



# Stress and Anxiety Among Parents of Transition-Aged Children with Autism Spectrum Disorder: a Systematic Review of Interventions and Scales

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## Abstract

The period between adolescence to young adulthood can be stressful for parents of transition-aged children (14 to 22 years old) with autism spectrum disorder. A systematic review was undertaken to examine if existing interventions address the unique parental stressors of this phase and if the scales used to measure parental stress and anxiety are suitable for this group. Of the 9813 studies screened, only 13 studies met the inclusion criteria. Findings indicated that interventions focused on mindfulness, social functioning, or multiple components, of which only two addressed the transition period and only three specifically targeted parents of this age group. Moreover, of the six scales which assessed stress or anxiety, none were designed for these parents. Findings highlight the urgent need for more suitable scales and targeted interventions.

**Keywords** Stress · Anxiety · Transition-aged · Autism · Parent · Intervention

Autism spectrum disorder (ASD) is characterized by challenges in areas such as social interaction, communication, repetitive behaviors, and limited interests. In the USA, the number of 8-year-old children living with ASD has risen from 1 in 59 children in 2014 to 1 in 44 in 2018 (Maenner et al., 2021), while approximately 80% of adults with ASD continue to live with their families after high school (Shattuck et al., 2011).

## The Transition Phase

Despite multiple transitions in the lives of all individuals, one period of particular importance for individuals with ASD is that spanning from adolescence to young adulthood (Wisner-Carlson et al., 2020). During this transition, decisions can have a significant impact on desired adult outcomes such as academic achievement, employment, community participation, and independent living. To ensure support and enhance outcomes during this phase, transition services are mandated for students with an Individualized Education Plan (IEP) by the 2004 re-authorization of the Individuals with Disabilities Education Act (IDEA; IDEA, 2004).

Unfortunately, outcomes for individuals with ASD remain bleak. Only 58% have paid employment after high school, 25% are socially isolated, only 36% attend college or vocational education, and over 25% receive no services to support adult outcomes (Roux et al., 2015). As a result, there has been a call for research specifically addressing this period of transition (Interagency Autism Coordinating Committee (IACC), 2017). Although the age range to define this period varies, it is generally considered to begin at 14 lasting through 22 years of age (Chen et al., 2019; Suk et al., 2020; U.S. Department of Health and Human Services, 2017).

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The period of adolescence is also characterized by many children beginning to desire autonomy and asserting their independence (Matsuo et al., 2015; Sosnowy et al., 2018). Parental rights transfer to the child typically at the age of 18, and as a result, children assume a new role, rights, and responsibilities (United States Department of Education, 2017). However, continuing deficits for children with ASD in areas such as communication, social functioning, and planning inhibit the ability of the child to flourish (Wisner-Carlson et al., 2020). Moreover, challenging behaviors such as self-injurious behavior and aggression (Oti-Boadi et al., 2020; Wong et al., 2020; Yu et al., 2018) and additional co-morbidities such as anxiety may persist or exacerbate at this time (Kaat & Lecavalier, 2015; van Steensel et al., 2011).

Recently, several studies have examined the transition period from the perspective of parents, and findings highlight that this phase is marked by *unique* stressors that impact the quality of life (Lee & Shivers, 2019). During this time, parents take on numerous roles such as planning and decision-making (Bianco et al., 2009) while navigating a fragmented landscape to ensure continuity of care as their child enters adult systems (Federal Partners in Transition Workgroup, 2015). As such, the effort required to plan and access transition-related information has a cascading effect on parent health and overall wellbeing. Furthermore, as parents begin to age themselves, they begin to worry about their child's ability to attain adulthood goals and hope to start planning for their child's future (Oti-Boadi et al., 2020). Other stressors such as limited financial resources, lack of social support, isolation, and parenting efficacy also adversely influence outcomes and the transition experience (Marsack-Topolewski & Graves, 2020; Mason, 2012; Sosnowy et al., 2018; Wong et al., 2020; Yu et al., 2018).

## Parent Mental Health

It has been well established that providing care for a child with ASD has a significant impact on parental mental health (Estes et al., 2013; Valicenti-McDermott et al., 2015). Two commonly examined outcomes are stress and anxiety in the ASD literature (Al-Farsi et al., 2016; Conner et al., 2013). While some studies have examined what effect the child's age may have on parental mental health, there is mixed and conflicting evidence on whether it improves or declines as the child ages (Gray et al., 2014; Kousha et al., 2016; McStay et al., 2014; Pozo & Sarriá, 2015; Tehee et al., 2009). Despite this, it is clear that these parents continue to experience stress and anxiety across their lifespan (Dizdarevic et al., 2020; Lee & Shivers, 2019).

## Interventions

Supporting the mental health of parents via interventions is imperative (Agbaria, 2020; Sopaul, 2019) given that unaddressed stress and anxiety can have adverse effects on the family stemming from the interdependence in a parent–child relationship (Barker et al., 2011; Bones et al., 2019; Bonis, 2016; Dardas & Ahmad, 2014; Reichman et al., 2008). At this time, a vast amount of literature exists on interventions for parents and their *young* children with ASD (Devescovi et al., 2016; Feinberg et al., 2014; Ingersoll & Wainer, 2013). However, there is growing recognition for more targeted interventions (especially those that address stress and anxiety) for parents and transition-aged children with ASD (Benson, 2015; Bones et al., 2019; Karst & Van Hecke, 2012). As such, as a first step, it is necessary to identify the characteristics of interventions that focus on parental stress and anxiety in the existing literature on transition-aged youth (Maglione et al., 2012; Yoo et al., 2014). This will allow future studies to build on and fill any gaps which may be identified.

## Stress and Anxiety Scales

It is equally important to ensure that the stress and anxiety scales which have been used in these interventions are valid and reliable. Choosing scales for intervention studies is a purposeful decision, which should be aligned with the characteristics of the study's population and purpose (Coster, 2013). Unfortunately, studies have brought to light that scales that do not align with the study population are being inappropriately used. For example, Hayes and Watson (2013) found that the Parenting Stress Index (PSI) which is designed for parents of children between 3 months and 10 years old (Abidin, 1995) had been utilized among parents of children with disabilities and those older than the recommended age range (Fedele et al., 2010; Hastings et al., 2006). This is problematic as the scale may not capture the unique factors impacting levels of stress in parents raising a child with a disability (McStay et al., 2014; Silva & Schalock, 2012), and even more specifically ASD (such as effort in coordinating healthcare), while also not capturing the stressors associated with the respective stage of life (such as transition planning for post-secondary education or employment). As such, it is imperative to review the scales currently being utilized to ensure that they are suitable and valid for parents of children with ASD in transition ages.

## Aim of the Review

Several systematic reviews have assessed stress and anxiety scales among non-disability populations (Brunton et al., 2015; Webb et al., 2018) and some have recently examined

interventions for parents of children with ASD (Merriman et al., 2020; Rutherford et al., 2019; Shalev et al., 2020). However, to the best of our knowledge, no systematic review has focused on (1) identifying both parent and child interventions that assess stress and anxiety outcomes specifically among parents of transition-aged children with ASD, or (2) reviewing the stress and anxiety scales utilized for this population.

## Method

This review was based on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Moher et al., 2009) guidelines.

### Study Eligibility Criteria

Studies were eligible for inclusion if they were peer-reviewed intervention studies assessing stress and/or anxiety using a quantitative self-report scale specifically among parents of transition-aged children with ASD. Non-English language studies were included. However, studies were limited to those published within the last decade (2010–2021) as done similarly in other systematic reviews as it allowed us to focus on recent intervention approaches to ensure relevance to the continuously developing field (Benevides et al., 2020; Hillman et al., 2020). Studies were excluded if they used biomarkers for stress/anxiety or were a medical intervention.

Transition-aged children were defined as those youth with ASD between the ages of 14–22 years old as done in previous literature (Chen et al., 2019). Given that many ASD intervention studies recruit from within a wide age range and do not always stratify groups by age in their demographic information, the number of transition-aged children in a study that met all other inclusion criteria was statistically estimated (if this was not explicit from the manuscript or available from the author).

