

## Introduction

- One in every 59 children in the US has ASD (CDC, 2018)
- Many symptoms of ASD have a profound impact on the daily experience of caregivers/parents
- A groundbreaking study conducted at Johns Hopkins found that caregiving actually increased longevity by 18%. “When caregiving is done willingly, at manageable levels, and with individuals who are capable of expressing gratitude, it is reasonable to expect that health benefits might accrue” (Roth, 2013)
- On the other hand, parents of children with ASD experience higher levels of stress, anxiety/depression, sleep disturbance/fatigue, and perceptions of being stigmatized.

## Health-Related Quality of Life (HRQOL)

The mental and physical health of caregivers is irrevocably linked to outcomes for the recipient of care (such as response to intervention)

Weakened antibody response to flu vaccine, poor neuroendocrine functioning, and higher resting cortisol rates have been found in mothers of children with ASD

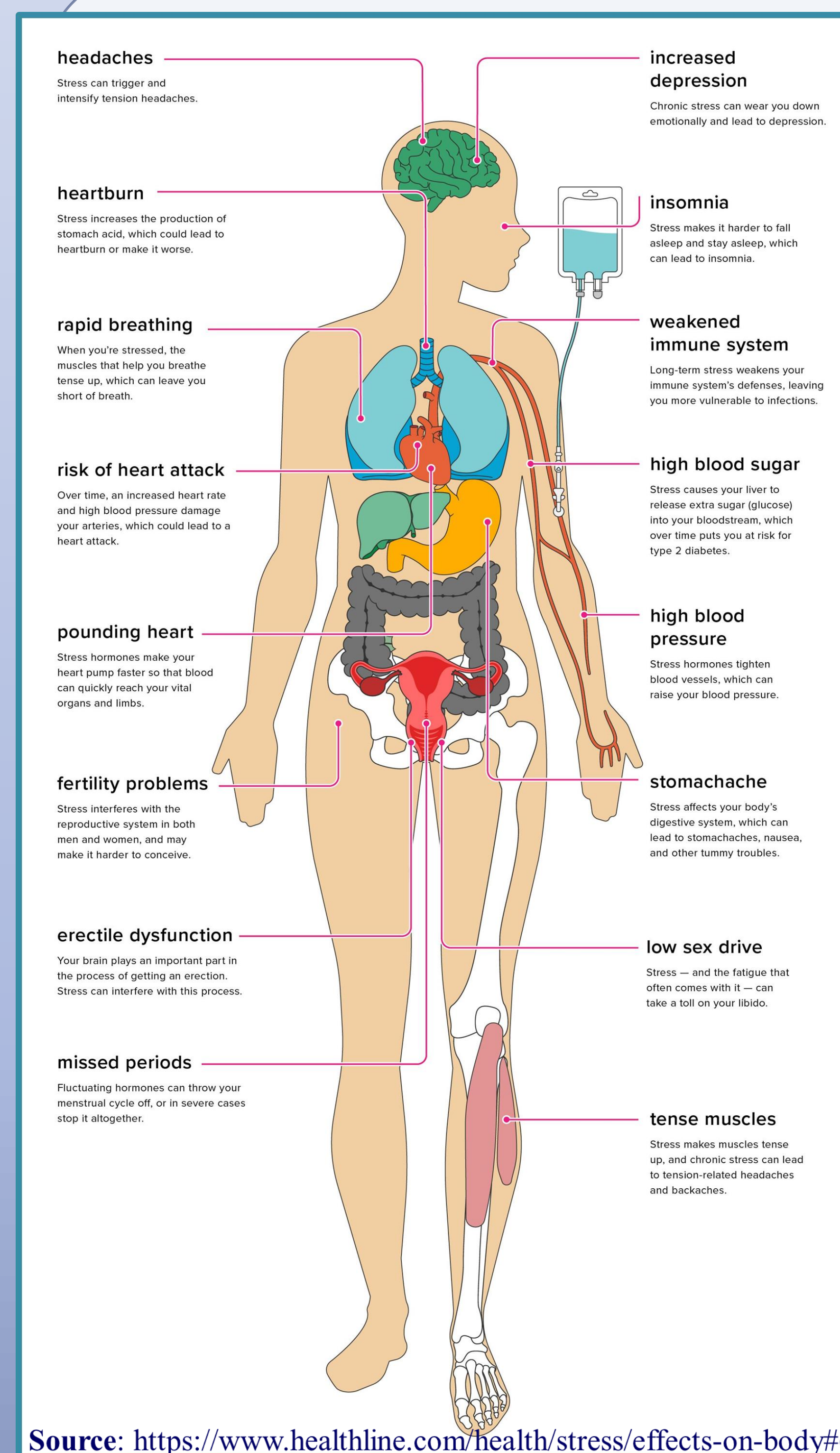
Although some resources such as respite and support groups may be available; many parents feel overwhelmed seeking out these resources or experience other barriers to accessing services

These resources may not be specifically tailored to families of youth with ASD.

