Caregiver depression in families living with autism spectrum disorder: A meta-analysis based on ecological systems theory

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Abstract

Background: Depressive symptoms in family caregivers of persons with autism spectrum disorder are highly prevalent, however the impact of family and social support systems on caregivers' mental health outcomes is unclear. *Aim:* To review and map correlates of caregivers' depressive symptoms using an ecological systems framework. *Methods:* Thirty-four studies, comprising a pooled sample of 4,968 caregivers, were identified from the Embase, PsycINFO and PubMed databases. Study reporting quality was assessed using the QualSyst tool. Pearsons *r,* along with fail-safe *N*s and heterogeneity, were calculated using random effects modelling. The moderating effect of informal support (perceived, received, network characteristics) was examined. *Results:* Studies provided good to excellent methodological detail. Weak-to-moderate associations (r_w range = -.199 to -.406) were noted between lowered depressive symptoms with positive family unit functioning, relationship quality (marital and parent-child), and informal support (from partners, family, friends). These results were not moderated by the operationalisation of informal support. *Conclusions:* Clinicians should assess the social and family networks of caregivers to identify those most vulnerable to developing depression. Intervention effectiveness can be enhanced by involving relevant family members in treatment.

Declaration

This thesis contains no material which has been accepted for the award of any other degree of diploma in any University, and, to the best of my knowledge, this thesis contains no material previously published except where due reference is made. I give permission for the digital version of this thesis to be made available on the web, via the University of Adelaide's digital thesis repository, the Library Search and through web search engines, unless permission has been granted by the School to restrict access for a period of time.

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Chapter 1

Introduction

Autism Spectrum Disorder

Classification and diagnosis. Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterised by persistent deficits in social communication and interaction, together with restricted, repetitive interests or behaviours (American Psychiatric Association, [APA], 2013). Other challenges associated with ASD may include cognition and learning difficulties, sensory sensitivities, and problems with emotional regulation – all of which can impair an individual's ability to perform normal activities of daily living (Booth, Keenan, & Gallagher, 2018; Marshall, Kollia, Wagner, & Yablonsky, 2018).

The diagnostic construct of autism has been the subject of much debate. Originally defined as a form of childhood schizophrenia, autism was reclassified as a pervasive developmental disorder (PDD) in the third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III; APA,1980). The DSM-III criteria for PDD included very restrictive and concrete symptoms (e.g., gross deficits in language development; abnormal responses to the environment) (APA, 1980). The concept of autism was then broadened in DSM-IV to include four subtypes: Asperger's disorder (characterised by impaired social interaction and restricted behaviours, with no delays in language or cognitive development), Rett syndrome (affecting movement and coordination), childhood disintegrative disorder (characterised by sudden regressions in development), and pervasive developmental disorder not otherwise specified (PDD-NOS; APA, 1987, 1994). However, many questioned the diagnostic validity of these autism subtypes (Grzadzinski, Huerta, & Lord, 2013). Autism was later collapsed into a single spectrum disorder in DSM-5 in recognition of its varying symptom presentation and wide-ranging levels of severity (Marshall et al., 2018). At the same time, Rett syndrome was removed from the ASD category due to its unique aetiology (APA, 2013). The current DSM-5 diagnostic criteria for ASD have been mirrored in the 11th revision of the International Classification of Diseases and Related Health Problems (ICD-11), a widely-used diagnostic tool for epidemiology and health management developed by the World Health Organisation (WHO, 2018).

ASD is typically identified in early childhood, with symptoms often presenting from around 18 months of age and persisting over the life course (Baxter et al., 2015; Blumberg et al., 2013). In addition to primary cognitive and behavioural symptoms, comorbidities such as attention deficit hyperactivity disorder (ADHD), anxiety and depressive disorders can complicate the clinical picture of ASD (Booth et al., 2018; Sharma, Gonda, & Tarazi, 2018).

Aetiology and epidemiology. An early aetiological theory, known as the refrigerator-mother hypothesis, attributed the cause of ASD to emotionally cold parenting practices (Kanner, 1943). Today, the disorder is believed to arise from complex gene-environment interactions (Y. S. Kim & Leventhal, 2015; Lichtenstein, Carlström, Råstam, Gillberg, & Anckarsåter, 2010)

ASD is one of the most commonly occurring developmental disorders worldwide (Australian Bureau of Statistics [ABS], 2012; Olusanya et al., 2018). Notably, the prevalence of ASD has steadily increased over the past two decades. Estimates from the United States indicate that 1 in 150 children were diagnosed in 2000 (Fisher & Zangrillo, 2015; Sharma et al., 2018) compared to 1 in 36 children in 2017 (Zablotsky, Black, & Blumberg, 2017). Similarly, the Australian Bureau of Statistics (2015) estimates that the number of ASD diagnoses increased in Australia by 40% in the last decade: 1 in 70 children are now diagnosed with this disorder (May, Sciberras, Brignell, & Williams, 2017). The observed increase in the reported prevalence of ASD is commonly attributed to greater awareness of the disorder, more inclusive diagnostic criteria and more precise diagnostic measures – rather than reflecting a true increase in the presence of the disorder (Elsabbagh et al., 2012; Fisher & Zangrillo, 2015; Sharma et al., 2018).