Estimates were calculated in Excel using *t*-distribution calculations (rather than normal distribution calculations given the small sample sizes in the studies; SAS Institute Inc., n.d.) using the function T.DIST ( $x$ , degrees\_freedom, TRUE). Here,  $x$  was the value at which we wanted to evaluate the distribution (which was calculated twice for each study, for both the upper and lower age range of 22 and 14, minus the reported mean age of the children); degrees of freedom was calculated by subtracting the reported sample size of children by 1; while TRUE reflected the cumulative distribution function. Both T.DIST values (for less than 22 and less than 14) were then subtracted from each other and converted into a percentage. This provided a statistical estimate of the percentage of children who were transition-aged between 14 and 22 in the study. Please see Table 2

for details on the *t*-distribution calculation and estimates. To ensure rigor in the systematic review, studies that were estimated to have at least 50% of children in the transition-age range using the *t*-distribution calculations or author report were included.

### Information Source and Search Strategy

Four databases PsycINFO, MEDLINE, CINAHL, and EMBASE were searched electronically by one reviewer on July 6, 2021, for the period 2010 to 2021 using keyword combinations and indexed vocabulary. The complete search strategy can be seen in Table 1. Reference lists of relevant studies were also hand searched.

### Study Selection

Studies were exported to Covidence (a web-based platform for screening articles for systematic reviews) after duplicates were identified and removed. Two reviewers participated in all stages of the review as outlined in Fig. 1 to minimize bias. In the first stage, both reviewers screened all titles and abstracts to assess eligibility. Substantial inter-rater agreement was obtained (Cohen's kappa value of 0.72) and both reviewers met to discuss discrepancies until they reached an agreement. All studies retained for the second stage of screening for full-text review were also reviewed by both authors to ascertain if studies were an intervention assessing parental stress/anxiety using a self-report quantitative scale among a sample of probable transition-aged youth with ASD.

Of the 294 full-texts reviewed, 246 studies were excluded. Most commonly, this was because children with ASD in the study were not transition-aged. Both reviewers had 100% agreement that the remaining 48 full-text studies needed to be further assessed to estimate if at least 50% of the parents in the study were those of transition-aged children (using *t*-distribution statistics which utilized the sample size and mean age of children from each study, in the event authors had not reported this explicitly). Both reviewers agreed that only 13 studies met the final inclusion criteria.

We requested 14 full texts from the Interlibrary Loan Internet Accessible Database (ILLiad) as they were not accessible via an extensive web-based search. However, the full texts of three studies remained inaccessible (Javad et al., 2018; Sabourin et al., 2013; Sood et al., 2018) and as such could not be included in the review.

### Data Collection and Data Items

The authors of studies that had insufficient details in their manuscript to infer the number of transition-aged children or stress/anxiety scale used were emailed twice if needed. Of

**Table 1** Complete search strategy

Database	Search strategy
Medline Proquest	(MESH.EXACT("Burnout, Psychological") OR MESH.EXACT("Anxiety") OR MESH.EXACT("Psychological Distress") OR MESH.EXACT("Stress, Psychological") OR Anxi* OR stress* OR distress* OR "emotional availability") AND (MESH.EXACT("Single Parent") OR MESH.EXACT("Mothers") OR MESH.EXACT("Fathers") OR MESH.EXACT("Parents") OR Parent* OR mother* OR father* OR family OR families OR maternal OR paternal) AND (MESH.EXACT("Developmental Disabilities") OR MESH.EXACT.EXPLODE("Child Development Disorders, Pervasive") OR ASD OR autism* OR "developmental disability*" OR PDD OR Asperger* OR "developmental disorder" OR "childhood disintegrative" OR "pervasive developmental" OR "high functioning autism")
PsycINFO	(MAINSUBJECT.EXACT("Caregiver Burden") OR MAINSUBJECT.EXACT("Psychological Stress") OR MAINSUBJECT.EXACT("Stress") OR MAINSUBJECT.EXACT("Anxiety") OR MAINSUBJECT.EXACT("Distress") OR Anxi* OR stress* OR distress* OR "emotional availability") AND (MAINSUBJECT.EXACT("Fathers") OR MAINSUBJECT.EXACT("Family") OR MAINSUBJECT.EXACT.EXPLODE("Single Parents") OR MAINSUBJECT.EXACT("Adoptive Parents") OR MAINSUBJECT.EXACT("Mothers") OR MAINSUBJECT.EXACT("Parents") OR Parent* OR mother* OR father* OR family OR families OR maternal OR paternal) AND (MAINSUBJECT.EXACT.EXPLODE("Autism Spectrum Disorders") OR ASD OR autism* OR "developmental disability*" OR PDD OR Asperger* OR "developmental disorder" OR "childhood disintegrative" OR "pervasive developmental" OR "high functioning autism")
CINAHL	Anxi* OR stress* OR distress* OR "emotional availability" OR (MM "Anxiety") OR (MM "Stress, Psychological") OR (MM "Caregiver Burden") AND Parent* OR mother* OR father* OR family OR families OR maternal OR paternal OR (MM "Parents") OR (MM "Adoptive Parents") OR (MM "Biological Parents") OR (MM "Fathers") OR (MM "Mothers") OR (MM "Parents of Disabled Children") AND ASD OR autism* OR "developmental disability*" OR PDD OR Asperger* OR "developmental disorder" OR "childhood disintegrative" OR "pervasive developmental" OR "high functioning autism" OR (MM "Asperger Syndrome") OR (MM "Autistic Disorder") OR (MM "Pervasive Developmental Disorder-Not Otherwise Specified") OR (MM "Developmental Disabilities")
Embase	("anxiety"/de OR "caregiver burnout"/de OR "family stress"/de OR "distress syndrome"/de OR "emotional stress"/de OR anxi* OR stress* OR distress* OR "emotional availability") AND (adoptive AND "parent"/de OR "mother"/de OR "father"/de OR "family"/de OR "parent"/de OR parent* OR mother* OR father* OR family OR families OR maternal OR paternal) AND ("autism"/de OR "asperger syndrome"/de OR "childhood disintegrative disorder"/de OR "pervasive developmental disorder not otherwise specified"/de OR "developmental disorder"/de OR asd OR autism* OR "developmental disability*" OR pdd OR asperger* OR "developmental disorder" OR "childhood disintegrative" OR "pervasive developmental" OR "high functioning autism")

the 17 authors originally contacted, seven did not respond and their studies could not be included in the screening (Benn et al., 2012; Brehm et al., 2021; Ede et al., 2020; Elfert & Miranda, 2015; Hampel et al., 2015; Smith et al., 2012; Whitney & Smith, 2015).

For the 13 studies included in the final review, both reviewers extracted data from each study which was tabulated on an excel spreadsheet to ensure accuracy. Some items which were extracted included the name of the intervention, name(s) of scales used, duration and design of the intervention, and sample size and mean age of the children with ASD.

### Risk of Bias in Individual Studies

All studies which were included in the final review were examined for methodological rigor using a protocol designed by Hawker et al. (2002). This critical appraisal tool evaluates nine components of studies as seen in Table 3. Each component was assessed using a 4-point Likert scale and was scored and summed (4 = good, 3 = fair, 2 = poor, 1 = very poor) resulting in a total quality score for each study. Given the lack of grading parameters by Hawker et al. (2002), this study mirrored those utilized in a recent systematic review:

"high quality" (30–36 points), "medium quality" (24–29 points), and "low quality" (9–23 points; Braithwaite et al., 2017). Two reviewers independently scored and rated each study that qualified for final inclusion, and had differing overall quality ratings for two of the 13 studies. As a result, both reviewers met to discuss each of the nine grading components used by Hawker et al. (2002) until a consensus was reached.

