



# Impact of Respite Care Services Availability on Stress, Anxiety and Depression in Military Parents who have a Child on the Autism Spectrum

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## Abstract

**Objective** Parenting an autistic child can affect a family's well-being. Finding resources is critical. This pilot study looked at respite's impact on parental stress, anxiety, and depression in military families and demographic factors associated with presence of respite care.

**Method** Participants completed three surveys on anonymous basis, including two standardized surveys measuring parental stress and anxiety/depression. Data analysis used Chi-square test and regression analysis.

**Results** Parents receiving respite reported less stress and anxiety/depression. Respite utilization was associated with absence of comorbid conditions in child and other variables. Predictor variables for parental stress and anxiety/depression included presence of comorbid conditions in child.

**Conclusion** Respite care may be linked to lower parental stress, anxiety, and depression, but more study is needed.

**Key Phrases** Respite Care · Autism · Military · Stress · Anxiety

## Introduction/Background

### Causes of Parental Stress in Parents with a Child on the Autism Spectrum

Raising a child on the autism spectrum increases risk for parental stress and a variety of parental mental health diagnoses (Hayes & Watson, 2013). These parental risks are higher than raising either typically developing children (Dunn et al., 2001) or children with other chronic medical conditions (Benjak et al., 2009; Bitsika et al., 2004; Micali et al., 2004; Singer, 2006). There has been an increasing amount of research in recent years looking at the specific

factors that increase these risks in parents. (Falk et al., 2014; Sim et al., 2017; Derguy et al., 2016).

Demographic factors, social determinants of health, and other related factors that have been studied to date in families with a child with autism spectrum disorder (ASD) include parents' pre-existing history of mental health problems, socioeconomic status, ethnicity, educational level of the parent or parents, gender of parent, marital status of parent, degree of child's social relatedness, functional impairments of the child, severity of ASD symptoms, presence of other emotional and behavioral problems and neurodevelopmental diagnoses, degree of self-regulation skills for the child with ASD, and presence of a social support system for parents (Hayes & Watson, 2013; Van Steijn et al., 2014; Ekas & Whitman, 2010; Yorke, 2018; Efstratopoulou, 2022; Dunn et al., 2001; Hsiao, 2018; Kim et al., 2020). Medical system-based concerns such as access to care, disparity of services, and perceived parental concerns regarding their health care providers' knowledge of ASD and lack of communication with their provider have also been positively tied to increased parental stress (Bonis, 2016; Smith et al., 2020). Improving parents' perceived social support, parental resilience, and parental efficacy can be impactful

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in reducing emotional/behavioral problems in children with ASD (Hayes & Watson, 2013; Minghui, 2021) which in turn has been tied to reducing stress levels as well as symptoms of anxiety and depression in parents with a child with ASD (Hastings, 2003). While parental perceptions of stress can give good insight into how to best help match these families with correct supports, the specific sources of parental stress need to be addressed as well simultaneously to effect real positive change (Hamlyn-Wright, 2007).

### **Stress Management, Importance of Social Support, and Definition and Benefits of Respite Care**

As the prevalence of autism spectrum disorder increases in the United States (Maenner et al., 2020), the identification of the most effective supports for families becomes more critical so that parents can practice effective stress self-management and in turn bolster parental self-efficacy and resilience. A low level of social support has been found to be a powerful predictor of depression and anxiety in parents with a child with ASD (Boyd, 2002). Social support can be both informal and formal with formal sources of social supports being from medical or community-based organizations and agencies that can provide specific services to aid these families (Boyd, 2002). Parents with a child with ASD who have social supports in place are more likely to implement positive coping strategies and report increased physical and emotional well-being (Mackintosh, 2005; Weiss 2002).

One resource that has been studied in medical literature as a source of social support that can benefit stress, anxiety, and depression in parents with a child with ASD is respite care. Respite care, defined as temporary relief for caregivers (Brenner et al., 2016), reduces parental stress in families raising children with a variety of medical conditions, to include autism spectrum disorder (Eaton, 2008; Whitmore & Snethen, 2018). Respite care allows for a break from the daily demands of caring for a child with special health care needs (Otsuki, 2020). There is evidence in the literature to support that parents of a child with ASD report significant caregiver burden and a major component of that burden is the hours spent per week engaged in direct care for their child, including provision of ongoing support for children with ASD in their activities of daily living (Marsack-Topolewski, 2021). The amount of time spent in direct care increases significantly with lower global adaptive functioning and increased emotional and behavioral regulation concerns for the child with ASD (Salomone, 2018). The potential for emotional burn out is a concern when considering that many of these parents must balance the needs of their special needs children along with all the other responsibilities they manage in family, work, and life (Woodgate et al., 2015). Using more traditional sources of care such

as daycare or babysitters is not an option for many families with a child with ASD due to the complexity of their medical, emotional, and behavioral health needs of the child with ASD (Whitmore, 2018). By providing an opportunity for a parent to engage in self-care activities for their well-being, respite care resources indirectly improve parental emotional and mental resilience and psychological adjustment when managing their spectrum child's behaviors (Krakovich et al., 2016; Remedios et al., 2015). Stability of a parental unit in the home has been positively associated with better family resilience when raising a child with ASD (Sim 2018). To that purpose, respite care has also been found in the literature to help directly improve the stability of the marriage relationship (Harper et al., 2013).

### **Stressors for Military Families with ASD Child**

Active-duty military service creates unique challenges and disruptions for families raising a child with autism spectrum disorder (Davis et al., 2016). These stressors include isolation from the extended family and supports, frequent geographic relocation, frequent temporary duty assignments that take the active duty military parent out of the home for prolonged and repeated periods of time, and wartime deployments with resultant anxiety about the service member's safety and well-being while simultaneously tasking the remaining parent with sole management of household affairs. Stressful experiences, such as maintaining resources needed by a child on the autism spectrum when faced with relocation or separations, potentially impact both individual well-being and the family dynamic (Davis & Finke, 2015; Lester & Flake, 2013).

Studies demonstrate that single parents raising a child with autism spectrum disorder encounter more psychological stress than families with two parents raising a child on the spectrum (McAuliffe et al., 2017). Likewise, there is medical literature that suggests respite care services in a single parent home can significantly improve emotional well-being (Dyches et al., 2016). Single-parent military families have been found in the medical literature to experience similar challenges as single-parent civilian families, such as increased time pressure, economic strain, and family instability (Skomorovsky et al., 2016), but with compiled military specific stressors that active duty military service brings to these families as listed above. The similarities as well between a single-parent civilian home and a military home that also becomes functionally single parented due to military duty requirements taking the active duty military parent out of the home, highlight the need for research on the benefits of respite care for military families raising a child on the autism spectrum disorder spectrum.

## Limitations of Current Military Resources

The United States military has long recognized the burdens carried by families due to the needs of the services. The Exceptional Family Member Program (EFMP) was established by the US Army in 1979 to ensure medical services required by families with special needs could be met prior to reassignment to overseas locations. The Military Family Act of 1985 subsequently led to the gradual establishment of additional support benefits to military services, to include eventual establishment of respite services in response to the escalation of deployment frequency and duration following the events of 9/11. While Department of Defense programs like EFMP exist to limit the frequency of relocations and ensure relocation to locations able to meet the medical needs of special needs military families, they lack standardization across services. Additionally, the availability of potential resources and services, to include respite care services, varies widely between different services and geographic locales. This was highlighted in the May 2018 report published by the Government Accountability Office (GAO) which cautioned that the wide variations in support could potentially lead to gaps in assistance (GAO, 2018).