ASD is observed at a higher rate among males: with a ratio of one female for every four males diagnosed (APA, 2013; Fombonne, 2003, 2009). Interestingly, a recent meta-analysis involving a pooled sample of 53,712 persons with ASD, found male-to-female ratios closer to 3:1 (Loomes, Hull, & Mandy, 2017). The underlying reasons for this gender difference are unclear, although there is some debate that ASD in females is significantly under-diagnosed (Beggiato et al., 2017; Frazier, Georgiades, Bishop, & Hardan, 2014; Russell, Steer, & Golding, 2011).

Role and Challenges of Caregiving

Up to 85% of those diagnosed with ASD experience lifelong functional difficulties that affect their ability to live independently, requiring some level of assistance from family members (Volkmar & Pauls, 2003). Family caregivers are usually the parents of the child but may also include grandparents, adult siblings, step-parents or adoptive/foster parents (ABS, 2012). Caring for and supporting a child with ASD can have far-reaching consequences. Families may experience financial strain due to continuous time pressures (i.e., increased advocacy and involvement in their child’s health care and education), that limit opportunities for paid work (Karst & Van Hecke, 2012; Lord & Bishop, 2010; J. Q. Morrison, Sansosti, & Hadley, 2009; Sawyer et al., 2010). Although there is considerable variation in how individual caregivers adapt to the demands of their role, there is consistent evidence that the high level of care needed to raise a child with ASD can negatively impact upon parents’ health and wellbeing (Karst & Van Hecke, 2012). In particular, parents of children with ASD experience higher levels of psychological distress than parents of typically developing children but also higher levels in comparison to parents of children with other developmental disorders (e.g., Down syndome, intellectual disability, cerebral palsy; Almansour, Alateeq, Alzahrani, Algeffari, & Alhomaidan, 2013; Bitsika, Sharpley, & Bell, 2013; Blacher & McIntyre, 2006; Dabrowska & Pisula, 2010; Singer, 2006; Zablotsky, Bradshaw, & Stuart, 2013).

Depression in Caregivers of Persons with ASD

The personal and social impact of ASD is compounded by elevated rates of caregiver depression (Karst & Van Hecke, 2012). This includes major depressive disorder (MDD); a common mood disorder characterised by persistent feelings of sadness or hopelessness and a loss of interest in previously enjoyed activities (APA, 2013). Caregivers are also likely to endorse psychological, behavioural and physical symptoms of depression that do not meet MDD criteria, including feelings of worthlessness or guilt; concentration difficulties and indecisiveness; fatigue; and changes in appetite or weight (APA, 2013; Singer, 2006).

Prevalence and measurement. Estimates of MDD range from 25-77% in caregivers of children with ASD, with a reported lifetime prevalence of up to 59% (Amirian et al., 2017; Carter, Martinez-Pedraza, & Gray, 2009; Charnsil & Bathia, 2010; Dyches, Christensen, Harper, Mandleco, & Roper, 2016; Gatzoyia et al., 2014). This is a stark contrast to the estimated rate of 10-15% reported in the general population (APA, 2013). Available prevalence estimates are, however, characterised by substantial between-study heterogeneity in how depression is conceptualised and measured. The few ASD studies that have defined depression ‘caseness’ based on the ‘gold standard’ structured clinician interview (i.e., recurrent episodes that meet diagnostic criteria for MDD; Bailey Jr., Golden, Roberts, & Ford, 2007), have generally reported lower estimates (e.g., 26%; Charnsil & Bathia, 2010) in comparison to studies that have relied on self-reported depression severity ratings based on designated clinical ‘cut-off’ scores (e.g., 77%; Dyches et al., 2016). In addition, inconsistent use of cut-off scores, as typically seen in psychotherapy research, may call these estimates into question (Barlow, 2015). Given that subthreshold depressive symptoms are important indicators of caregiver health (England & Sim, 2009), standardised and well-validated measures which define depression on a continuum of symptom severity are important for clinical evaluation and research. These measures include depression subscales from instruments that assess broader aspects of psychological functioning (e.g., Hospital Anxiety and Depression Scales; Zigmond, & Snaith, 1983) in addition to comprehensive depression-specific tools (e.g., Beck Depression Inventory; Beck, 1967).