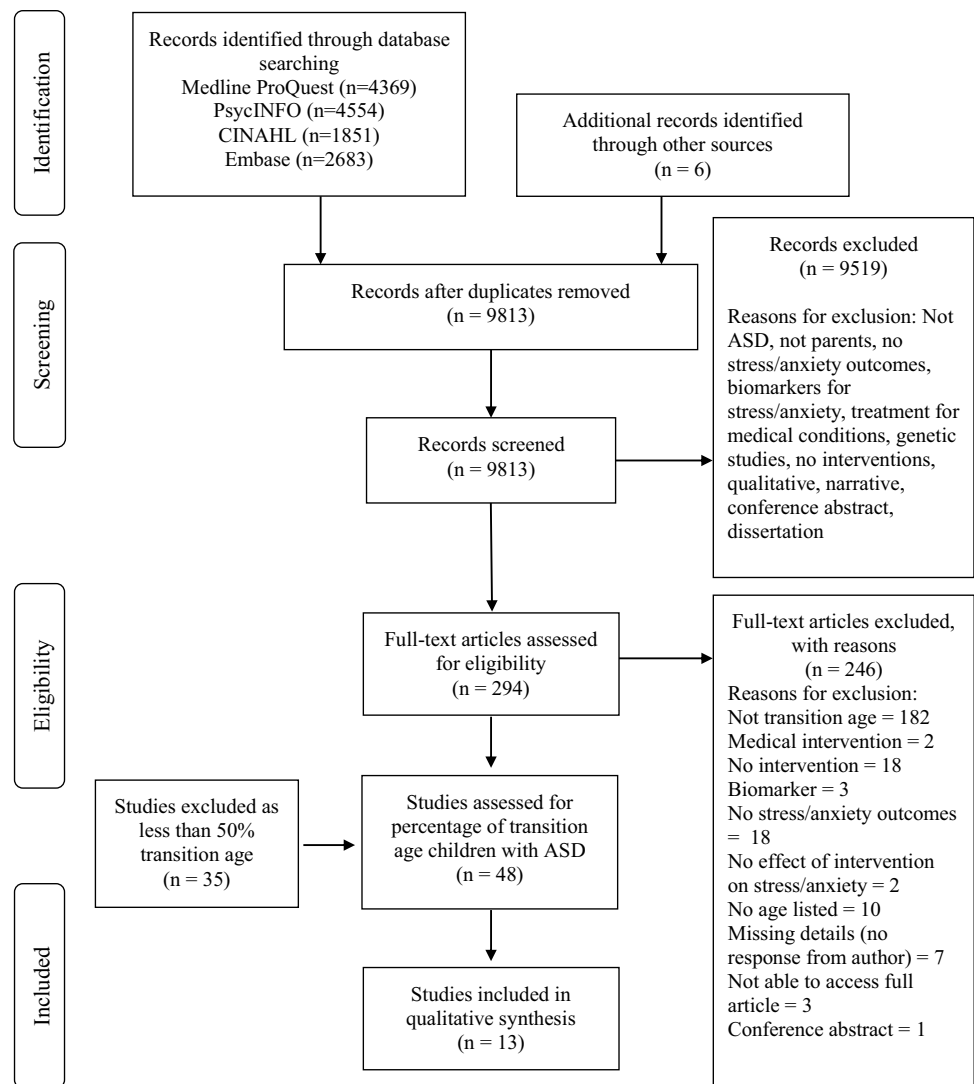
### Synthesis of Results

Data was analyzed and presented qualitatively to identify the characteristics of interventions and stress/anxiety scales utilized.

### Results

A total of 294 full texts were reviewed of which 48 studies were assessed for inclusion based on the 50% criteria for transition-age children with ASD. Reasons for excluding studies were maintained at the full-text stage and can be seen in the PRISMA flowchart (Fig. 1; Moher et al., 2009), but most commonly included a study not targeting

Fig. 1 PRISMA flowchart



parents of transition-age children which was the focus of this review. Only 13 studies met this systematic review's final inclusion criteria. Five studies were conducted in the USA, three in Canada, and one each in Spain, Italy, Australia, Korea, and China. Although all studies in this review were required to meet or exceed the 50% threshold of transition-aged children with ASD, only three studies (Singh et al., 2014; Siracusano et al., 2021; Smith et al., 2018) met this criterion at 100% by specifically targeting this age group (Table 2). Sample sizes in the study ranged from 3 to 77. Quality assessments indicated that 10 studies were of high quality, one of medium quality, and two of low quality (Table 3). The most common reason impacting quality scores was sampling as many studies did not justify their sample size, had small sample sizes, or did not explain the recruitment source and attrition sufficiently.

## Interventions

A review of the 13 studies revealed that most interventions targeted parents only ( $n=8$ ) rather than both parent and child simultaneously ( $n=5$ ). Of the studies that focused only on parent-targeted interventions, three studies further limited their focus to only mothers of children with ASD. Overall, interventions were broadly designed to address stressors related to either (1) the child's challenging behaviors, emotional regulation, relationships, and social functioning, or (2) parental wellbeing via mindfulness practices. Only two studies specifically addressed the needs of children with ASD transitioning to adulthood (Siracusano et al., 2021 and Smith et al., 2018) and two offered a virtual intervention (Lunsky et al., 2021 and Siracusano et al., 2021). The following section summarizes the characteristics of the 13 interventions

**Table 2** *T*-distribution calculations

Authors	Child ( <i>n</i> )	Child		For 22: <i>X</i> = age limit—mean	For 14: <i>X</i> = age limit—mean	df = <i>n</i> - 1	TDIST: less than 22	TDIST: less than 14	<i>T</i> -DIST final value	% children between 14 and 22
		Age range	Mean							
Bellone et al. (2021)	13	7 to 18	10.9	11.1	3.1	12	1.000	0.9954	0.0046	0.46
Bourke-Taylor et al. (2019)	36	5—19	10.1	11.9	3.9	35	1.00	0.9997	0.0002	0.02
Choque et al. (2017)	150	7—17	12.05	9.95	1.95	149	1.00	0.9734	0.0265	2.65
	146		11.59	10.41	2.41	145	1.00	0.9913	0.0086	0.86
Clifford & Minnes (2013)	20	2—22	9.32	12.68	4.68	19	1.00	0.9999	0.000	0.01
	25	3—17	9.81	12.19	4.19	24	1.00	0.9998	0.000	0.02
Corona et al. (2019)	25	12—17	13.8	8.2	0.2	24	1.00	0.5784	0.422	42.16
Dykens et al. (2014)	243	2—54	10.85	11.15	3.15	242	1.00	0.9990	0.001	0.09
Ferraioli & Harris (2013)	15	NR	NR	-	-	-	-	-	-	6.60*
Fung et al. (2018)	33	3—20	10.4	11.6	3.6	32	1.00	0.9994	0.001	0.05
Ghoneim (2018)	30	3—18	7.36	14.64	6.64	29	1.00	0.9999	0.000	0.00
Gika et al. (2012)	11	4.5—17	7.5	14.5	6.5	10	1.00	0.9999	0.000	0.00
Hall et al. (2016)	42	3—16	11.63	10.37	2.37	41	1.00	0.9887	0.011	1.13
	28		11.21	10.79	2.79	27	1.00	0.9952	0.005	0.48
Ho et al. (2021)	19	10 to 18	13.7	8.3	0.3	18	1.000	0.616	0.383	38.38
	18		12.5	2.1	1.5	17	1.000	0.924	0.075	7.60
Hwang et al. (2015)	6	8—15	11.16	10.84	2.84	5	0.99	0.9818	0.018	17.00*
Johnson et al. (2014)	32	0—19	10.3	11.7	3.7	31	1.00	0.9995	0.000	0.04
Jones et al. (2018)	21	4—16	10.53	11.47	3.47	20	1.00	0.9987	0.001	0.12
Jonsson et al. (2019)	23	8—17	13.04	8.96	0.96	22	1.00	0.8262	0.174	17.37
	27		12.63	2.83	1.37	26	1.00	0.9087	0.091	9.12
Karst et al. (2015)	32	11—16	14.1	7.9	-0.1	31	1.00	0.4604	0.540	<b>53.95</b>
	32		13.4	1.5	0.6	31	1.00	0.7235	0.276	27.64
Kuhlthau et al. (2020)	51	2 to >17	NR	-	-	-	-	-	-	29.4*
Lunsky et al. (2021)	40	16—39	20.92	5.32	-6.92	39	0.857	1.38	0.856	<b>85.66</b>
Lunsky et al. (2018)	40	3—20	10.4	4.36	3.6	39	1.00	0.9995	0.000	0.04
Lunsky et al. (2017)	26	16—40	22.7	5.4	-8.7	25	0.245	0.000	0.245	24.52
	24	17—38	22.7	6	-8.7	23	0.24	0.000	0.245	24.55
Lunsky et al. (2015)	22	NR	21.1	7.1	-7.1	21	0.81	0.000	0.811	<b>81.08</b>
Martin et al. (2019)	137	3—28	9.7	12.3	4.3	136	1.00	0.9999	0.000	0.00
Mazzucchelli et al. (2018)	6	12—16	15.14	1.53	-1.14	-	-	-	-	<b>66.7*</b>
McConkey & Samadi (2013)	28	3—17	7.82	4.86	6.18	27	1.00	0.9999	0.000	7.00*
McLay et al. (2022)	41	3—15	7.19	3.48	6.81	40	1.000	1	1.73	0.00
Medda et al. (2021)	24	4—19	9.42	8.6	4.58	23	1.000	0.9999	6.63	0.01