While there is more available qualitative research on how respite care services improve quality of life for families with a child with ASD, there is a relative paucity of evidence-based medical literature quantifying its impact. A recent review done by Whitmore (2016), for example, included 11 primary research reports examining the impact of respite care services on stress in families with children with ASD. The majority of these included studies in the review did not use standardized screeners with documented internal and external validity and reliability in the medical literature to quantify impact that respite care had on parental stress and none of the included studies looked at the impact respite care services had on reported anxiety and depression symptoms. There is also no research assessing respite care's impact in military families. This pilot study is the first to quantitatively examine the influence respite care services have on the level of perceived parental stress and risk for depression in military parents with a child with autism spectrum disorder. The primary aim was determining the impact of respite care service on the presence and degree of anxiety and depression symptoms in the parents. The secondary purpose was determining the impact of aspects of family/home life or unique diagnostic aspects of the child's autism spectrum disorder on the severity of parental stress and symptoms of anxiety and depression.

## Methods

### Participant Eligibility and Enrollment

This was an anonymous survey-based descriptive pilot study of active-duty military parents with a child with autism spectrum disorder. This study was open to enrollment to all active-duty military families receiving care at two military facilities in the Pacific Northwest, enrolled in the Exceptional Family Member Program (EFMP), and having at least one child with a current Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-5; American Psychiatric Association, 2013) diagnosis of autism spectrum disorder living in the home. As this is a pilot study, a required sample size was not calculated. An estimation of the potential population of interest was calculated, however, from 2019 EFMP enrollment data. Of the 4000 families enrolled in EFMP locally, approximately 15% (600 patients) carried an active diagnosis of autism spectrum disorder spectrum disorder (International Classification of Diseases, Tenth Revision; ICD-10 code: F84.0). An Institutional Review Board (IRB) reviewed the protocol for this study in its entirety and gave approval to the principal investigator prior to the start of this study.

### Study Design

Packets containing three different surveys were distributed to the caregiver for completion. Parents and caregivers who met enrollment criteria were recruited to this study by designated administrative and professional staff working in the Developmental Behavioral Pediatric/Neurodevelopmental Pediatric Clinics at each facility involved in the study. Eligible parents and caregivers were also recruited by EFMP System Navigators who work with military families on accessing available resources. Surveys were handed out in person by staff upon check-in for patient visit after EFMP status was confirmed along with presence of at least one child in the home with an active ASD diagnosis. Surveys were also emailed securely by EFMP System Navigator staff who worked hand in hand with these families on resource management after confirmation of presence of at least one child in the home with ASD and EFMP enrollment. Packets that were handed out in clinic were completed by family and given to administrative staff before leaving the facility that day. EFMP System Navigators who emailed families survey packets collected completed survey packets by secure email from families. Consent for participation in this study was implied by voluntary completion of the survey packets and this voluntary choice was outlined in detail for parents and caregivers on the Research Study Cover Page/Information sheet included with each survey packet.

Surveys included a self-created demographic survey, the Perceived Stress Scale-10 (PSS-10) (Cohen, 1988), and the Patient Health Questionnaire-4 (PHQ-4) (Kroenke, 2009). Details and instructions on how to complete each of the surveys was included for parents/caregivers who voluntarily completed the survey packets. Eligible parents and caregivers were instructed directly as well to complete the survey packet only once, regardless of how many children they had with autism spectrum disorder. Lists of parent names who had completed survey were kept by the administrative staff who were responsible for handing out survey packets to avoid families completing survey more than once. These lists were maintained independently and not associated with the specific results of the survey packets, were maintained securely by these staff members, and were not accessible by the principal investigator of the study to maintain anonymity of study design. Only the principal investigator for this study compiled demographic data and scored questionnaires from these completed survey packets. The goal was to make 100% contact with all eligible families for the study based on population estimate calculated from 2019 EFMP data. As 119 families returned completed survey packets and there were 600 eligible families for the study, this reflected a survey return rate of 19.8%.

The demographic survey was developed by the principal investigator for this study using available knowledge from evidence-based literature regarding demographic factors connected with increased stress, anxiety, and depression symptoms in parents raising a child with autism spectrum disorder (Hsiao, 2018) (see Appendix 1). In designing the questionnaire, the principal investigator did employ best practice guidelines in writing survey questions, including writing survey questions that were short, concise, and specific, keeping questions free of bias, arranging questions in logical order without influencing responder, and ensuring response options for closed-ended questions were mutually exclusive. The survey included questions on the makeup of the home, the presence of military specific stressors, parental psychological health and wellbeing, and specific details related to the child's autism spectrum disorder diagnosis and comorbid conditions. The parental psychological health and well-being questions included questions regarding a parental history of treatment for anxiety or depression, as well as mitigating or protective measures such as participation in self-care activities for their own mental and emotional well-being. The comorbid medical, neurodevelopmental, and behavioral conditions enumerated on the survey included attention deficit hyperactivity disorder (ADHD), anxiety disorder, depression, or mood disorder, genetic or chromosomal disorder, sleep disorder or insomnia, global developmental delay, intellectual disability, and specific learning disabilities. Parents were also given a choice of "Other"

for this question if there were other chronic medical conditions of note for their child. For families with more than one child with autism spectrum disorder, the parent was directed on both the Research Study Cover Page/Information Sheet included with each survey packet and on the demographic survey itself to complete the questionnaire only once as stated above and to consider the child with the most severe autism spectrum disorder symptoms when answering questions regarding specifics related to the autism spectrum disorder diagnosis.

## Selection of Study Outcome Measures

Selection priorities for the standardized questionnaires used in this study included: (1) brevity of the scale, (2) good internal and external validity and reliability of the scale demonstrated in evidence-based medicine studies, and (3) open permission for use of the scales. Additionally, specific questions regarding suicidal or homicidal ideation were avoided as these would pose a critical ethical conflict in an anonymous survey study. Parents were provided multiple civilian and military mental health resources on the Research Study Cover Page/Information Sheet included with each survey packet. These resources were all freely available on a self-referral basis, and readily accessible if concerns regarding significant anxiety/depression symptoms were elicited and parents wanted support and help.

The PSS-10 is a quantitative measure that utilizes a five-point Likert-type scale (1 = never, 2 = rarely, 3 = sometimes, 4 = often, and 5 = always with reversal of scores on the four positive items, e.g., 0 = 4, 1 = 3, 2 = 2, etc.) and then summing across all 10 items. Items 4, 5, 7, and 8 are the positively stated items. Scores ranging from 0 to 13 would be considered low stress, scores ranging from 14 to 26 would be considered moderate stress, and scores ranging from 27 to 40 would be considered high perceived stress. The PSS-10 has been well-validated in the medical literature (Cohen & Williamson, 1988; Cohen & Janicki-Deverts, 2012; Lee, 2012). The PSS-10 possesses adequate internal consistency (Roberti et al., 2006; Denovan et al., 2019), moderate convergent validity with stressful life events (e.g., Mitchell et al., 2008), and good concurrent validity with mental health problems such as depression and anxiety (Baik et al., 2019). The 4-item Patient Health Questionnaire-4 (PHQ-4) is an ultra-brief self-report questionnaire that consists of a 2-item depression scale (Patient Health Questionnaire-2 or PHQ-2) and a 2-item anxiety scale (Generalized Anxiety Disorder 2-item or GAD-2). The PHQ-4 likewise utilizes a four-point Likert-type scale (0 = not at all, 1 = several days, 2 = more than half the days, 3 = nearly every day). PHQ-4 total score ranges from 0 to 12, with categories of psychological distress being: None (0–2), Mild (3–5), Moderate (6–8), and

Severe (9–12). The PHQ-4 has also been well validated in the medical literature (Kroenke et al., 2009; Löwe 2010). Studies have demonstrated that the PHQ-4 is a valid tool for detecting both anxiety and depressive disorders with both good internal reliability as well as construct validity and factorial validity (Kroenke et al., 2009).