Family Functioning, Social Support, and Caregiver Depression

The high prevalence of depressive disorder and symptoms in caregivers of persons with ASD has led to a large body of research assessing associated risk and protective factors. One of the key contributory factors for poor mental health among this caregiver group, over and beyond individual child characteristics (e.g., ASD severity), is family functioning. Family functioning includes levels of *adaptability,* or a family’s ability to adjust when encountering stressors (Minuchin, 1974); *cohesion,* or the extent to which family members share an emotional bond (Bendixen et al., 2011); *flexibility,* or the amount of change that is possible in family rules, roles and leadership (Olson & Gorall, 2003); and levels of *conflict* (Kelly, Garnett, Attwood, & Peterson, 2008). Disruptions to family functioning can have implications for the dyadic relationships within it, namely (a) the *parental* subsystem, comprising relationships between the caregiver and the child with ASD; (b) the *marital* subsystem, or relationships between spouses/couples; and (c) the *sibling* subsystem, including interactions between the child with ASD and their siblings (Factor, 2019; Meadan, Halle, & Ebata, 2010; Turnbull, Turnbull, Erwin, & Soodak, 2006). It follows that a well-functioning family provides support for family members and contributes to positive outcomes for parents and children alike, whereas poor family functioning can have reciprocal, negative effects on the entire family unit (Karst & Van Hecke, 2012; Renzaho, Mellor, McCabe, & Powell, 2013).

Closely linked to family functioning and caregiver wellbeing is the wider social support system (e.g., McIntyre & Brown, 2018). Social support is a multidimensional construct that includes emotional, psychological, and physical support (Dunst, Trivette, & Cross, 1986). For caregivers of persons with ASD, both *informal* social support from friends, family, spouses, and parents of other children with disabilities, alongside *formal supports* provided through an agency or organisation (e.g., from medical professionals or respite care providers) are critical (Bristol & Schopler, 1983). A further distinction has been made between *perceived support*, or a caregiver's perceptions of the availability and quality of social support, *received support* that has been recently provided, and *network characteristics*, or physical features of the interpersonal environments through which support is received (e.g., network size, geographic proximity; Benson, 2012; Haines, Beggs, & Hurlbert, 2002; Hartwell & Benson, 2007; Wills & Shinar, 2000). Perceived support appears to have a greater impact on caregiver wellbeing compared to received support, and may also mediate the effects of network characteristics on caregiver wellbeing, in general (Benson, 2012; del-Pino-Casado, Frias-Osuna, Palomino-Moral, Ruzafa-Martinez, & Ramos-Morcillo, 2018).

Bronfenbrenner's Ecological Systems Theory of Human Development

The complex and dynamic interaction between family and social support systems can be represented by Bronfenbrenner's Ecological Systems Theory (Bronfenbrenner, 1977, 1986). Indeed, a recent scoping review emphasised the need for future research to be guided by this theory, in order to consolidate current understanding of the key environmental influences on wellbeing in families of children with ASD (Tint & Weiss, 2016). Bronfenbrenner (1977, 1986) identified four systems within which humans grow and develop (see Figure 1):

(a) *Microsystem*, or interactions between the caregiver and their immediate environment (e.g., spouse, children, friends, family, support services).

(b) *Mesosystem,* involving connections between microsystem components (e.g., family functioning, sibling interaction).

(c) *Exosystem*, or elements in the caregiver's indirect environment that can influence the microsystem (e.g., child's school, respite care facilities, other support services).

(d) *Macrosystem*, representing the broader cultural, social, economic and legal contexts in which the other systems operate (e.g., cultural understandings of ASD).

The *micro-* and *mesosystems*, in particular, combine to have a direct (or proximal) impact upon how caregivers function (Bronfenbrenner, 1995; Tint & Weiss, 2016). These two key systems are discussed in the following section.

Microsystem.

Marital relationship quality. This multidimensional construct includes both subjective (e.g., satisfaction, happiness) and objective (e.g., conflict) characteristics of the marital relationship (Lewis & Spanier, 1979; Glenn, 1990). A meta-analysis of four cross-sectional studies found that higher levels of marital satisfaction were associated with fewer depressive symptoms in caregivers of children with ASD (Sim, Cordier, Vaz & Falkmer, 2016). Subsequent studies have reported similar effects, although the association between marital relationship quality and depression symptom severity has varied in magnitude (r = -.16 to -.46; Benson & Kersh, 2011; Da Paz, Siegel, Coccia, & Epel, 2018; Timmons, Willis, Pruitt, & Ekas, 2016). Concerningly, longitudinal data suggests that marital quality can negatively predict depression symptom severity in caregivers two years later (Benson & Kersh, 2011).