**Table 2** (continued)

Authors	Child (n)	Child		For 22: X = age		For 14: X = age		df = n-1	TDIST: less than 22	TDIST: less than 14	T-DIST final value	% children between 14 and 22
		Age range	Mean	SD	limit—mean	limit—mean						
Mills et al. (2021)	63	3—25	11.3	7.2	10.7	2.7	2.7	62	1.000	0.9955	0.004	0.45
Moss et al. (2014)	26	8—17	11.74	2.53	10.26	2.26	2.26	25	1.00	0.9836	0.016	1.64
Radley et al. (2014)	3	10—14	12.4	NR	9.6	1.6	1.6	2	0.99	0.8746	0.120	33*
Ridderinkhof et al. (2018)	45	8—19	13.03	2.72	8.97	0.97	0.97	44	1.00	0.8313	0.169	16.87
Rios et al. (2020)	23	3—20	11.26	4.34	10.74	2.74	2.74	22	1.000	0.994	0.0059	0.60
Ruble et al. (2018)	36	2.3—15	6.9	3.9	15.1	7.1	7.1	35	1.00	0.9999	0.000	0.00
Ruiz-Robledillo et al. (2015)	6	NR	15	6.48	7	-1	-1	5	0.999	0.1816	0.818	<b>81.79</b>
Salem-Guirgis et al. (2019)	23	12—23	15.65	2.57	6.35	-1.65	-1.65	22	1.00	0.0565	0.943	<b>94.34</b>
Samadi et al. (2013)	37	3—17	8.2	2.92	13.8	5.8	5.8	36	1.00	0.9999	0.000	8.6*
Schiltz et al. (2018)	NR	11—16	13.58	1.46	8.42	0.42	0.42	-	-	-	-	<b>54.54*</b>
Schultz et al. (2012)	16	11—14	12.68	1.36	9.32	1.32	1.32	15	1.00	0.8966	0.103	10.33
	10		12.62	1.13	9.38	1.38	1.38	9	1.00	0.8995	0.100	10.04
Singh et al. (2019)	47	13—17	15.15	NR	6.85	-1.15	-1.15	46	1.00	0.1280	0.872	<b>87.20</b>
	45	13—17	15.56	NR	6.44	-1.56	-1.56	44	1.00	0.0629	0.937	<b>93.70</b>
Singh et al. (2021)	65	9—14	12.17	1.62	9.83	1.83	1.83	64	1.00	0.9640	0.036	3.60
	65		11.8	1.65	10.2	2.2	2.2	64	1.00	0.9842	0.016	1.57
	65		11.95	1.68	10.05	2.05	2.05	64	1.00	0.9777	0.022	2.22
Singh et al. (2014)	3	15—19	16.66	NR	5.33	2.66	2.66	-	-	-	-	<b>100.00*</b>
Siracusano et al. (2021)	23	14—20	16.82	-	-	-	-	-	-	-	-	<b>100.00*</b>
Smith et al. (2018)	16	14—17	15.56	-	-	-	-	-	-	-	-	<b>100.00*</b>
	25		15.36	-	-	-	-	-	-	-	-	<b>100.00*</b>
Spruin et al. (2018)	11	10—16	12.7	2.12	9.3	1.3	1.3	10	1.00	0.8886	0.111	11.14
Verschuur et al. (2019)	13	8—14	11.2	2.2	10.8	2.8	2.8	12	1.00	0.9919	0.008	0.80
	13	3—11	6.11	3.2	15.89	7.89	7.89	12	1.00	0.9999	0.000	0.00
Wright et al. (2015)	38	2—16	8.76	2.86	13.24	5.24	5.24	37	1.00	0.9999	0.000	0.00
	24		9.25	4.08	12.75	4.75	4.75	23	1.00	0.9999	0.000	0.00
Yoo et al. (2014)	23	12—18	14.04	1.64	7.96	-0.04	-0.04	22	1.00	0.4842	0.516	<b>51.58</b>
	24		13.54	1.5	8.46	0.46	0.46	23	1.00	0.6750	0.325	32.49
Zu et al. (2019)	8	4—20	11.75	2.32	10.25	2.25	2.25	7	1.00	0.9704	0.030	2.96
	8		14.13	5.07	7.87	-0.13	-0.13	7	0.99	0.4501	0.550	<b>54.98</b>

Note: Numbers in bold typeface identify studies which meet or exceed the criteria of having at least 50% of children with ASD between the ages of 14 and 22

NR not reported

\* Actual percentage of transition-aged children as reported in study or author response to email

**Table 3** Quality rating of individual studies

Author (year)	Title and abstract	Introduction and aims	Method and data	Sampling	Data analysis	Ethics and bias	Findings and results	Transferability/generalizability	Implication usefulness	Total score	Quality rating
Karst et al. (2015)	4	4	4	3	4	4	4	3	3	33	High
Lunsky et al. (2015)	4	4	3	3	3	4	3	3	4	31	High
Lunsky et al. (2021)	3	4	4	3	4	3	4	3	4	32	High
Mazzucchelli et al. (2018)	4	4	3	2	3	4	4	3	3	30	High
Ruiz-Robledillo et al. (2015)	4	3	4	2	4	3	4	2	4	30	High
Salem-Guirgis et al. (2019)	4	4	3	3	4	4	4	3	3	32	High
Schiltz et al. (2018)	3	3	2	2	4	2	4	2	3	25	Medium
Singh et al. (2019)	3	3	3	3	4	4	4	4	4	32	High
Singh et al. (2014)	4	3	4	4	4	4	4	4	3	34	High
Siracusano et al. (2021)	4	2	2	2	2	3	4	2	2	23	Low
Smith et al. (2018)	4	4	4	4	4	4	4	3	3	34	High
Yoo et al. (2014)	4	4	4	3	4	4	4	3	4	34	High
Zu et al. (2019)	2	2	2	3	3	2	3	2	2	21	Low

and highlights their unique components under the following sub-headings: mindfulness, social functioning through the Program for the Education and Enrichment of Relational Skills (PEERS) intervention, and multi-component interventions (Rutherford et al., 2019). See Table 4 for study details.

### Mindfulness

Six intervention studies in this review directly targeted the parent's ability to cope with stress and manage their mental health. Lunsky et al. (2015) offered 22 parents a "Coping with Stress" intervention designed to enhance mindfulness, cope with stress, and improve mindful parenting. The intervention comprised of components from both the mindfulness-based cognitive therapy (MBCT) and mindfulness-based stress reduction (MBSR) programs, which included training and discussions, meditation practices, and breathing exercises. The "loving-kindness meditation" which is part of MBSR was especially relevant to address the guilt many parents feel in regard to their caregiving and frustration towards their child. To ensure that the intervention allowed parents to support each other, the number and length of the sessions were increased. Moreover, to accommodate older parents, all session activities were simplified and conducted sitting on a chair, and the voices of the facilitators were louder. The intervention was found to reduce stress in parents from pre- to post-intervention as measured by the stress subscale from the Depression Anxiety and Stress Scale (DASS-21), although no significant change was reported in mindfulness or mindful parenting.

A previously administered in-person intervention by Lunsky et al. (2017) was modified to an online platform to make it suitable for busy caregivers in a recent study by Lunsky et al. (2021). This mindfulness intervention offered to 39 parents aimed to assess the effectiveness of a virtual intervention, and its impact on parental stress, depression, and mindfulness. As such, adapted sessions were shortened and a technology facilitator and two-parent advisors provided support. Findings from the study indicated that parents were satisfied with the virtual program and had improved levels of mindfulness, and lower levels of stress and depression maintained at 3-month follow-up as measured by the DASS-21.