### Procedure for Survey and Data Collection

Survey packets were collected on a rolling basis for a period of eight months from January–September 2020. The survey packets were not piloted prior to distribution for the study. Packets were collected, de-identified and securely stored by administrative staff members and then provided to the principal investigator (PI) for data collation. Responses, including demographic variables (Table 1) and PSS-10 and PHQ-4 scores, were tabulated in a spreadsheet for data analysis utilizing the Statistical Package for Social Sciences (SPSS) Software (version 24). Raw data was checked by the investigators of this study for reliability with test-retest method when inputted into SPSS. Outliers were included in data analysis. An independent samples test was first performed on the means of the PHQ-4 and PSS-10 scores, depending on presence or absence of respite care and it was found that data could not be treated normatively for data analysis. PSS-10 and PHQ-4 scores were identified as the dependent variables for data analysis; while eleven demographic variables were identified as independent predictor variables with the potential to confound the analysis or critically impact the PSS-10 and PHQ-4 scores (Table 2). These independent predictor variables were selected a priori by the principal investigator of the study using theoretical deduction as well as available medical literature of the demographic variables most associated with parental stress, anxiety, and depression with a child with ASD (Hsiao, 2018; Bonis, 2016).

Chi-square tests of association were done that identified statistically significant associations between the presence of respite services and the other predictor variables. A multivariate ordinal logistic regression analysis was utilized to calculate the strength of effect of each critical independent predictor variable on the two dependent outcome measures for this study (PHQ-4 and PSS-10 scores). Multi-collinearity was assessed using standardized beta coefficients. P-values of less than 0.05 were regarded as statistically significant.

## Results

### Sample Population and Missing Data

A total of 119 survey packets were collected over the eight-month period. Frequency distribution of all the demographic

variables collected from the parent surveys, including the critical demographic (independent) variables of the 119 survey respondents is summarized in Table 1. The eleven identified critical demographic (independent) variables and two dependent variables are listed in Table 2. Among the survey study participants ( $n = 119$ ), there was no missing data for scores from any of the outcome measures (PHQ-4 and PSS-10 questionnaires). There likewise was no missing data for any of the predictor variables except for “Severity of Autism” where 34 (28.6%) of the 119 parents reported their child’s level of autism as “Unknown.” Only 85 responses, therefore, as supposed to 119 responses, were included in data analysis for “Severity of Autism.”

### Frequency Distribution of Demographic Variables

Notably only 27 families (22.7%) reported the presence of respite care services in the home. Additionally, 34 families (28.6%) had 2 or more children with autism spectrum disorder diagnoses, 99 families (83.2%) reported their child with autism spectrum disorder had other comorbid conditions, and over one-third (37.8%) had three or more children total in their home. Most of the families surveyed were comprised of a two parent home with one military spouse and one civilian spouse (84.2%) and were Army families (76.4%). In terms of ethnicity, 61.3% of the parents who completed survey packets identified as Caucasian/White for ethnicity. Over 80% of the parents reported at least having completed some college in terms of education level. The vast majority of the ASD children in the study had the presence of a comorbid medical or behavioral diagnosis (83.19%). Over half (52.90%) of parents reported a history of anxiety and/or depression treatment for themselves within the last five years of completing the survey. Frequency distributions were also calculated for both of the outcome (dependent) variables (see Table 3; Fig. 1, and Fig. 2).

### Results of Chi-Square Calculations Between Predictor Variables

Statistical relationships and chi square calculations between the presence of respite services and other identified critical predictor variables are presented in Table 4. Respite care presence was associated with higher level of military rank ( $p < 0.001$ ), higher parent education level ( $p = 0.006$ ), more children in the home ( $p = 0.013$ ), ethnicity ( $p = 0.0410$ ), and lack of comorbid conditions ( $p = 0.001$ ). Statistical significance was found between receipt of respite services and these five predictor variables.

**Table 1** Frequency Distribution of Predictor Variables and Other Demographic Factors

	Frequency	Valid Percentage
Gender of Parent Completing Survey		
Female	93	77.20%
Male	26	21.80%
Age of Parent Completing Survey		
18–24	5	4%
25–34	42	35%
35–44	60	50%
45–54	11	9.20%
>55	1	0.80%
Ethnicity of Parent Completing Survey		
Caucasian/White	73	61.30%
African-American/Black	9	7.60%
Hispanic/Latino	27	22.70%
Asian	4	3.40%
Native Hawaiian or other Pacific Islander	4	3.40%
American Indian or Alaskan Native	2	1.60%
Employment Status of Parent Completing Survey		
Active duty military	30	25.20%
Full-time or part-time civilian employment out of home	24	20.20%
Work from Home/Self-Employed	9	7.60%
Stay at Home Parent	56	47%
Highest Level of Education of Parent Completing Survey		
Graduate/Professional Degree	16	13.40%
College Degree	33	27.80%
Some College	49	41.20%
High School Diploma/Equivalent	19	16%
Some High School	2	1.60%
Make-Up of Home		
Two Parent Home- Dual Active Duty Military	7	5.80%
Two Parent Home- Active Duty Military/Retired Military	11	9.20%
Two Parent Home- Active Duty Military/Civilian Spouse	100	84.2%
Single Parent Home- Active Duty Military Home	1	0.80%
Service Branch of Active Duty Military Member		
Army	91	76.40%
Navy	13	11%
Air Force	15	12.60%
Rank of Active Duty Military Sponsor in Family <sup>1</sup>		
Junior enlisted (rank of E-5 and below)	28	23.50%
Senior enlisted (rank of E-6 and above)	76	63.86%
Junior officer (rank of O-1 to O-3)	4	3.40%
Senior officer (rank of O-4 and above)	11	9.24%
Number of Children in the Home		
1 children	29	24.40%
2 children	45	37.80%
3 children	22	18.50%
4 or more children	23	19.30%
Number of Children on Autism Spectrum in the Family		
1 child	85	71.40%
2 children	25	21.00%
More than 2 children	9	7.60%
Age Range of Child on Autism Spectrum in the Family <sup>2</sup>		
Preschool Aged (ages 2–4)	30	25.20%
School Aged (ages 5–10)	56	47%
Adolescent (ages 11–18)	33	27.80%

**Table 1** (continued)

	Frequency	Valid Percentage
Level of Severity of Child on Autism Spectrum <sup>2</sup>		
Level 1 (mild)	17	14.30%
Level 2 (moderate)	53	44.50%
Level 3 (severe)	15	12.60%
Unknown	34	28.60%
Presence of Comorbid Medical Conditions along with ASD diagnosis		
Yes	99	83.19%
No	20	16.81%
Psychotropic Medication Management for Child on Autism Spectrum		
Yes	59	49.60%
No	60	50.40%
Use of Applied Behavior Analysis (ABA) Therapy Services for ASD Child <sup>2</sup>		
Yes	70	58.80%
No	49	41.20%
History of Treatment for Anxiety/Depression for Parent Completing Survey <sup>3</sup>		
Yes	63	52.90%
No	56	47.10%
Presence of Military Specific Stressors Impacting Family in Last Five Years <sup>4</sup>		
Yes	112	94.20%
No	7	5.80%
Endorsement of Self-Care Activities for Parent Completing Survey <sup>5</sup>		
Yes	97	81.50%
No	22	18.50%
Presence of Respite Care Services in the Home <sup>6</sup>		
Yes	27	22.70%
No	92	77.30%
<b>Total</b>	<b>119</b>	

<sup>1</sup> for dual active duty military family, highest service member rank in family given

<sup>2</sup> if more than one child with autism, age range, level of severity, and ABA status only asked for most severely affected child

<sup>3</sup> A positive history of treatment of anxiety/depression for parent included current treatment or treatment within last 5 years

<sup>4</sup> Defined as military deployments, military moves, frequent temporary duty assignments that take active duty military member out of the home

<sup>5</sup> Defined as parent taking time to do something for themselves or practicing positive coping strategies

<sup>6</sup> 85.2% of families receiving respite care received from EFMP resources; 15.8% from state sources (i.e. DDA)