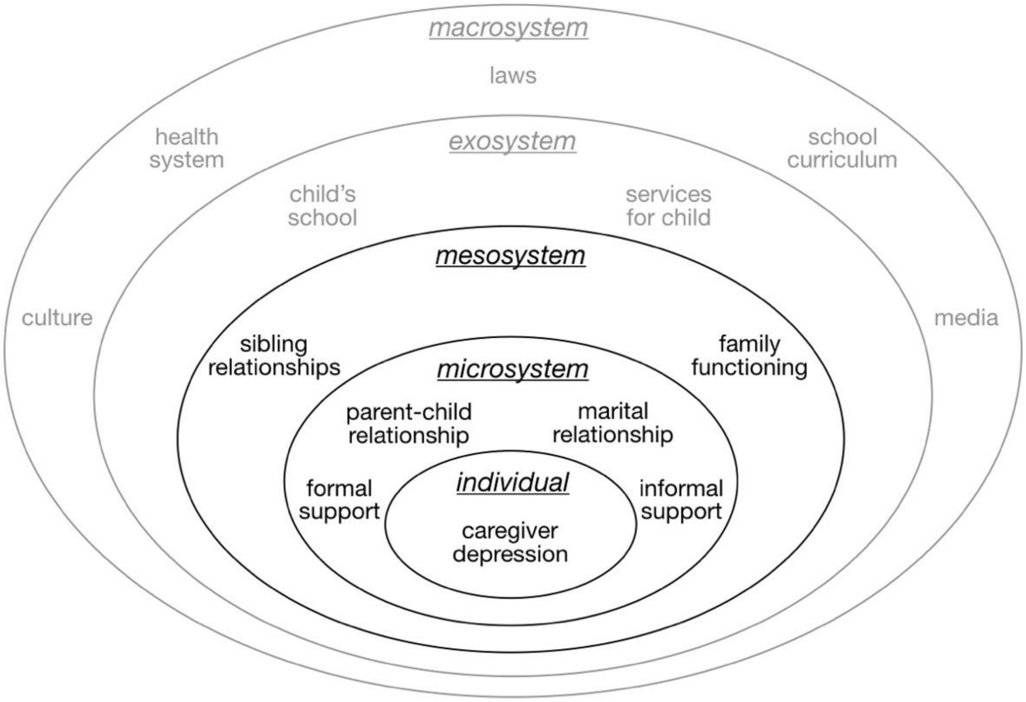

Figure 1. Caregiver depression, family functioning and social support from an ecosystems perspective. Adapted from “Ecosystemic assessment of families of a child with cancer returning to school”, by S. J. Buehler, 1999, *ProQuest Dissertations & Theses Global* (304547620).

The relationship between social support and marital relationship quality has also been established. Meta-analytic data involving a pooled sample of 557 parents found that, on average, couples raising a child with ASD experienced less relationship satisfaction compared to parents of typically developing children; with social support cited as a key protective factor (Sim et al., 2016).

Parent-child relationship. There is some evidence that the parental subsystem, particularly the parent-child relationship, may be enhanced following a child’s diagnosis of ASD (Hoffman, Sweeney, Hodge, Lopez-Wagner, & Looney, 2009). Specifically, parents of children with ASD are more likely to attribute their child’s challenging behaviour to symptoms of the disorder, rather than to the child’s personality, and this is associated with reduced emotional toll from responding to challenging child behaviour (Whittingham, Sofronoff, Sheffield, & Sanders, 2008). Interestingly, parents have reported a close relationship with their child with ASD, even years after receiving a diagnosis (Hoffman et al., 2009; Montes & Halterman, 2007), with the relationship helping to improve parents’ communication skills, patience, empathy, and psychological and emotional strength (Cridland et al., 2014).

There are, however, conflicting findings in this area. Longitudinal data suggests that the quality of the mother-child dyad in families of children with ASD may not be predictive of changes in maternal depressive symptoms over time (Baker et al., 2011). Cross-sectional studies have also produced inconsistent findings: significant, inverse relationships between parent-child relationship quality and caregiver depression have been noted, as have non-significant effects (Davis & Carter, 2008; García-López, Sarriá, & Pozo, 2016; Hastings, Kovshoff, Ward, Degli Espinosa, Brown, & Remington, 2005; Neff & Faso, 2015, Teague, Newman, Tonge, & Gray, 2018).

Informal support. In families of persons with ASD, access to informal sources of support may help to reduce feelings of helplessness, isolation, and psychological distress (Bromley, Hare, Davison, & Emerson, 2004; Cooley, 1994). Engaging with other families has been highly endorsed as a positive source of instrumental (i.e., advice-seeking) and emotional support (i.e., to reduce stress and social isolation; Mandell & Salzer, 2007; Twoy, Connolly, & Novak, 2007). There is also evidence that spousal support is integral, particularly if partners have shared responsibilities within the household (Boyd, 2002).

Perceived support, in particular, has been linked to reduced depressive symptoms in family caregivers (Ingersoll & Hambrick, 2011; E. S. Kim, & B. S. Kim, 2009; Sawyer et al., 2010). Less critical is received support: caregivers appear to report similar levels of wellbeing regardless of the frequency or intensity of the supports that they actually access (Benson, 2012; Pakenham, Samios, & Sofronoff, 2005; Timmons et al., 2016). Studies investigating associations between caregiver depressive symptoms and various network characteristics are less clear. For example, there is some evidence that network size does not significantly impact on caregiver depressive symptoms (Benson, 2012; Lin, Orsmond, Coster, & Cohn, 2011), whereas Smith, Greenberg and Seltzer (2012) reported a significant negative relationship.