Ruiz-Robledillo et al. (2015) implemented a pilot "Mindfulness-Based Program" (MBP) intervention with six parents of adolescents with ASD and seven parents of typically developing adolescents. Both groups of parents attended sessions which were comprised of meditations, training, discussions, and breathing exercises. The intervention aimed to improve parental mood (anxiety, negative mood, and feelings of anger), health, and stress (which unique to this study was assessed using cortisol levels, and as such excluded as a variable of interest for this review). However, aligned with the focus of this systematic review, the study



**Table 4** Characteristics of studies included in final review

Author (year)	Name of intervention	Name of stress/anxiety scale	Intervention participant	Sample size & demographics of parents	Duration	Design	Assessment	Outcomes of interests	Unique components
<b>Mindfulness interventions</b>									
Lunsky et al. (2021)	Group Virtual Mindfulness-Based Intervention	Depression, Anxiety, and Stress Scale – Modified 14-item	Parent (mothers & fathers)	$n = 39$ $F = 89.7\%$ Age $M (SD) = 52.68 (6.87)$	6 weeks (6 sessions; 1.5 h each)	Single group; no control	3 (pre, post, and at 3-month follow-up)	Parental stress, depression, and mindfulness	Virtual synchronous delivery, parent advisors
Lunsky et al. (2015)	Coping with Stress	Stress subscale from the Depression Anxiety Stress Scale	Parent (mothers & fathers)	$n = 22$ $F = 86.4\%$ Age $M (SD) = 56.7 (9.2)$	6 weeks (6 sessions; 2 h each)	Single group; no control	2 (pre and post)	Mindfulness, mindful parenting, and stress	Adapted to older parents
Ruiz-Robledo et al. (2015)	MBP: Mindfulness-Based Program	State Anxiety Inventory (Spanish)	Parent (mothers & fathers)	$n = 6$ & $7$ $F = 92.3\%$ Age $M (SD) = 46.3 (4.32)$ 83.3% married; 83.3% university education; 75% employed; 83.3% do not use cigarettes; BMI 24.81	5 weeks (9 sessions; 2 h each)	Two groups	3 (pre, mid, and post)	Anxiety, mood and anger, health and stress	Stress measured through cortisol markers
Salem-Guirgis et al. (2019)	MYMind	Depression, Anxiety, and Stress Scale	Parent (mothers and fathers) & Child	$n = 23$ $F = 87\%$ Age $M (SD) = 50.5 (5.25)$ 71.4% White; 39.1% university degree; 78.3% married; 42.9% employed full-time	9 weeks (9 sessions; 1.5 h each) + 1 booster session (9 weeks post-program)	Single group; no control	4 (2 pre and 2 post)	Mindfulness, parent depression, stress and anxiety and youth emotion regulation and autism symptoms	Both parent and child included in a mindfulness intervention

Table 4 (continued)

Author (year)	Name of intervention	Name of stress/anxiety scale	Intervention participant	Sample size & demographics of parents	Duration	Design	Assessment	Outcomes of interests	Unique components
Singh et al. (2019)	MBPBS: Mindfulness-Based Positive Behavior Support	Perceived Stress Scale-10	Parent (only mothers)	$n=47$ & 45 $F=100\%$ Age $M=47.91$ & 48.82	40 weeks (10-week control period; 3 sessions held over 3 days and 30 weeks of practice)	Two groups; no control	3 (2 pre and 1 post)	Maternal stress levels and aggressive, disruptive, and compliance behaviors among children	Two components of intervention: mindfulness and support for challenging behaviors in children
Singh et al. (2014)	MBPBS: Mindfulness-Based Positive Behavior Support	Perceived Stress Scale-10	Parent (only mothers)	$n=3$ $F=100\%$ Age $M=40.3$	48 weeks (1 pre-training session followed by 4 weeks of practice, then 8 sessions over 8 weeks followed by practices at home)	Single group; no control	4 (2 pre and 2 post)	Maternal stress levels of mothers, and aggressive, disruptive, and compliance behaviors among children	One-on-one training; Two components of intervention: mindfulness and support for challenging behaviors in children; 100% transition age
Social functioning interventions									
Karst et al. (2015)	PEERS	Stress Index for Parents of Adolescents	Parent (mothers and fathers) & Child	$n=32$ & 32 $F=73\%$ Age $M$ (SD) = 46.1 (4.6) & 46.6 (5.6)	16 weeks (14 sessions; 1.5 h each)	Two groups	2 (pre and post)	Family chaos, parenting stress, and parenting self-efficacy	Small groups; randomized control trial
Schiltz et al. (2018)	PEERS	Stress Index for Parents of Adolescents & Beck Anxiety Inventory	Parent (mothers and fathers) & Child	$n=77$ $F=80.52\%$ Age $M=46.6$ (4.96) 88.3% White; 90.9% non-Latino; 45.5% household income over 100 K	14 weeks (14 sessions; 1.5 h each)	Two groups	2 (pre and post)	Child's challenging and social behaviors, parental stress, depression and anxiety and parental involvement	Small groups; Randomized control trial

Table 4 (continued)

Author (year)	Name of intervention	Name of stress/anxiety scale	Intervention participant	Sample size & demographics of parents	Duration	Design	Assessment	Outcomes of interests	Unique components
Yoo et al. (2014)	PEERS – Korean Version	State and Trait Anxiety Inventory	Parent (mothers and fathers) & Child	$F = 99.5\%$	14 weeks (14 sessions; 1.5 h each)	Two groups	3 (1 pre and 2 post including one at 3-month follow-up)	Teens social ability, ASD symptoms, depression, anxiety and behavioral problems. Parental depression, state and trait anxiety	Culturally adapted PEERS intervention in Korean; Randomized control trial
Multi-component interventions									
Mazzucchelli et al. (2018)	Building Bridges Triple P	Depression Anxiety Stress Scales	Parent (mothers and fathers)	$n = 9$	8 weeks (8 sessions; 11.5 h total)	Single group; no control	3 (1 pre and 2 post including one at 3-month follow-up)	Adolescent problem behaviors; parent dysfunctional disciplining styles; parent depression, anxiety and stress	In-person and phone sessions; parents identify a goal they want to achieve
Siracusano et al. (2021)	TrASDition Training	Parental Stress Index Short Form	Parent (mothers and fathers)	None reported	6 months (6 videos; 20 min each)	Single group; no control	2 (pre and 6 month follow-up)	Child's adaptive functioning, repetitive and problematic behaviors and parental stress	Virtual delivery; high and low functioning ASD; focus on transition challenges; 100% transition age
Smith et al. (2018)	Transitioning Together	Perceived Stress Scale-10	Parent (mothers and fathers) & Child	$n = 16$ & $25$ $F = 88\%$ 95% White; 75% completed bachelor's degree; Median household income \$75,000	8 weeks (8 sessions plus 2 pre-family joining sessions)	Two groups	2 (pre and post)	Parent depression, general life stress, and problem-solving, parent-child relationships and adolescent outcomes (social interactions, autism symptoms and social engagement)	Focus on transition period; parents identify goals in joining sessions; 100% transition age

Table 4 (continued)

Author (year)	Name of intervention	Name of stress/anxiety scale	Intervention participant	Sample size & demographics of parents	Duration	Design	Assessment	Outcomes of interests	Unique components
Zu et al. (2019)	Psychoeducational intervention: social skills training (PEERS) & knowledge about ASD	Beck Anxiety Inventory (Chinese)	Parent (only mothers)	$n = 8$ & $8$ $F = 100\%$ Age $M$ (SD) = 43.63 (3.6) & 43.63 (9.06) 100% completed minimum high school; most full-time homemakers	12 weeks (12 sessions; 1.5 h each)	Two groups; no control	3 (pre-mid-post)	Parents' positive/negative language, depression, anxiety and child's ASD symptoms	Speech patterns of mothers

$F$  female, Age  $M$  (SD) age mean (standard deviation)

measured levels of state anxiety using the Spanish version of the State-Trait Anxiety Inventory (STAI-S). Findings indicated that although both groups of parents saw improved depression, somatic symptoms, and general health over the course of the intervention, the caregiver group experienced a greater change. However, anxiety, mood, and stress were improved only when each pre-post session was evaluated independently versus any statistically significant change over the intervention period.

Singh et al. (2014) undertook a proof-of-concept study with three mothers of transition-aged children with ASD. The intervention "Mindfulness-Based Positive Behavior Support" (MBPBS) combined one-on-one mindfulness-based training with knowledge on how to integrate positive behavior support (PBS). The decision to pair both mindfulness and PBS components was intended to overcome the stress, frustration, fatigue, and attrition parents report when participating in behavioral training programs. Moreover, this intervention was designed to support personal transformation (i.e., supporting more than just reductions in parental distress) which would allow mothers to intuitively apply mindfulness practices when managing challenging behaviors. The intervention assessed changes in the child's incidence of aggression, disruptive behaviors, compliance with instructions, and parental stress. All outcomes, including parental stress which was measured using the Perceived Stress Scale-10 (PSS-10), showed statistically significant improvement across the intervention.