**Table 2** Critical Variables for Analysis

Dependent (Outcome) Variables	Independent (Predictor) Variables
1. PHQ-4 Score (0–12)	1. Presence/absence of respite care services
2. PSS-10 Score (0–40)	2. History of anxiety/depression for parent
	3. Level of severity of autism for child
	4. Presence of comorbid conditions for child with autism
	5. Number of children in the home with autism
	6. Number of children total being raised in the home
	7. Presence of military specific stressors for the family
	8. Active duty service for the military parent (Army, Navy, Air Force)
	9. Highest level of education for parent
	10. Age of parent
	11. Ethnicity/race of parent

**Table 3** Frequency Distribution of Outcome (Dependent) Variables

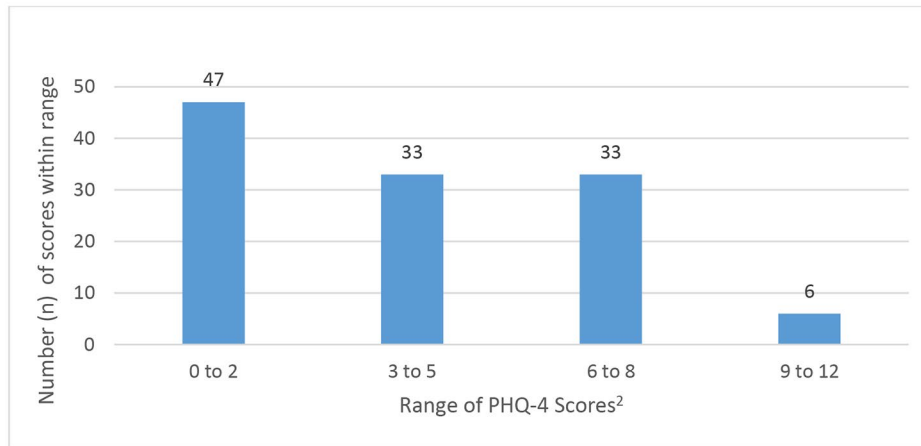
Total Number of Responses (n)	Valid = 119 Missing = 0	Score from PHQ-4 <sup>a</sup>	Score from PSS-10 <sup>b</sup>
Mean Response		4.14	17.58
Standard Deviation		3.076	8.038
Minimum		0	0
Maximum		10	34

<sup>a</sup>PHQ-4 scores range from 0 to 12 [none (0–2), mild (3–5), moderate (6–8), and severe (9–12)]

<sup>b</sup>PSS-10 scores range from 0 to 40 [0–13 = low; 14–26 = moderate; 27–40 = high]

**Multivariate Ordinal Logistic Regression Analysis Results- Impact of Predictor Variables on PHQ-4 and PSS-10 scores (Outcome Variables)**

After adjustment for the critical confounding predictor variables identified in Table 2, the decrease in both the PHQ-4 scores and PSS-10 scores, thereby reflecting less reported severity of symptoms of anxiety, depression, and perceived stress, were statistically significant for families receiving



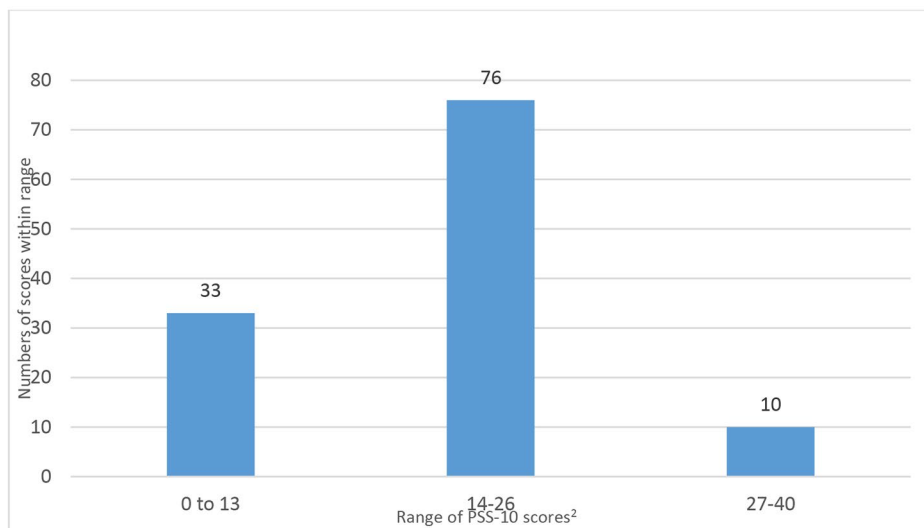
**Fig. 1** Frequency Distribution of PHQ-4 Scores<sup>1</sup>  
Range of PHQ-4 Scores<sup>2</sup>

<sup>1</sup>Mean PHQ response 4.14; SD 3.076; Minimum 0, Maximum 10

<sup>2</sup>PHQ-4 scores range from 0 to 12 (none (0–2), moderate (6–8), and severe (9–12))

respite care services with  $p=0.017$  and  $p=0.016$ , respectively (see Table 5). There were several critical confounding predictor variables that had a statistically significant impact on the two outcome measures. For the PHQ-4 scores, a positive history of parental anxiety or depression was the largest contributor ( $p=0.001$ ) to increases in the PHQ-4 scores. The presence of comorbid medical or behavioral conditions for the child with ASD was associated with higher scores ( $p=0.01$ ) on the PHQ-4 and suggesting, therefore, a higher degree of anxiety/depression symptoms in those parents. For each one child less in the home, there was a corresponding decrease of 0.513 (se:0.244) at  $p=0.03$  on the PHQ-4 score.

This suggested that less children in the home was associated with a decreased level of reported anxiety/depression symptoms in these parents. Similar predictor variables had statistically significant impact on the PSS-10 score. A positive parental history of anxiety or depression was again the largest contributor ( $p$ -value of 0.001) to increases in PSS-10 scores. This suggested that a history of anxiety or depression for the parent was associated with increased perceived stress. The presence of comorbid medical or behavioral conditions for the child with ASD ( $p=0.001$ ) was also associated with increased scores on the PSS-10. A lower level of parental education ( $p=0.01$ ), with each level decrease,



**Fig. 2** Frequency Distribution of PSS-10 Scores<sup>1</sup>  
Range of PSS-10 scores<sup>2</sup>

<sup>1</sup>Mean PSS-10 response 17.58; SD: 8.038; Minimum 0, Maximum 34

<sup>2</sup>PSS-10 scores range from 0 to 40 [low (0–13), moderate (14–26), and high (27–40)]



**Table 4** Relationship between Presence of Respite Care Services with Other Predictor Variables with Chi-Square Values (X2)