Formal support. Formal supports can fulfil certain needs, such as counselling services to reduce stress, or psychoeducation to assist caregivers in understanding autism (Whitaker, 2002). However, the effects of such supports on caregiver wellbeing are not clear, possibly due, in part, to the use of small convenience samples in the ASD literature that may not generalise to the wider caregiver population. Affordable and high quality services have been shown to buffer the negative effects of caregiving (Taylor & Warren, 2012). However, non-significant relationships between various measures of formal support and depression symptom severity in caregivers have also been reported (Clifford & Minnes, 2013; Kuhn et al., 2018; Ruiz-Robledillo et al., 2014). It may be that the stress-buffering effect of formal support is enhanced when multi-component interventions – involving both child- (e.g, respite, behavioural training) and caregiver-focused services (e.g., individual counselling) – are sought, as opposed to child services alone (Ruiz-Robledillo et al., 2014; Singer, Ethridge, & Aldana, 2007).

Mesosystem.

Family unit functioning. Compared to families with typically developing children, caregivers of children with ASD have generally reported lower family adaptability, flexibility, and cohesion, poorer communication and increased conflict (Gau et al., 2012; Hartley et al., 2010; Higgins, Bailey, & Pearce, 2005). All of these aspects are associated with higher levels of caregiver depressive symptoms (Beer, Ward, & Moar, 2013; Hastings et al., 2005). Conversely, positive influences of ASD have been reported, including improved communication and greater empathy among family members (Cridland, Jones, Magee, & Caputi, 2014). These positive relationships are not only maintained but may even improve over time (Gray, 2002).

Sibling functioning. Though typically developing siblings have life-long relationships with their brother or sister with ASD, sibling dyads have been understudied (M. S. Smith & Elder, 2010). Moreover, there is a lack of consensus in the literature about the quality of these relationships and their impact on typically developing siblings. While impaired intimacy between siblings has been noted (M. S. Smith & Elder, 2010), so too have positive relationships – this is despite typically developing children potentially experiencing unequal parental attention, in addition to challenging behaviour, poor communication and limited relational reciprocity from their sibling with ASD (Rivers & Stoneman, 2003). Interestingly, parents of children with ASD tend to be less positive about the sibling relationships than the sibling themselves (Macks &

Reeve, 2007; Rivers & Stoneman, 2003). The link between sibling functioning and caregiver depressive symptoms is also unclear. Significant and non-significant associations have been identified. This may, in part, be due to the use of different measures of sibling functioning, which assess either the impact of the child with ASD (e.g., emotional/behavioural adjustment, receiving unequal parental attention), or the quality of the sibling relationship (Meyer, Ingersoll, & Hambrick, 2011; Tudor, Rankin, & Lerner, 2018).

Current Study

In sum, environmental factors appear to regulate caregiver mental health among families living with ASD. The interaction of these factors is, however, unclear with mixed findings relating to the role of family (parent-child relationship, sibling functioning) and social resources (informal vs. formal, perceived vs. received vs. network characteristics) in caregiver depression. The current review uses a well-established framework, Bronfenbrenner's Ecological Systems Theory (Bronfenbrenner, 1977, 1986), to consolidate the available data and provide an overview of conflicting findings. Meta-analytic techniques, considered to be the 'gold standard' of evidence-based healthcare and a useful decision-making tool, will be used for this purpose (Haidich, 2010). A meta-analysis increases sample size, statistical power and accuracy of effect-size estimates compared with a single study (Borenstein, Hedges, Higgins, & Rothstein, 2009). The combined findings of this review may, in turn, help to inform the development of targeted interventions to prevent and/or manage depressive symptoms in this vulnerable caregiver group.

The specific aims are to:

1. Examine the associations between depressive symptoms in caregivers of persons with ASD and measures of family functioning and social support, clustered according to the relevant ecological systems. That is:
    - i. Microsystem: a) marital relationship quality; b) parent-child relationship; c) informal support; d) formal support
    - ii. Mesosystem: a) family unit functioning; b) sibling functioning
2. Explore the major sources and extent of heterogeneity among studies through subgroup analyses, namely the potential moderating role of support type on caregiver depression:
    - i. Informal support (perceived, received, network characteristics)
    - ii. Formal support (caregiver-, child-, caregiver- and child-focused)
3. Assess the risk of methodological bias and evaluate the strength of evidence through a critical appraisal of the reporting quality of all included studies.

Chapter 2

Method

Literature Search

Three electronic databases (Embase, PsycINFO, PubMed) were searched for the period between January 1980 – when autism was first recognised as a developmental disorder (APA, 1980) – and August 2019. A comprehensive list of search terms was compiled in order to source studies that examined both the population and outcome of interest (i.e., ‘caregivers’ AND ‘autism’ AND ‘depression’). Search terms were deliberately kept broad to ensure that all relevant data could be captured. Search terms were also tailored to each database to include all relevant indexing terms, truncation and wildcard operators (see Appendix A for complete logic grids). An expert research librarian was consulted to refine search terms and ensure accuracy. Additional studies were identified through searching the reference lists of all included studies and relevant reviews (see Appendix B for a list of reviews). This process identified two additional eligible studies.