Singh et al. (2019) conducted a larger-scale MBPBS intervention study using two groups: 47 mothers of adolescents with ASD and 45 mothers of adolescents with intellectual disability (ID). Both groups participated in the MBPBS intervention similar to the previous study (Singh et al., 2014) where mothers in both groups observed their child's daily aggressive and disruptive behaviors and assessed compliance. These were found to be statistically improved among both ASD and ID groups. In addition, self-report stress levels of mothers as assessed by the PSS-10 were also significantly reduced among both groups.

Salem-Guirgis et al. (2019) conducted the "Mymind" mindfulness intervention with 23 parents and 23 youth with autism, making it the only mindfulness intervention in this review to offer concurrent sessions to both parent and child dyads which encompassed mindfulness content and cognitive behavior therapy. Similar to the other studies discussed above, both groups learned mindfulness-based skills, meditations, breathing exercises, and reviewed practices for homework. In addition, parents in this study were taught how to support their children to reinforce mindfulness practices at home. It was hypothesized that youth with ASD would report improved emotional regulation and autism symptoms, and both groups would experience enhanced mental health and mindfulness across

the intervention. Youth with ASD experienced improved emotional regulation, autism symptoms, and adaptive skills but no change in mindfulness at any time point. Parents reported improved mindfulness, but no significant changes in regards to parental depression, anxiety, or stress as assessed by the DASS-21 across the intervention or post-program. However, interestingly, there was some improvement in parental mental health outcomes during the baseline period which the authors noted as a potential waitlist effect.

### Social Functioning—the PEERS Intervention

Of the 13 studies included in this review, three studies directly targeted the persistent challenges related to social functioning, communication, and behaviors common among children with ASD. These studies utilized the PEERS intervention (Laugeson & Frankel, 2010) which is designed for “adolescents with high-functioning ASD” (Karst et al., 2015, p. 752) and included both parent and child participants. Parent involvement and participation is an important characteristic of the PEERS program for two reasons: first, to ensure that parents can support their child in generalizing the acquired social skills to their day-to-day life, and second, to address family factors (such as parenting self-efficacy) that influence the child’s environment and success.

Karst et al. (2015) undertook a randomized control trial with 64 parent–child dyads (with 32 pairs in the experimental and waitlist control group respectively). The intervention aimed to enhance social functioning by providing skills and training about “initiating and maintaining friendships in adolescence” using current social and relationship norms (Karst et al., 2015, p. 757) in a small group format. Parent–child dyads participated in sessions separately but simultaneously. Adolescent sessions encompassed homework review, delivery of a new lesson (such as handling disagreements, and appropriate use of humor), and active participation through role-play and rehearsals. Parent sessions reviewed the homework assignments their child had already finished or would be completing and discussed the contents of that week’s lesson. Parent discussions were encouraged to remain within the context of the PEERS program rather than extending to informal support conversations. Using a pre-post assessment, outcomes related to parenting self-efficacy, family chaos, and stress (as measured by the Stress Index for Parents of Adolescents; SIPA) were assessed. All outcomes had observed reductions in the experimental group, although they were not statistically significant.

A study by Schiltz et al. (2018) also examined the effects of the PEERS intervention on youth with ASD and their parents ( $n=77$ ) using a subsample from another randomized control trial of the PEERS study which did not assess parent outcomes (Schohl et al., 2014). In addition to assessing the impact of the *intervention* on parent depression and anxiety

in this study using the Beck Anxiety Inventory (BAI), the authors examined the association between the child’s *challenging behaviors* and parental stress (as measured by the SIPA), depression, and anxiety and the influence of these factors on parental involvement (defined as “frequency of parent–child interactions and parental awareness of events and activities in their child’s life”; Schiltz et al., 2018, p. 1170). Findings confirmed the effect of challenging behaviors on parental stress, depression, and parental involvement. Although the effect of the intervention on levels of parental stress was not measured, the intervention lowered parental depression but was only modestly significant, with no statistically significant change in levels of anxiety.

A culturally adapted version of the PEERS intervention was conducted in South Korea by Yoo et al. (2014). Although the overall structure and elements of the original manualized intervention were retained as explained in detail earlier, the authors adapted the sessions for relevance to Korean youth (such as jokes, common social networking sites, and teen activities). Using a randomized control design, 23 parent–child dyads participated in the intervention group with another 24 dyads in the delayed treatment control group. Both self-report and observational data were used to assess outcomes from this intervention. Teens with ASD in the intervention group demonstrated statistically significant improvement in “social skills knowledge, interpersonal skills, and play/leisure skills” (Yoo et al., 2014, p. 145) in addition to a reduction in ASD and depressive symptoms. Parental depression in the experimental group reduced significantly from pre- to post-, while state and trait anxiety of parents as measured by the STAI-S revealed a statistically significant reduction in state anxiety among mothers of the intervention group. Unfortunately, at the 3-month follow-up, no significant maintenance effects were detected.

### Multi-Component Interventions

Four studies in this review offered interventions encompassing multiple components within their sessions which included skills for managing challenging behaviors, emotional support for parents, training on managing emotions, and parent education on topics such as social skills, knowledge about ASD, and transitions. Three studies targeted only the parent while one study included both parent and child in the intervention.

Zu et al. (2019) designed an intervention to address emotional management and enhance social skills training for mothers of children with ASD. Mothers from two different cities, Shanghai ( $n=8$ ) and Taichung ( $n=8$ ), participated in a semi-structured intervention that focused on providing mothers a forum to share feelings and have discussions. In addition, a new topic was covered at each session such as knowledge about ASD, availability of social

services, holding realistic expectations, managing marital relationships, and seeking social support from others. One session specifically focused on teaching mothers how to promote social skills among their children utilizing the PEERS method. Zu et al. (2019) did not provide details on what aspects of the extensive PEERS topics were covered in the 1-day session dedicated to social skills training. Furthermore, unlike the previously described studies which used the PEERS intervention, Zu et al. (2019) only included parents in the intervention. A unique aspect of this study, however, was the evaluation of the mothers' speech patterns (as mothers may use negative language in response to their child's challenging behaviors) which may lead to worsening parent-child responses. During the intervention and across both groups, "frequency of positive emotional words increased and negative emotional words decreased" (Zu et al., 2019, p. 1). Depression levels were significantly decreased across both groups and throughout the intervention, while anxiety as measured by the Chinese version of the BAI was reduced but not statistically significant. Although children were not part of the intervention, they were assessed for autism symptoms. These were reduced throughout the intervention which the authors contributed to the improved maternal positive speech, depression, and anxiety levels.

Mazzucchelli et al. (2018) conducted a pilot study to assess the feasibility of the "Building Bridges Triple P" (BBTP) manualized intervention. The BBTP was designed to specifically target the unique needs of parents of adolescents with ASD by providing training and education in the following areas: (a) enhancing parent's understanding of their teenager's behaviors, (b) building skills to teach their child appropriate behaviors and manage challenging behaviors, and (c) encouraging their child to be socially engaged. Nine parents attended group sessions that were designed to provide peer support and also participated in private telephone sessions to address each family's individual needs. The intervention was further tailored for each family, by asking parents to identify a target behavior in their adolescent they desired to change, and a percentage for improvement that would signify the accomplishment of their goal. Behaviors that parents selected to change in their adolescents included "spending less time on the computer or iPad, going to bed and not using electronic devices by 9 pm, and talking positively to siblings" (Mazzucchelli et al., 2018, p. 52). All except one parent reported an accomplishment of their goal by the end of the program. It was also expected that parent-report of their adolescent behavior and emotional and prosocial problems would improve, along with positive changes in parent outcomes of parenting self-efficacy, discipline style, and depression, stress, and anxiety which was measured using the DASS-21. Findings indicated an improvement in adolescent behavior, and all parental

outcomes at post-intervention and statistically significant improvement at the 3-month follow-up for all outcomes except for parental anxiety.

Smith et al. (2018) designed a manualized intervention called "Transitioning Together" which specifically targeted the period of transition, ensuring that the needs of families and their adolescents with ASD leaving high school were met. Using a randomized waitlist control design, 16 parent-child dyads participated in the intervention group while 25 were part of the control group. Prior to the commencement of the intervention, parent-child dyads and invited family members attended private "joining sessions" (Smith et al., 2018, p. 6) designed to build rapport and discuss goals. Following this, dyads attended sessions held concurrently but in separate rooms. Parent sessions addressed content such as ASD in adulthood, planning for post-secondary education and employment, problem-solving, community involvement, and legal issues such as guardianship and trusts. Sessions also provided parents an opportunity for social support. Adolescent sessions covered social skills, goal setting, and, similar to the parent sessions, problem-solving. Using a pre-post intervention assessment, parent depression, stress, and problem-solving skills were measured. In addition, parent-child relationships were measured by quality, burden, expressed emotion about their child related to positivity, happy/proud, warmth, and criticism, while adolescent outcomes were related to social interactions, autism symptoms, and social engagement. Parents in the intervention group showed statistically significant improvement in depression and problem-solving, but no change in stress as measured by the PSS-10 and parent-child relationships. Changes in adolescents' autism symptoms were not significant in the intervention group, although social interactions and social engagement increased significantly.