Other Predictor Variables	Respite Care Services in Home				Total (N)	Pearson's Chi-Square Value (X <sup>2</sup> )	df	p
	Yes		No					
	n	%	n	%				
<b>Number of Children with Autism in Family</b>	1	16	59.3%	69	75%	85		
	2	8	29.6%	17	18.5%	25		
	3 or more	3	11.1%	6	6.5%	9		
	<b>Total (N)</b>	27	100%	89	100%	119	2.541	2
<b>Severity of Autism</b>	Level 1	1	10.0%	16	21.3%	17		
	Level 2	8	80.0%	45	60%	53		
	Level 3	1	10.0%	14	18.7%	15		
	<b>Total (N)</b>	10	100%	75	100%	85 <sup>a</sup>	1.508	2
<b>Presence of Comorbid Medical or Behavioral</b>	Yes	17	63.0%	82	89.1%	99		
	No	10	37.0%	10	10.9%	20		
	<b>Total (N)</b>	27	100%	92	100%	119	10.222	1
<b>Total Number of Children in the Home</b>	1	2	7.4%	27	29.3%	29		
	2	14	51.9%	31	33.7%	47		
	3	3	11.1%	19	20.7%	22		
	4 or more	8	29.6%	15	16.3%	23		
	<b>Total (N)</b>	27	100%	92	100%	119	14.487	5
<b>Age of Parent Completing the Survey</b>	18–24	0	0.0%	5	5.4%	5		
	25–34	10	37%	32	34.8%	42		
	35–44	15	55.5%	45	48.9%	60		
	45–54	2	7.5%	9	9.8%	11		
	>55	0	0.0%	1	1.1%	1		
<b>Total (N)</b>	27	100%	92	100%	119	10.387	7	0.168
<b>History of Anxiety or Depression for Parent</b>	Yes	13	48.1%	51	55.4%	64		
	No	14	51.9%	41	44.6%	55		
	<b>Total (N)</b>	27	100%	92	100%	119	0.446	1
<b>Ethnicity of Parent</b>	Caucasian/White	18	66.7%	54	58.7%	72		
	African-American/Black	0	0.0%	9	9.8%	9		
	Hispanic/Latino	4	14.8%	23	25%	27		
	Asian	5	18.5%	4	4.3%	9		
	Native Hawaiian or Other Pacific Islander	0	0.0%	0	0.0%	0		
	American Indian or Native Alaskan	0	0.0%	2	2.2%	2		
	<b>Total (N)</b>	27	100%	92	100%	119	9.944	4
<b>Highest Educational Level of Parent</b>	Some High School	0	0.0%	2	2.3%	2		
	High School Diploma or Equivalent	0	0.0%	19	20.7%	19		
	Some College	14	51.9%	35	38.0%	49		
	College Degree	5	18.5%	28	30.4%	33		
	Graduate or Professional Degree	8	29.6%	8	8.7%	16		
	<b>Total (N)</b>	27	100%	92	100%	119	18.522	5
<b>Rank of Active Duty Parent in Family</b>	Junior Enlisted (E-1 to E-5)	0	0.0%	28	30.4%	28		
	Senior Enlisted (E-6 and above)	19	70.4%	59	64.1%	78		
	Junior Officer (O-1 to O-3)	3	11.1%	1	1.1%	4		
	Senior Officer (O-4 and above)	5	18.5%	4	4.4%	9		
	<b>Total (N)</b>	27	100%	92	100%	119	20.124	3
<b>Military Specific Stressors in Last 5 Years</b>	Yes	25	92.6%	87	94.6%	112		
	No	2	7.4%	5	5.4%	7		
	<b>Total (N)</b>	27	100%	92	100%	119	0.147	1

**Table 5** Multivariate Ordinal Logistic Regression Analysis of Impact of Predictor Variables on Outcome Variables (PHQ-4 and PSS-10 scores)

Independent (Predictor) Variables	PHQ-4 score					PSS-10 score				
	Unstandardized Coefficients		Standardized Coefficient ( $\beta$ )	t score	p value <sup>c</sup>	Unstandardized Coefficients		$\beta$	t score	p value <sup>c</sup>
	B	Standard Error (SE-B)				B	SE-B			
# of Children with Autism	-0.677	0.590	-0.127	-1.146	0.255	-0.124	1.447	-0.009	-0.086	0.932
Severity of Autism	-0.304	0.493	-0.065	-0.617	0.539	-1.126	1.210	-0.095	-0.930	0.355
Comorbid Medical or Behavioral Conditions	3.585	1.359	0.265	2.638	<b>0.010</b>	11.095	3.332	0.323	3.330	<b>0.001</b>
# of Children in Home	-0.513	0.244	-0.218	-2.105	<b>0.039</b>	-0.688	0.597	-0.115	-1.152	0.253
Age of Parent Completing Survey	-0.183	0.291	-0.080	-0.627	0.532	0.134	0.714	0.023	0.187	0.852
History of anxiety or depression for parent completing survey	2.404	0.638	0.415	3.769	<b>&lt;0.001</b>	5.604	1.564	0.381	3.584	<b>0.001</b>
Ethnicity of Parent	-0.194	0.242	-0.089	-0.804	0.424	0.305	0.592	0.055	0.514	0.609
Highest Educational Level of Parent	-0.515	0.342	-0.173	-1.506	0.136	-2.203	0.838	-0.293	-2.629	<b>0.010</b>
Rank of Active Duty Military Parent	0.986	0.518	0.274	1.904	0.061	2.222	1.270	0.243	1.750	0.084
Presence of Military Specific Stressors	0.989	1.263	0.081	0.763	0.436	3.342	3.095	0.108	1.080	0.284
Presence of Respite Care Service	-2.413	0.986	-0.272	0.2.446	<b>0.017</b>	-5.946	2.417	-0.264	-2.460	<b>0.016</b>

<sup>a</sup> Dependent variable #1

<sup>b</sup> Dependent variable #2

<sup>c</sup> p < 0.05 indicated statistically significant association

led to a corresponding decrease in PSS-10 scores of 2.20 (se:0.83) at p=0.01.

## Discussion

Our pilot study was the first to look at the impact of respite services on symptoms of stress, anxiety, and depression in military parents with a child with autism spectrum disorder. Our findings, namely the decreased scores on both the PHQ-4 and PSS-10 questionnaires after adjustment for identified confounding predictor variables suggests respite care utilization has a positive impact on symptoms of anxiety, depression, and stress in these families. Additionally, our study revealed an association between the presence of respite services and several demographic variables to include higher level of military rank, higher level of parental education, more overall children in the home, and the absence of comorbid medical conditions in the child with autism spectrum disorder. Our findings highlight the potential importance of respite care services as a viable and critical resource for active-duty military families raising a child with autism spectrum disorder and emphasize the need to optimize access to respite services to enhance the well-being and resilience of these families.

## Impact of Other Predictor Variables on the Primary Outcome Measures

While existing evidence in the medical literature qualitatively demonstrates potential benefits of respite care services for families with a child with autism spectrum disorder (Krakovich et al., 2016; Whitmore, 2016), this pilot study is unique, as there are very few studies that have attempted to quantify the difference respite services make in perceived parental stress and symptoms of anxiety and depression using standardized screeners with documented internal and external validity and reliability. A parental history of anxiety and/or depression was the most significant contributing predictor variable on the scores on both outcome measures for our study; making vigilant screening of parental mental health history and sources of stress in daily life of critical importance for healthcare professionals. Smith (2010) compared the daily chronic level of stress encountered by mothers with adolescent children with autism spectrum disorder to that encountered by combat soldiers. As nearly 100% of the parents surveyed also reported the presence of additional military stressors in the previous five years, the potential impact of that compounded stress becomes concerning. It has been well reported in the medical literature that military specific stressors, especially deployment, increases the risk for mental health concerns for both military spouses and children (Cunitz et al., 2019). Accounting for these additional stressors is of utmost importance when considering resources to support these families.

## Association Between Presence of Respite Care and Demographic Variables

The identification of demographic disparities accentuates the need for vigilance by the health care system to the impact of social determinants of health (SDOH) on utilization of available resources. By establishing positions for EFMP Systems Navigators tasked with matching families with special needs children with critical resources, the military recognizes the need for care coordination. Our data would suggest, however, that a gap potentially exists in reaching those families at greatest risk based on SDOH such as ethnicity and level of education. This is an additional concern of course as ethnicity and level of parental education are already significant risk factors for predicting increased parental stress when raising a child with ASD (Kim, 2020; Hsiao 2018). Despite the military having universal access to standardized health care, identification of rank as an important contributor variable raises concerns that more junior ranks may be unaware of or unable to access available resources. In addition, these junior ranks make far less money than those military members of more senior rank and financial status is another identified risk factor for increased stress in parents with a child with ASD (Hsiao, 2018). This association needs to be assessed carefully, however, as there were only fifteen officers represented in our study population and the input from these officers may not be reflective of the military officer population as a whole. A recent systematic qualitative review of parental perceptions and individual experiences with respite services expounded upon some of the major barriers parents face in accessing available respite care resources for their child with ASD (Cooke et al., 2020). This review highlights the need for families with autism spectrum disorder children to receive better education and counseling on the benefits of respite care; and the need to dispel emotional barriers to seeking out help and resources. Though the diagnosis and treatment of ASD occurs in a multitude of settings, healthcare professionals play an increasingly pivotal role in supporting families in accessing vital support services to include respite care (Malik-Soni et al., 2021).