Study Eligibility

Studies had to meet each of the following criteria to be eligible for inclusion:

1. The sample was drawn from a population of family caregivers (e.g., parents, grandparents, stepparents), aged 18 years or older, of one or more persons with autism.
2. Autism was diagnosed in accordance with one of two major international classification systems: the DSM or the ICD. Diagnoses included:
   - Infantile autism (DSM-III; APA, 1980);

  - Autistic disorder, PDD-NOS (DSM-III-R; APA,1987);
  - Autistic disorder, Asperger's disorder, PDD-NOS, childhood disintegrative disorder (DSM-IV; APA, 1994);
  - Autistic disorder, Asperger's disorder, PDD-NOS, childhood disintegrative disorder (DSM-IV-TR; APA, 2000);
  - Childhood autism, atypical autism, Asperger syndrome, other pervasive developmental disorders, pervasive developmental disorder-unspecified (ICD-10; WHO, 2004);
  - Autism spectrum disorder (DSM-5; APA, 2013); and
  - Autism spectrum disorder (ICD-11; WHO, 2018).

3. Caregivers' current-state depressive symptoms were assessed on a continuous scale using a validated, multi-item self-report measure (see Appendix C for a list of included depression measures).
4. Studies reported a bivariate relationship between depression symptom severity and at least one family functioning (unit functioning, marital relationship, parent-child relationship, sibling functioning), or social support (formal or informal) variable that was measured at the same time point: cross-lagged correlations can be problematic due to missing data and covariates that change over time (Gibbons et al., 1993; Hamaker, Kuiper, & Grasman, 2015).
5. Cohort, cross-sectional and longitudinal studies were eligible, as were intervention studies that provided baseline data.
6. The data provided could be converted to a Pearson's correlation coefficient (e.g., means, standard deviations, or one-way ANOVAs; Thalheimer & Cook, 2002).

7. A full-text version was published in a journal in English. There is no evidence of English-language restrictions impacting on meta-analytic results (A. Morrison et al., 2012).

Studies were excluded if they met any of the following criteria:

1. The sample included professional (paid) caregivers (e.g., support workers).
2. Multiple neurodevelopmental disorders were examined (e.g., ADHD, intellectual developmental disorder), whereby data for the ASD group could not be separately extracted.
3. The sample included diagnoses of Rett syndrome; a disorder which was removed from the autism category in the DSM-5 (APA, 2013).
4. Only nonparametric data were provided (e.g., Spearman's rank correlation coefficient), as conversions to parametric Pearson's correlations result in sampling variance being underestimated (Rupinski & Dunlap, 1996).
5. Conference abstracts were ineligible as they often lack detailed methods and results necessary for critical appraisal and data synthesis (Balshem et al., 2013).

Study screening was undertaken using Covidence systematic review software (Veritas Health Innovation). To detect selection bias, a random sample of 50 full-text articles were screened by a second reviewer (postgraduate psychology student, S.P.). Inter-rater reliability was substantial (Viera & Garrett, 2005), with reviewers agreeing in 98% of cases (k = .66). The one discrepant paper was discussed and full agreement was reached.

Data Extraction, Preparation and Organisation

In accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines (see Appendix D; Moher, Liberati, Tetzlaff, & Altman, 2009), a purposely designed data extraction sheet was used for collating data for each study (see Appendix E; Moher, Liberati, Tetzlaff, & Altman, 2009). Extracted data included:

- Study characteristics (e.g., sample size, country, study design, depression, family functioning and social support measures used);
- Demographics for caregivers (e.g., mean age and standard deviation [*SD*], gender, marital status, employment status) and children (e.g., mean age and *SD*, gender, ASD diagnosis);
- Depression measurement (e.g., mean depression score, *SD* and associated severity classification); and
- Effect size data (e.g., Pearson's correlation *r;* means and *SD*s for two groups, one-way ANOVA).

The data for two studies required recalculation prior to analysis. Clifford and Minnes (2013) reported means and *SD*s for three groups: never accessed support, accessed support in the past, and currently accessing support. The data for the first two groups were combined to produce two distinct groups (i.e., not currently accessing vs currently accessing support) which were subsequently converted to standardised mean differences and then *r*. A second study reported results of a one-way ANOVA (i.e., high vs low support; Gill & Harris, 1991), which were converted to *r* using *The Meta Analysis Calculator* (Lyons & Morris, 2019).

For ease of data interpretation, effect sizes were grouped according to the family functioning and social support domains that they represented within the *micro-* (marital relationship quality, parent-child relationship, informal support, formal support) and *mesosystems* (family unit functioning, sibling functioning). One paper reported an effect size for a combined measure of formal and informal support (i.e., respite care provided by either a family member or support agency; Dyches et al., 2016); this was categorised as formal support due to the inclusion of professional services. Informal support correlates were further grouped into four subdomains, each representing a different source of support: (a) family and friends (i.e., support received from a combination of sources), (b) family, (c) friends, and (d) partner. Finally, to ensure consistent interpretation of effect sizes across multiple family functioning and social support domains, the direction of some standardised scales were rescaled so that higher values reflected greater levels of functioning or support (e.g., daily measure of marital conflict reverse coded to reflect greater harmony/reduced conflict; Timmons et al., 2016).