Siracusano et al. (2021) designed a virtual program "TrASDition Training" to teach 23 parents of transition-age youth the skills and strategies necessary to navigate the transitional period. Parents were provided access to six online video lessons addressing six critical themes: communication, adaptive skills, interpersonal relationships, change, daily skills scheduling, and sexuality. Each video was designed with specific goals and suitable for both "low- and high-functioning ASD individuals" (Siracusano et al., 2021, p. 4). Parents also participated in weekly phone calls with the research team over the 6 months to ensure they were actively engaged with the online program. The study measured parental adaptive functioning, parental stress (as measured by the Parental Stress Index Short Form; PSI-SF), and repetitive and problematic behaviors of ASD youth. Findings revealed a significant improvement in adaptive functioning and stress, but no significant decrease in problematic ASD behaviors.

## Stress and Anxiety Scales

In this review, six different scales to assess parental stress/anxiety were identified. Seven studies only assessed stress, three studies only measured anxiety, and three studies assessed both stress and anxiety. The section below highlights the characteristics of each of the six scales.

### Depression, Anxiety and Stress Scale – 21 (DASS-21; Lovibond & Lovibond, 1995)

The DASS-21 contains three subscales to assess depression, anxiety, and stress. Each subscale comprises seven questions for a total of 21 questions. Using a 4-point scale (0 = “did not apply to me at all” to 3 = “applied to me very much”), participants report on how they felt over the past week. The DASS-21 was utilized by four studies within this review, with two studies using the full scale (Mazzucchelli et al., 2018; Salem-Guirgis et al., 2019), one using only the stress and depression subscales (Lunsky et al., 2021), and one study using only the stress subscale (Lunsky et al., 2015). Two studies (Lunsky et al., 2015; Salem-Guirgis et al., 2019) pointed out that it was possible that the scales used were not sensitive enough to assess changes in participants from pre-post intervention. Lunsky et al. (2015) also noted that perhaps utilizing alternate stress scales such as the Parental Stress Scale (PSS; Berry & Jones, 1995) or the Parenting Stress Index (PSI; Abidin, 1995) may be a more useful measure. They elaborated that the Isolation subscale of the PSI would be especially useful to assess the impact of interventions that provide parental support on feelings of isolation.

### Perceived Stress Scale-10 (PSS-10; Cohen & Williamson, 1988)

The PSS-10 assesses the perceived level of stress in the past month and measures the frequency with which participants find their lives to be unpredictable, overloaded, and uncontrollable. The scale uses a 5-point scale (0 = “never” to 4 = “very often”) to provide a total score of *general life stress*, with higher totals indicating greater levels of stress. Three studies utilized the PSS-10 in this review (Singh et al., 2014, 2019; Smith et al., 2018). The use of this scale was questioned by Smith et al. (2018) given that this scale measures general life stress rather than stress related to parenting an adolescent with ASD. As such, the authors also suggested the use of the PSI (Abidin, 1995) or the Questionnaire on Resources and Stress (Konstantareas et al., 1992) as a more suitable and sensitive measure.

### Parental Stress Index—Short Form (PSI-SF; Abidin, 1995)

The PSI-SF is designed to assess the level of stress among parents of children between 3 months and 10 years old and is an abbreviated 36-item scale derived from the full PSI. The PSI-SF is grouped into three subscales: Parental Distress, Parent–Child Dysfunctional Interaction, and Difficult Child. For 33 of the items, respondents use a Likert scale (1 = “strongly disagree” to 5 = “strongly agree”) while 3 items follow a non-Likert response choice. Only one study utilized the PSI-SF in this review (Siracusano et al., 2021) and explained that this scale was chosen to specifically capture parental stress versus general life stress.

### Stress Index for Parents of Adolescents (SIPA; Sheras et al., 1998)

The SIPA is a 90-item scale that identifies areas of stress with regard to three specific components arising from parent-adolescent interactions: The Adolescent Domain, Parent Domain, and the Adolescent-Parent Relationship Domain. Scores from each of these are summed to provide a total parenting stress score. The SIPA is designed specifically for parents of adolescents between the ages of 11 to 19 years and was used by two studies in this review (Karst et al., 2015; Schiltz et al., 2018). Although Karst et al. (2015) used the SIPA, they pointed out the need to further examine the effect of the PEERS intervention on stress “with an increased sample size and/or use of a more sensitive measure (perhaps an ASD-focused instrument)” (Karst et al., 2015, p. 761). Similarly, Schiltz et al. (2018) referred to the need for more measures that are validated for an ASD sample.

### Beck Anxiety Inventory (BAI; Beck & Steer, 1990)

The BAI assesses levels of anxious symptoms an individual experienced over the past month. The 21 items have four Likert scale options (0 = “not at all” to 3 = “severely—it bothered me a lot”) which when summed provides a total score indicating minimal, mild, moderate, or severe levels of anxiety. Two studies used the BAI in this review (Schiltz et al., 2018; Zu et al., 2019) with one using the Chinese version of the scale (Zu et al., 2019). These authors also expressed concern about the limitations of the BAI due to the “specific components of anxiety that the BAI measures,” which may not reflect the worry or rumination that parents of adolescents with ASD may experience (Schiltz et al., 2018, p. 1176).

### State and Trait Anxiety Inventory (STAI-S and STAI-T; Spielberger et al., 1983)

The STAI-S and STAI-T are each 20-item scales that measure two different types of anxiety. The STAI-S measures state anxiety which assesses temporary feelings of anxiousness at the current moment while the STAI-T measures trait anxiety, which determines the stable levels of anxiety an individual experiences. Participants self-report using a 4-point Likert scale (0 = “nothing” to 4 = “plenty”). One study in this review used only the STAI-S administered using the Spanish version (Ruiz-Robledillo et al., 2015) and a second study used both the STAI-S and STAI-T in the Korean form (Yoo et al., 2014).

## Discussion

This systematic review examined interventions that addressed stress and/or anxiety among parents of transition-aged youth with ASD and the respective scales used to assess these mental health outcomes. Despite the vast literature base which was reviewed, only 13 studies met the inclusion criteria of which only three studies specifically targeted the transition-age group (Singh et al., 2014; Siracusano et al., 2021; Smith et al., 2018) and only two interventions focused on stressors directly related to transitioning to adulthood (Siracusano et al., 2021 and Smith et al., 2018). It is evident that most intervention research continues to focus on *young* children and their families with ASD. Although the ongoing investment in early childhood has contributed to improved outcomes among children with ASD, it is crucial for future research to prioritize interventions targeting the transition years to support better outcomes in both parents and their children across the lifespan (Wisner-Carlson et al., 2020).

Furthermore, this review finds that of the six scales which assessed stress or anxiety in the included studies, none were designed for this group of parents. This adds useful evidence to support the development of more sensitive and suitable stress/anxiety scales for parents of transition-aged children with ASD. The following sections discuss the gaps and implications for future research, practice, and policy with respect to intervention areas, study design, and scales.

## Intervention Areas

All interventions in this review focused on parental stress/anxiety outcomes given the implications of parental well-being on the family system. However, interventions differed in the pathway by which they addressed these parental outcomes. Some studies targeted these outcomes directly through secondary engagement strategies for coping (Piazza

et al., 2014) such as mindfulness training. These strategies are especially necessary for this population given that the many problems they face regarding parenting a child with ASD may not always have immediate solutions (Lunsky et al., 2015). Moreover, such interventions help parents develop an acceptance of their situation (Piazza et al., 2014). Other studies in this review targeted parental stress/anxiety by focusing on indirect factors and utilizing primary engagement strategies (Piazza et al., 2014). These strategies address the stressors which have the potential to be managed, reduced, and alleviated through planning and problem-solving (Piazza et al., 2014) such as skills to actively cope with the child’s challenging behaviors, social functioning, and transition planning. Although seven studies targeted indirect factors, most focused on social functioning, and only two studies focused on transition planning.

