, OR 3.4, 95% CI 1.7 - 4.1, $p < .0001$ .	Family, church and school important to physical and emotional coping
	FCG social support predicted QOL	$r^2 = -.37, \beta = .41, p < .01$	
Meaning-Focused Coping	correlates with FCG developmental burden	$r = -.45, p < .01$	Family member support helped the FCG to cope physically and emotionally.
	correlates with FCG overall burden	$r = -.37, p < .001$	
Self-efficacy	moderates FCG burden	$F(7, 131) = 13.57, p < .001, \beta = -.46, p < .001$	1) FCGs reported their love and affection reciprocated although not expressible by their loved one; 2) the autism was responsible for aggressive and/or disruptive behaviors by their loved one.
	FCG self-efficacy predicted by increased community involvement, $\beta = .28, p = .006$ , and also by less choice making by the adult with ASD, $\beta = -.32, p = .004$	$r^2 = .109, F = 3.59, p = .009$	

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