Risk of Bias Assessment

The reporting quality of each study, including aspects related to study design and power, sample selection, and data reporting, was assessed using the *QualSyst* tool (Kmet, Lee, Research, & Cook, 2004). Three criteria specific to intervention studies were excluded, as they were not applicable to the observational data analysed. Each study was therefore rated against 11 pre-specified criteria (i.e., *criterion met* = 2, *criterion partially met* = 1, *criterion not met* = 0; see Appendix F) and a summary score (ranging from 0 to 1; total score ÷ total possible score) calculated (see Appendix G). Additionally, the percentage of included studies that received scores of 0, 1, and 2 was calculated for each criterion. This quality assessment was conducted jointly by the student researcher (V.S.) and research project supervisor (D.D.).

Effect Size Calculations

Effect size data were entered into Comprehensive Meta-analysis software (CMA Version 3; Borenstein et al., 2013). A random-effects model was used for all meta-analyses, allowing for variation in the 'true' effect sizes due to sampling error and methodological differences between studies (Cumming, 2012; Lipsey & Wilson, 2001). In cases where a study provided multiple effect sizes for a given meta-analysis (e.g., mothers vs. fathers; American vs Taiwanese caregivers), these data were averaged so that each study only contributed a single effect estimate to any pooled *r* (Lipsey & Wilson, 2001). This involved all *r*s being transformed to standardised Fisher's *Z* scores, averaged, and back-transformed into *r,* thereby minimising potential underestimation of the effect size, which occurs in simple *r* averaging procedures (Borenstein et al., 2009; Corey, Dunlap & Burke, 1998; Silver & Dunlap, 1987). To accommodate for greater sampling error and higher variability in effect sizes from smaller samples, *r*s were weighted by each study's inverse variance prior to pooling (r_w; Lipsey & Wilson, 2001). Effect sizes were interpreted according to Cohen's guidelines (1988), with correlations of .20, .50, and .80 representing small, medium, and large associations, respectively. The direction of *r* was standardised so that a negative value indicated that higher levels of functioning or support were associated with lower depression ratings.

Finally, to examine the precision of each effect size, 95% confidence intervals (CIs) were calculated for each *r* and r_w. Confidence intervals not containing zero indicate a significant relationship (Cumming, 2012). In addition, *p* values were calculated to determine the statistical significance of both individual and pooled *r*s.

Three statistics were used to assess between-study heterogeneity. First, the *Q* statistic provided a test of significance for heterogeneity by analysing the ratio of observed variation to within-study error. A significant *p*-value for *Q* (i.e., $p < .05$) suggests sufficient evidence to reject the null hypothesis that all studies share the same true effect size (Borenstein et al., 2009). In addition, tau (τ), analogous to a *SD* of the true effect sizes (Borenstein et al., 2009), and I^2, which represents the ratio of true effect variance to total variance in the observed effects, were calculated (Borenstein et al., 2009). I^2 values were interpreted according to Higgins, Thompson, Deeks, and Altman's (2003) guidelines, with 25%, 50%, and 75% indicating small, moderate, and high amounts of variance, respectively.

To assess publication bias arising from the pervasive 'file-drawer' problem (Borenstein et al., 2009), Orwin's Fail-safe *N* (N_{fs}) was calculated. This statistic represents the number of hypothetical non-significant studies that would be required to reduce the individual and pooled *r*s to small, non-significant effects (i.e., $r_{\text{w}} = \pm .10$; Orwin, 1983, Zakzanis, 2001). A result was considered robust to publication bias if the N_{fs} for a given effect exceeded the number of studies contributing data to that effect (i.e., $N_{\text{fs}} > N_{\text{studies}}$).

Sensitivity and Moderator Analyses

To identify potential outlier effects, a sensitivity analysis was conducted for any meta-analyses involving more than three studies. Here, the meta-analysis was re-run, removing one study at a time (Borenstein et al., 2009). Results were considered meaningful if the magnitude of an effect size (Cohen, 1988) or its associated *p* value (Borenstein et al., 2009) changed.

The potential moderating effect of support type (i.e., perceived, received, network characteristics) was additionally evaluated for the informal support domain – the only domain that had sufficient statistical power for subgroup analysis (i.e., $N_{\text{studies}} \geq 10$; N_{studies} per subgroup ≥ 3; Fu et al., 2010, Higgins & Altman, 2008). An additional subgroup analysis was planned for exploring the role of formal support type (i.e., caregiver-, child-, caregiver- and child-focused), but was not possible due to an insufficient number of studies contributing data ($N_{\text{studies}} = 5$). Between-group differences were statistically tested using a Q-test of homogeneity (analogous to an analysis of variance). A mixed-effects model, consisting of a random effects model within subgroups and a fixed effect model across subgroups, was used for this analysis (Borenstein et al., 2009).