### Utilization of Respite Care in the Population Study

The relatively low 22.6% utilization of respite care service resources by the military families surveyed is concerning but may be attributable to the Army affiliation of the majority of the surveyed parents. Differences between the military services in administration of EFMP programs and resources creates correspondingly disparate access to respite care for active-duty families with a child with autism spectrum disorder. One concerning finding from the study was that

children with comorbid medical and behavioral diagnoses in addition to their diagnosis of autism spectrum disorder were less likely to receive respite resources. This population of children is potentially more vulnerable and at greater risk for more serious health outcomes. This suggests that respite care is not optimized for the military ASD population and presents a potential avenue for future work. By improving access to respite care, increasing both number and quality of available respite providers, and increasing education and awareness of the potential benefits of respite, the military services may begin to close the gaps.

It is difficult to assess how whether our relatively small number of 22.6% respite care utilization rate is reflective of the respite care utilization rate in the civilian population as it is difficult to compile this data on a national level. One major reason for this is that utilization of respite care resources in the civilian world varies widely from state to state. This is due to the fact that one major source of respite care for many civilian families with a child with autism spectrum disorder is based on whether a family is able to qualify for a Medicaid waiver. Qualifying criteria for a Medicaid waiver based on a diagnosis of autism spectrum disorder alone (without consideration of other comorbid medical diagnoses) is determined by each state individually. Likewise, wait lists for services after a family qualifies for a Medicaid waiver also vary significantly from state to state. Furthermore, respite care provider availability is also influenced by a family's geographic location as well. It does raise a significant concern, however, related to the military families raising a child on the autism spectrum who are trying to access respite care resources through civilian sources, namely Medicaid. Military families do not, at this present time, have interstate reciprocity of their Medicaid waivers when they receive military orders and complete a permanent change of duty station. If a military family has a Medicaid waiver in the state where they are currently stationed and are dependent upon services afforded to them by this waiver, they are not able to seamlessly connect to these same resources upon moving to a new state without going through the process for a new Medicaid waiver according to that individual's state qualification criteria. This presents another possible additional challenge that military families face, therefore, with being able to access non-military sources of respite care for their autism spectrum disorder child.

### Study Limitations

We were unable to address the level of autism spectrum disorder severity in our study due to missing data. The DSM-5 changed the way we diagnose autism spectrum disorder in terms of a spectrum disorder and with that change came

the assignment of level of severity. As our study relied on parental self-report on anonymously administered surveys, it is possible a significant portion of parents could not report the level of severity assigned to their child's autism spectrum disorder diagnosis due to ambiguity of the severity scale itself, changes in the assigned level over time, or poor communication between the diagnosing provider and the parent. Whatever the cause, a clearer and more specific ASD severity scale is needed if future studies are to consider this as a potential contributing variable.

While we identified important areas for future research and directions for advocacy and change, there are also limitations in our study. As this is a pilot study with limited sample size, larger studies are needed to validate our findings. In addition, due to the small sample size of this study and the breakdown of the data into multiple categories, some of the calculations in the chi square analysis were unstable due to the small number of entries in the cells. This only emphasizes more that these results and drawn conclusions can only be suggestive and not definitive. The COVID-19 pandemic was an important event occurring during the course of data collection for our study, and may have contributed to caregiver stress, anxiety, and depression. The majority of the surveys reviewed in this study were collected by EFMP System Navigators who work directly with EFMP enrolled families, helping match these families with available resources and other supports. As enrolled families self-refer for EFMP System Navigator assistance, there is the possibility of a sampling bias as parents who reach out actively for assistance for resources and supports may also be experiencing higher levels of stress, anxiety, or depression at baseline.

Self-reported survey data is also subject to recall and reporting biases. While the anonymously based survey design for the study of course prevented a review of medical records to confirm a medical diagnosis of ASD for each family, the surveys were only distributed from care points where ASD children were being actively managed. As the survey package did, however, include sensitive questions regarding a parent's mental health, the anonymous survey design of our study likely helped decrease concerns for response bias in this respect. In addition, another significant limitation for the study was the lack of a pilot test of the survey prior to the roll-out of the study to be able to implement additional best practice guidelines with improving clarity and accuracy of parental responses.

### Potential Directions for Future Study

With our study results demonstrating positive benefits from provision of respite services, further analysis of the systems in place at the current time is needed to improve access and

utilization of respite care; focusing on flexibility and accessibility of respite services. Refining the definition of what constitutes respite care could also be important in being able to improve a family's utilization of this resource. In prior respite care studies, families cited that the ability to use extended family as respite care providers, emphasis on quality of the respite care provider, and the use of a respite care resource that provided a strong social and community model were all important considerations for families considering the utilization of respite care as a resource for their family (Dyches et al., 2016; Wilkie & Barr, 2008; Benderix et al., 2006). Recognizing these findings, future efforts to improve accessibility and standardization of respite care resources will need to focus on defining respite care in less restrictive terms and consider a variety of options for families to use the benefit. Options could include allowing extended family members to be formally trained and paid as approved respite care providers, and/or allowing utilization of community facilities and resources providing both respite for the parent and a social environment for the child.

Expansion of the study to include other military treatment facilities could improve the generalizability of the data to the entire military force. Changes in study design could potentially address limitations of our study in future work. Accessing personal health information for in-depth record review could help in ensuring integrity of collected data. Pre-screening followed by a formal recruitment process to create evenly distributed "intervention" (presence of respite care) and "control" (absence of respite care) groups would help control for confounding demographic and psychosocial factors. Finally, a prospective cohort design where baseline surveys are administered to parents and then periodically to track stress, anxiety, and depression would allow for better delineation between chronic issues and new concerns. While the study results seem to parallel some of the findings in civilian research among children with ASD in terms of demographic factors associated with utilization of respite care resources and disparities in service use (Smith et al., 2020), expanding the military population surveyed could potentially help with applying future results to the general civilian population.

### Conclusion

The study shows that parents receiving respite care support have lower reported symptoms of stress, anxiety, and depression after adjustments for confounding demographic variables. Provision of respite care services offers a clear benefit in supporting the overall wellness and resiliency of military families raising a child with autism spectrum disorder. It also highlights the importance of continued

awareness and recognition that social determinants of health impact families' ability to access respite care resources. Further analysis of respite care services as an independent contributor to parental stress, anxiety, and depression symptoms is needed using larger sample sizes more reflective of the active-duty military family population raising a child on the autism spectrum disorder spectrum.