Given that parents of young adults with ASD worry about their child’s future and wish to plan and make decisions (Marsack-Topolewski & Graves, 2020; Oti-Boadi et al., 2020), interventions must address this stressor. A recent cross-sectional study among parents of transition-aged children with ASD found that the quality of transition planning has a significant influence on parental mental health, and the transition experience (Wong et al., 2020). As such, future interventions should prioritize transitional support, which includes access to quality information related to resources and services such as Medicaid and Vocational Rehabilitation. Family readiness for the transition process (Martinez et al., 2012) should also be addressed through topics such as transfer of rights at adulthood and FERPA laws (Family Educational Rights and Privacy Act (FERPA), 2018). This is especially important given the inability of many parents to step back and hold high expectations for their children (Agarwal et al., 2020). Interventions should also emphasize parent education (Preece & Trajkovski, 2017) in regard to ASD across the lifespan and embed social support in their design as parents of this age group, in particular, seek this for improved mental health (Mason, 2012; Tuohy & Yazdani, 2016).

Findings from this review also revealed that only one study included children in its mindfulness intervention, despite the high rates of anxiety among transition-aged children with ASD (Kaat & Lecavalier, 2015; van Steensel et al., 2011) and the potential of mindfulness training to improve behaviors, ASD symptoms, and emotional regulation (Salem-Guirgis et al., 2019) which could consequently also lower parental stress and anxiety. Also missing from the findings is a focus on developing independent living skills, which has been shown to elicit great parental stress (Ponton et al., 2019). This is especially important given that about 80% of adults with ASD continue to live with their aging parents (Shattuck et al., 2011).



## Study Design

It is evident that there needs to be a push for more rigorous study designs to build a robust evidence-base for transition interventions. Only three studies in this review were randomized controlled trials (Karst et al., 2015; Smith et al., 2018; Yoo et al., 2014) and few had control groups. Moreover, most assessments were designed as simple pre-posts with only three studies that included a follow-up assessment at either 3- or 6 months post-intervention (Mazzucchelli et al., 2018; Siracusano et al., 2021; Yoo et al., 2014). Although the overall quality rating of these studies was high, they scored lower in the sampling category. In addition, most interventions targeted a wide age range of children with ASD. Future studies must use larger sample sizes, explain their recruitment source and attrition sufficiently, and focus on narrower age groups to ensure that the unique needs of each life stage are addressed (Salem-Guirgis et al., 2019).

Our findings further reveal that research on young adults between the *specific ages of 18 and 22* is even more sparse, given that only four studies included participants within this age group (Salem-Guirgis et al., 2019; Singh et al., 2014; Siracusano et al., 2021; Zu et al., 2019). It is also crucial for future interventions to consider parents of ASD participants with varying levels of severity, and to explicitly state their inclusion/diagnostic criteria in this regard. Only three studies in this review explicitly referred to the ASD participant's level of functioning (Karst et al., 2015; Siracusano et al., 2021; Smith et al., 2018) with no consistency found across the 13 studies in how severity was assessed.

Although all studies in this review assessed parental stress and/or anxiety, it was apparent that additional family outcomes were also measured such as family chaos, mindfulness, and parental involvement. Which outcomes to include in future interventions is an important point of consideration, as many parent characteristics such as self-efficacy mediate or moderate the effect of parental wellbeing (Pickard & Ingersoll, 2017). Furthermore, interventions should be designed to include both parent and child dyads, which have multiple benefits as discussed in the PEERS intervention. Interventions should also carefully consider the age of the parent in their design (Lunsky et al., 2015) and consider the length and commitment expected from parents to ensure that they can have a meaningful impact and reduce burden (Salem-Guirgis et al., 2019). Perhaps, given the likelihood that more parents are comfortable with a virtual platform as a result of the COVID-19 pandemic, more studies should consider the feasibility of this mode of delivery.

## Stress and Anxiety Scales

In addition to robust interventions, there is a need for valid and reliable assessments of parental stress and anxiety. This

is important as the stressors faced by parents of children with ASD and, specifically, transition-aged children with ASD are unique. However, none of the six scales utilized in this review were designed for parents of children with ASD or even disabilities in general, and all but two (the STAI-S/STAI-T and PSI-SF) were noted by the authors as a possible limitation to their findings. Most authors shared that the scales were most likely not sensitive enough to capture changes in this parent population and referenced the need for instruments that were specific to the ASD population.

For example, Smith et al. (2018) pointed out that the use of the PSS-10 may not have been appropriate given that it measures general life stress rather than parenting stress. While many scales have been developed to assess stress among the parent population, such as the Parental Stress Scale (PSS; Berry & Jones, 1995) and the PSI (Abidin, 1995) which are commonly used in ASD studies (Davis & Carter, 2008; Samadi et al., 2014; Wang et al., 2013), they do not focus on the unique and complex constructs which could capture the stress in parents raising a child with ASD (McStay et al., 2014; Silva & Schalock, 2012). Moreover, the PSI is designed for parents of children aged 3 months to 10 years of age (Abidin, 1995) which may not capture the specific experiences and stressors of the transition period. It is concerning that one author (Siracusano et al., 2021) used the short version of the PSI despite the ages of the children in their study ranging from 14 to 20 years old. In addition, two authors (Lunsky et al., 2015; Smith et al., 2018) in this review (who used a scale not designed for parents) suggested the use of the PSI as an alternative to enhance sensitivity. Although choosing a scale designed for parents would be more suitable, the transition age range of the participants in their respective studies and the intended age group of the PSI scale would not be aligned.

In 2012, the Autism Parenting Stress Index (APSI; Silva & Schalock, 2012) was developed to capture the specific stressors associated with caring for a child with ASD. The measure consists of 13 items and covers three domains of parenting stress: "core social disability, difficult-to-manage behavior, and physical issues" and is ranked on a 5-point scale. However, this scale has currently been psychometrically assessed among parents of *young children* under the age of 6. It is possible that none of the studies in this review utilized the APSI given the transition age of their study population. However, the suitability of this scale for older children with ASD should be examined in future research.

Scales used to assess anxiety in this review were also designed for the general population. Although the STAI-S was used in two studies and the STAI-T in one (Ruiz-Robledillo et al., 2015; Yoo et al., 2014) only state anxiety demonstrated any improvement during interventions. This is to be expected given that state anxiety measures the temporary and short-term change in anxiety levels. Even in one study with a 3-month follow-up that assessed trait

anxiety (Yoo et al., 2014), there was no significant change in these levels. This may imply that the intervention was not able to maintain its effectiveness over time, or may signal the need for more sensitive instruments for this population. Similarly, the BAI also does not assess for worry sufficiently or capture rumination which is commonly experienced among parents of children with ASD (Schiltz et al., 2018).

It is imperative, as intervention research moves forward, that the selection of measurement scales is guided by the population, purpose, and utility of the measure. Researchers should refrain from using scales based on their popularity and/or ease of administration. Failing to do so even in the most rigorously designed interventions may lead to the study being unable to detect changes in outcomes, or lead to inaccurate findings (Coster, 2013). Currently, stress scales have been designed for the general population, parents, and even parents of young children with ASD. However, there is a need to design stress and anxiety tools that are specific to the constructs and stressors relevant to the life stage (Rutherford et al., 2019) of the older child with ASD.

## Limitations

First, since studies were limited to a decade from 2010 to 2021, relevant studies before 2010 may have been omitted. Second, gray literature was excluded, while studies with no response from authors and inaccessible full texts could have led to publication bias. Third, some studies may have been inaccurately included or excluded given the need to estimate the number of children within our transition-age criteria using *t*-distribution calculations. Finally, given the extant literature on parental stress and anxiety, we limited the scope of this review to these two mental health outcomes for parents of transition-aged youth with ASD. However, future reviews should examine other parental outcomes such as depression and quality of life.

## Conclusion

There is growing awareness of the need for ASD research to span beyond childhood and specifically focus on the critical period of transition between adolescence and adulthood. Our findings highlight a gap that exists in regards to intervention focus, study design, and selection of stress and anxiety measurement tools for parents of transition-aged children with ASD. Future researchers could use this review to inform the design of their interventions to ensure they are aligned with the unique stressors of this period and the needs of the family.

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## Declarations

**Ethics Approval** This is a systematic review and no ethical approval is required.

**Conflict of Interest** The authors declare no competing interests.

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