There are discrepancies within the literature about what actually impacts HRQOL

Research needs to bridge the gap between services and the needs of parents to make services **desirable** and **accessible**.

HRQOL emphasizes an individual’s perception of his/her functioning and well-being rather than focusing on objective measures of health



Source: <https://www.healthline.com/health/stress/effects-on-body#6>

## Mixed Methods: Quantitative and Qualitative

HRQOL is complex and necessitates a multi-faceted research methodology

**Goals:** (1) to understand quantitatively which variables contribute to HRQOL for parents of children with ASD, (2) to determine qualitatively whether there were domains that were important but were not assessed in the quantitative evaluation, and (3) give voice to the daily lived experience of these individuals by qualitatively capturing a meaningful snapshot of their experience

**Questionnaires:** Zarit Burden Interview (ZBI); The Brief COPE; World Health Organization Quality of Life Scale Brief (WHOQOL-BREF); Positive Aspects of Caregiving Scale (PAC); The Interpersonal Support Evaluation List-12 (ISEL-12)

**Thematic Analysis:** Braun and Clarke (2006)

1. Familiarizing oneself with the data
2. Generating initial codes
3. Searching for themes
4. Reviewing themes
5. Defining and naming themes
6. Producing the scholarly report

## Results

*Hierarchical Regression Analysis Summary for Health-Related Quality of Life for Parents of a Child with ASD Regressed on Gender, Age, Total Annual Household Income, Child's Age, Tangible Social Support, Perceived Burden, and Maladaptive Coping (N = 365)*

Variable	b	SE	$\beta$	R <sup>2</sup>	$\Delta R^2$
<i>Model 1</i>					
Gender (male)	1.13*	.39	.15	.09	.09
Age	-.04*	.02	-.13		
Household income	.17**	.04	.23		
Child's age	.09*	.04	.14		
<i>Model 2</i>					
Gender (male)	.94*	.35	.13	.28	.19
Age	-.04*	.02	-.12		
Household income	.18**	.04	.23		
Child's age	.08*	.04	.12		
Tangible Social Support	.17**	.05	.19		
Burden	-.05**	.01	-.23		
Maladaptive coping	-.08*	.03	-.13		

Note. \* $p < .05$ . \*\* $p < .001$

*Descriptive Data of Continuous Study Variables*

Measure	N	M (SD)
Age	363	42.83 (8.16)
Child's age	365	10.75 (3.99)
Total number of children	365	2.03 (0.98)
Child's age at point of diagnosis with ASD	353	4.18 (2.59)

*Descriptive Data of Categorical Study Variables*

Measure	N	Percentage (%)
Gender	366	
Male	52	14
Female	314	86
Race	364	
Majority (Caucasian)	290	80
Minority	74	20
Marital Status	362	
Single	64	18
Married	298	82
Community Type	360	
Rural	112	31
Suburban	218	61
Urban	30	8
Educational Status	366	
High school degree or less	134	37
College degree	133	36
Graduate degree	99	27

Main themes identified through thematic analysis included social and community support, resources, lack of understanding about ASD demonstrated by others, experiences of the caregiver, caregiver coping strategies, and process of reaching a diagnosis of ASD. See the “lived experience” section for example of sub-themes and quotes. For a full list of qualitative Themes, Subthemes, and Definitions; see paper handout.

## The Lived Experience

- ❖ Research and education as invaluable:

“I just put it in Google and Googled and Googled it. Start talking to people, and then I kept Googling”

- ❖ Acceptance and adaptability:

“After the diagnosis, things of course got worse instead of better.” *She continued with the following:* “You know, within a year it got to be that we weren’t cringing at some of the things anymore. We were, I guess, sort of accepting that he was different. Um, that he just had different ways of expressing himself and of doing things. And of, um, just started to manage things a little bit better.” *Finally, she said:* “We’ve come miles. We have miles to go but things are so much better than they were.”

- ❖ Dissatisfaction with resources

“My child’s pediatrician [...], I thought she was fantastic for the run of the mill pediatric medical issues. But she had no idea about Autism. None. [...] Pediatricians are pretty useless when it comes to Autism.”

- ❖ Strain in Interpersonal Relationships

“Having [...] more than one kid there’s always that feeling of ‘am I giving them all equal time?’, ‘Do they feel equally loved?’ But when you have a special needs kid, there’s a lot of ramp up for me because I started with zero knowledge.”

## The Bottom Line

**Oxygen mask metaphor** – You’ve got to put on your own oxygen mask before helping others with theirs.

**And not just in emergencies!**

If we want to improve the lives of children with ASD we have to consider the health and overall well-being of caregivers.



## Acknowledgements and Contact Info

This project is dedicated to the parents of children with ASD that enthusiastically contributed their time. I can’t thank you enough.

You can reach me with questions or comments by email at [lbeamer@ggc.org](mailto:lbeamer@ggc.org)

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number T73MC22233, Leadership Education in Neurodevelopmental and Related Disorders Training Program. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.