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## References

- American Psychiatric Association (2013). *Neurodevelopmental Disorders*. In *Diagnostic and statistical manual of mental disorders* (5th ed.) <https://doi.org/10.1176/appi.books.9780890425596.dsm01>
- Baik, S. H., Fox, R. S., Mills, S. D., Roesch, S. C., Sadler, G. R., Klonoff, E. A., & Malcarne, V. L. (2019). Reliability and validity of the perceived stress scale-10 in Hispanic Americans with English or Spanish language preference. *Journal of health psychology, 24*(5), 628–639. <https://doi.org/10.1177/1359105316684938>
- Benderix, Y., Nordström, B., & Sivberg, B. (2006). Parents' experience of having a child with autism and learning disabilities living in a group home: a case study. *Autism: the international journal of research and practice, 10*(6), 629–641. <https://doi.org/10.1177/1362361307070902>
- Benjak, T., Vuletić, G. M., & Simetin, I. P. (2009). Comparative study on self-perceived health of parents of children with autism spectrum disorders and parents of non-disabled children in Croatia. *Croatian medical journal, 50*(4), 403–409. <https://doi.org/10.3325/cmj.2009.50.403>
- Bitsika, V., & Sharpley, C. F. (2004). Stress, anxiety, and depression among parents of children with autism spectrum disorder. *Australian journal of guidance and counselling, 14*(2), 151–161. <https://doi.org/10.1017/S1037291100002466>
- Bonis, S. (2016). Stress and parents of children with autism: A review of literature. *Issues in Mental Health Nursing, 37*(3), 153–163. <https://doi.org/10.3109/01612840.2015.1116030>
- Boyd, B. A. (2002). Examining the relationship between stress and lack of social support in mothers of children with autism. *Focus on Autism and Other Developmental Disabilities, 17*(4), 208–215. <https://doi.org/10.1177/10883576020170040301>
- Brenner, M., Connolly, M., Cawley, D., Howlin, F., Berry, J., & Quinn, C. (2016). Family and healthcare professionals' perceptions of a pilot hospice at home programme for children: a qualitative study. *BMC Palliative Care, 15*(1), 89. <https://doi.org/10.1186/s12904-016-0161-0>
- Cohen, S., & Williamson, G. M. (1988). Perceived stress in a probability sample of the U.S. In Spacapan S & Oskamp S (Ed.) *The Social Psychology of Health: Claremont Symposium on Applied Social Psychology* (pp 31–67). Sage Publications
- Cohen, S., & Janicki-Deverts, D. (2012). Who's stressed? Distributions of psychological stress in the United States in probability samples from 1983, 2006, and 2009. *Journal of Applied Social Psychology, 42*(6), 1320–1334. <https://doi.org/10.1111/j.1559-1816.2012.00900.x>
- Cooke, E., Smith, V., & Brenner, M. (2020). Parents' experiences of accessing respite care for children with autism spectrum disorder (ASD) at the acute and primary care interface: a systematic review. *BMC Pediatrics, 20*(1), 244 <https://doi.org/10.1186/s12887-020-02045-5>
- Cunitz, K., Döhlitzsch, C., Kösters, M., Willmund, G. D., Zimmermann, P., Bühler, A. H., Fegert, J. M., Ziegenhain, U., & Kölch, M. (2019). Parental military deployment as risk factor for children's mental health: a meta-analytical review. *Child and Adolescent Psychiatry and Mental Health, 21*(13), 26. <https://doi.org/10.1186/s13034-019-0287-y>
- Davis, J. M., & Finke, E. H. (2015). The experience of military families with children with Autism Spectrum Disorders during relocation and separation. *Journal of Autism and Developmental Disorders, 45*(7), 2019–2034. <https://doi.org/10.1007/s10803-015-2364-2>
- Davis, J. M., Finke, E., & Hickerson, B. (2016). Service delivery experiences and intervention needs of military families with children with ASD. *Journal of Autism and Developmental Disorders, 46*(5), 1748–1761. <https://doi.org/10.1007/s10803-016-2706-8>
- Denovan, A., Dagnall, N., Dhingra, K., & Grogan, S. (2019). Evaluating the perceived stress scale among UK university students: implications for stress measurement and management. *Studies in Higher Education, 44*(1), 120–133. DOI: <https://doi.org/10.1080/03075079.2017.1340445>
- Derguy, C., M'Bailara, K., Michel, G., Roux, S., & Bouvard, M. (2016). The need for an ecological approach to parental stress in autism spectrum disorders: The combined role of individual and environmental factors. *Journal of Autism and Developmental Disorders, 46*(6), 1895–1905. <https://doi.org/10.1007/s10803-016-2719-3>
- Dunn, M. E., Burbine, T., Bowers, C. A., & Tantleff-Dunn, S. (2001). Moderators of stress in parents of children with autism. *Community Mental Health Journal, 37*(1), 39–52. <https://doi.org/10.1023/a:1026592305436>
- Dyches, T. T., Christensen, R., Harper, J. M., Mandlco, B., & Roper, S. O. (2016). Respite care for single mothers of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 46*(3), 812–824. <https://doi.org/10.1007/s10803-015-2618-z>
- Eaton, N. (2008). 'I don't know how we coped before': a study of respite care for children in the home and hospice. *Journal of Clinical Nursing, 17*(23), 3196–3204. <https://doi.org/10.1111/j.1365-2702.2008.02630.x>
- Efstratopoulou, M., Sofologi, M., Giannoglou, S., & Bonti, E. (2022). Parental Stress and Children's Self-Regulation Problems in Families with Children with Autism Spectrum Disorder (ASD). *Journal of Intelligence, 17*:10(1):4. <https://doi.org/10.3390/jintelligence10010004>
- Ekas, N., & Whitman, T. L. (2010). Autism symptom topography and maternal socioemotional functioning. *American Journal on Intellectual and Developmental Disabilities, 115*(3), 234–249. <https://doi.org/10.1352/1944-7558-115.3.234>
- Falk, N. H., Norris, K., & Quinn, M. G. (2014). The factors predicting stress, anxiety, and depression in the parents of children with autism. *Journal of Autism and Developmental Disorders, 44*(12), 3185–3203. <https://doi.org/10.1007/s10803-014-2189-4>
- Hamlyn-Wright, S., Draghi-Lorenz, R., & Ellis, J. (2007). Locus of control fails to mediate between stress and anxiety and depression in parents of children with a developmental disorder. *Autism Spectrum Disorder, 11*(6), 489–501. <https://doi.org/10.1177/1362361307083258>
- Harper, A., Dyches, T. T., Harper, J., Roper, S. O., & South, M. (2013). Respite care, marital quality, and stress in parents of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 43*(11), 2604–2616. <https://doi.org/10.1007/s10803-013-1812-0>

- Hastings, R. P. (2003). Child behavior problems and partner mental health as correlates of stress in mothers and fathers of children with autism. *Journal of Intellectual Disability Research, 47*(4–5), 231–237. <https://doi.org/10.1046/j.1365-2788.2003.00485.x>
- Hayes, S. A., & Watson, S. L. (2013). The impact of parenting stress: a meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders, 43*(3), 629–642. <https://doi.org/10.1007/s10803-012-1604-y>
- Hsiao, Y. J. (2018). Autism spectrum disorders: family demographics, parental stress, and family quality of life. *Journal of Policy and Practice in Intellectual Disabilities, 15*, 70–79. <https://doi.org/10.1111/jppi.12232>
- Kim, I., Dababnah, S., & Lee, J. (2020). The influence of race and ethnicity on the relationship between family resilience and parenting stress in caregivers of children with autism. *Journal of Autism and Developmental Disorders, 50*, 650–658. <https://doi.org/10.1007/s10803-019-04269>
- Krakovich, T. M., McGrew, J. H., Yu, Y., & Ruble, L. A. (2016). Stress in parents of children with autism spectrum disorder: An exploration of demands and resources. *Journal of Autism and Developmental Disorders, 46*(6), 2042–2053. <https://doi.org/10.1007/s10803-016-2728-2>
- Kroenke, K., Spitzer, R. L., Williams, J. B., & Löwe, B. (2009). An ultra-brief screening scale for anxiety and depression: the PHQ-4. *Psychosomatics, 50*(6), 613–621. <https://doi.org/10.1176/appi.psy.50.6.613>
- Lee, E. H. (2012). Review of the psychometric evidence of the perceived stress scale. *Asian Nursing Research, 6*(4), 121–127. <https://doi.org/10.1016/j.anr.2012.08.004>
- Lester, P., & Flake, E. (2013). How wartime military service affects children and families. *The Future of Children, 23*(2), 121–141. <https://doi.org/10.1353/foc.2013.0015>
- Löwe, B., Wahl, I., Rose, M., Spitzer, C., Glaesmer, H., Wingenfeld, K., Schneider, A., & Brähler, E. (2010). A 4-item measure of depression and anxiety: validation and standardization of the patient health questionnaire-4 (PHQ-4) in the general population. *Journal of Affective Disorders, 122*(1–2), 86–95. <https://doi.org/10.1016/j.jad.2009.06.019>
- Maenner, M. J., Shaw, K. A., Baio, J., Washington, A., Patrick, M., DiRienzo, M., Christensen, D. L., Wiggins, L. D., Pettygrove, S., Andrews, J. G., Lopez, M., Hudson, A., Baroud, T., Schwenk, Y., White, T., Rosenberg, C. R., Lee, L. C., Harrington, R. A., & Huston, M. (2020). Prevalence of autism spectrum disorder among children aged 8 years - autism and developmental disabilities monitoring network, 11 sites, United States, 2016. *Morbidity and Mortality Weekly Report. Surveillance Summaries (Washington, D.C.: 2002), 69*(4), 1–12. <https://doi.org/10.15585/mmwr.ss6904a1>
- Mackintosh, V. H., Myers, B. J., & Goin-Kochel, R. P. (2005). Sources of information and support used by parents of children with autism spectrum disorders. *Journal on Developmental Disabilities, 12*(1), 41–52
- Marsack-Topolewski, C. N., Samuel, P. S., & Tarraf, W. (2021). Empirical evaluation of the association between daily living skills of adults with autism and parental caregiver burden. *PLoS One, 16*(1), e0244844. <https://doi.org/10.1371/journal.pone.0244844>
- Malik-Soni, N., Shaker, A., Luck, H., Mullin, A. E., Wiley, R. E., Lewis, M. E., Fuentes, J., & Frazier, T. W. (2021). Tackling healthcare access barriers for individuals with autism from diagnosis to adulthood. *Pediatric Research, 91*, 1028–1035. <https://doi.org/10.1038/s41390-021-01465-y>
- McAuliffe, T., Cordier, R., Vaz, S., Thomas, Y., & Falkmer, T. (2017). Quality of life, coping styles, stress levels, and time use in mothers of children with autism spectrum disorders: comparing single versus coupled households. *Journal of Autism and Developmental Disorders, 47*(10), 3189–3203. <https://doi.org/10.1007/s10803-017-3240-z>
- Micali, N., Chakrabarti, S., & Fombonne, E. (2004). The broad autism phenotype: findings from an epidemiological survey. *Autism: The International Journal of Research and Practice, 8*(1), 21–37. <https://doi.org/10.1177/1362361304040636>
- Mitchell, A. M., Crane, P. A., & Kim, Y. (2008). Perceived stress in survivors of suicide: Psychometric properties of the perceived stress scale. *Research in Nursing & Health, 31*(6), 576–585. <https://doi.org/10.1002/nur.20284>
- Otsuki, N., Fukui, S., & Sakaguchi, Y. (2020). Measuring the benefits of respite care use by children with disabilities and their families. *Journal of Pediatric Nursing, 53*, e14–e20. <https://doi.org/10.1016/j.pedn.2020.01.016>
- Remedios, C., Willenberg, L., & Zordan, R. (2015). A pre-test and post-test study of the physical and psychological effects of out-of-home respite care on caregivers of children with life threatening conditions. *Palliative Medicine, 29*(3), 223–230. <https://doi.org/10.1177/0269216314560008>
- Roberti, J., Harrington, L., & Storch, E. (2006). Further psychometric support for the 10-Item version of the perceived stress scale. *Journal of College Counseling, 9*(10), 1002/j.2161-1882.2006.tb00100.x
- Sim, A., Cordier, R., Vaz, S., Parsons, R., & Falkmer, T. (2017). Relationship satisfaction and dyadic coping in couples with a child with autism spectrum disorder. *Journal of Autism & Developmental Disorders, 47*, 3562–3573. <https://doi.org/10.1007/s10803-017-3275-1>
- Sim, A., Vaz, S., Cordier, R., Joosten, A., Parsons, D., Smith, C., & Falkmer, T. (2018). Factors associated with stress in families of children with autism spectrum disorder. *Developmental Neuropsychology, 21*(3), 155–165. <https://doi.org/10.1080/17518423.2017.1326185>
- Singer, G. H. (2006). Meta-analysis of comparative studies of depression in mothers of children with and without developmental disabilities. *American Journal of Mental Retardation: AJMR, 111*(3), 155–169. [https://doi.org/10.1352/0895-8017\(2006\)111\[155:MOCSO D\]2.0.CO;2](https://doi.org/10.1352/0895-8017(2006)111[155:MOCSO D]2.0.CO;2)
- Smith, L. E., Hong, J., Seltzer, M. M., Greenberg, J. S., Almeida, D. M., & Bishop, S. L. (2010). Daily experiences among mothers of adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 40*(2), 167–178. <https://doi.org/10.1007/s10803-009-0844-y>
- Salomone, E., Leadbitter, K., Aldred, C., Barrett, B., Byford, S., Charman, T., Howlin, P., Green, J., Couteur, A. L., McConachie, H., Parr, J. R., Pickles, A., Slonims, V., & The PACT Consortium. (2018). The association between child and family characteristics and the mental health and wellbeing of caregivers of children with autism in mid-childhood. *Journal of Autism & Developmental Disorders, 48*(4), 1189–1198. <https://doi.org/10.1007/s10803-017-3392-x>
- Skomorovsky, A., Norris, D., Bullock, A., & Evans, K. (2016). The impact of military life on the well-being of children in single-parent military families. *Journal of Military Veteran and Family Health, 2*, 29–36. <https://doi.org/10.3138/jmvfh.3753>
- United States Government Accountability Office. (2018). *Additional Opportunities to Reduce Fragmentation, Overlap, and Duplication and Achieve Other Financial Benefits. (GAO Publication Number 18-371SP)*. Washington, D.C.: U.S. Government Printing Office
- Smith, K. A., Gehricke, J. G., Iadarola, S., Wolfe, A., & Kuhlthau, K. A. (2020). Disparities in service use among children with autism: a systematic review. *Pediatrics, 145*(Supplement\_1), S35–S46. <https://doi.org/10.1542/peds.2019-1895G>
- van Steijn, D. J., Oerlemans, A. M., van Aken, M. A., Buitelaar, J. K., & Rommelse, N. N. (2014). The reciprocal relationship of

- ASD, ADHD, depressive symptoms, and stress in parents of children with ASD and/or ADHD. *Journal of Autism and Developmental Disorders*, 44(5), 1064–1076. <https://doi.org/10.1007/s10803-013-1958-9>
- Weiss, M. J. (2002). Hardiness and social support as predictors of stress in mothers of typical children, children with autism, and children with mental retardation. *Autism*, 6, 115–130. <https://doi.org/10.1177/1362361302006001009>
- Whitmore, K. E. (2016). Respite care and stress among caregivers of children with autism spectrum disorder: an integrative review. *Journal of Pediatric Nursing*, 31(6), 630–652. <https://doi.org/10.1016/j.pedn.2016.07.009>
- Whitmore, K. E., & Snethen, J. (2018). Respite care services for children with special healthcare needs: Parental perceptions. *Journal for Specialists in Pediatric Nursing: JSPN*, 23(3), e12217. <https://doi.org/10.1111/jspn.12217>
- Wilkie, B., & Barr, O. (2008). The experiences of parents of children with an intellectual disability who use respite care services. *Learning Disability Practice*, 11, 30–36. <https://doi.org/10.7748/ldp.11.5.30.s32>
- Woodgate, R. L., Edwards, M., Ripat, J. D., Borton, B., & Rempe, G. (2015). Intense parenting: a qualitative study detailing the experiences of parenting children with complex care needs. *BMC Pediatrics*, 15, 197. <https://doi.org/10.1186/s12887-015-0514-5>
- Yorke, E., Pippa, W., Weston, A., Rafla, M., Charman, T., & Simonoff, E. (2018). The association between emotional and behavioral problems in children with autism spectrum disorder and psychological distress in their parents: a systematic review and meta-analysis. *Journal of Autism and Developmental Disorders*, 48, 3393–3415. <https://doi.org/10.1007/s10803-018-3605-y>

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