Chapter 3

Results

Study Selection

The literature search yielded 5,123 results after date and language filters were applied (see Figure 2). This reduced to 3,474 citations once duplicate records were removed. Titles and abstracts were reviewed against the eligibility criteria, with 2,438 publications retained. The full-text versions of these remaining articles were retrieved and reviewed for eligibility, with a total of 42 studies identified for inclusion. Lead authors of 24 studies were emailed for additional data, with six responding. During screening, 13 studies involving overlapping samples were identified. These studies were combined and treated as five independent studies, to ensure no sample contributed more than one effect size to any pooled effect (see Appendix H). The study that provided the most recent data, or (in cases where data from the same time period were reported) the study with the largest sample size was deemed the lead study for the purpose of this review. This resulted in a final sample of 34 independent studies.

Study Characteristics

Participants were typically recruited from local autism groups, clinics, and university research registries (N_{range} = 20-479, Median N = 107; Appendix I). No individual study made up more than 10% of the pooled sample. The majority of studies were cross-sectional in design (N_{studies} = 30), with most studies originating in North America (N_{studies} = 18), followed by Australia (N_{studies} = 6), other Asia-Pacific countries (N_{studies} = 4), and Europe (N_{studies} = 4).

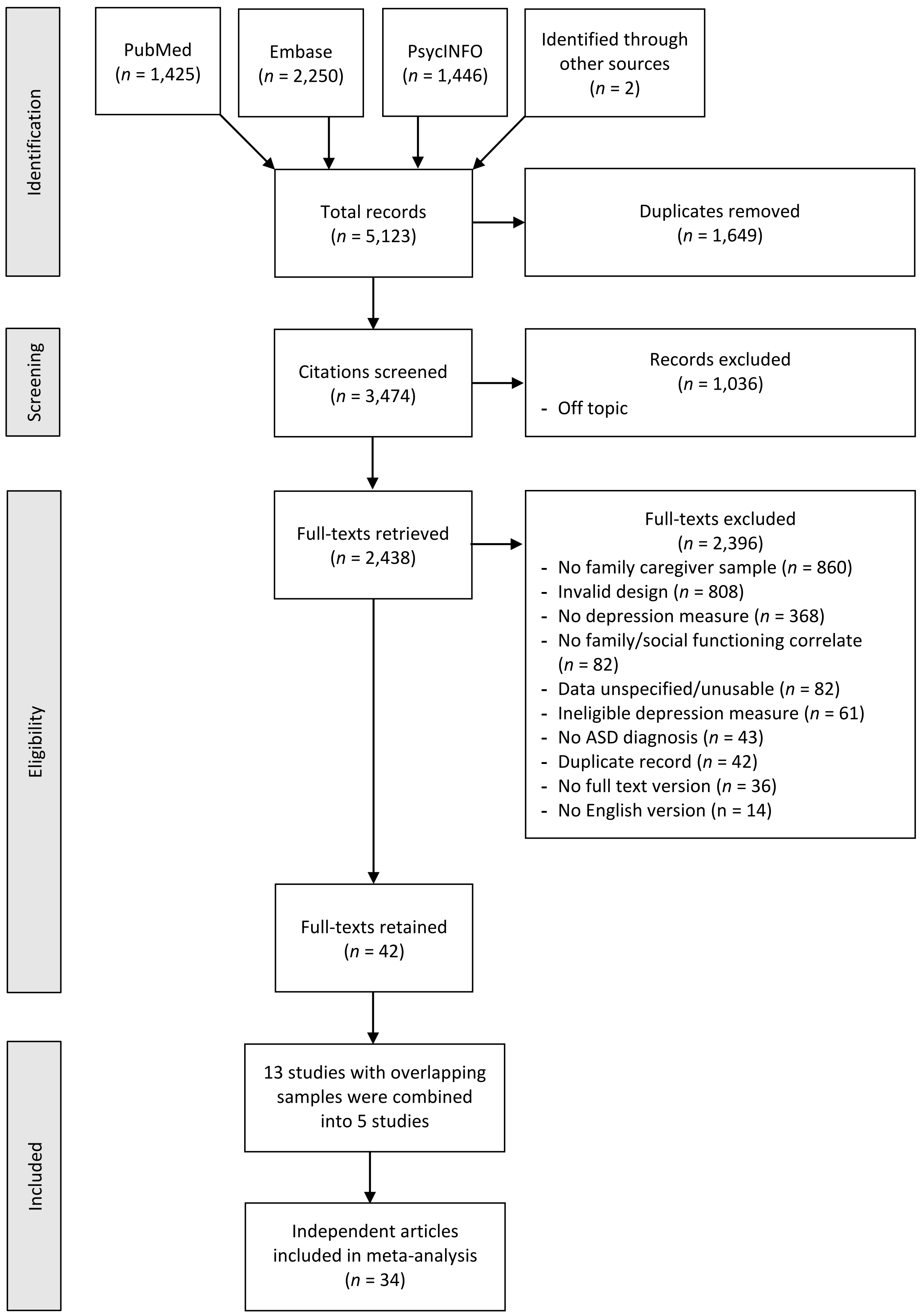

Figure 2. PRISMA flowchart for study selection process (Moher et al., 2009).

Depression symptoms were commonly measured by the Center for Epidemiologic Studies Depression Scale (CES-D; $N_{\text{studies}} = 15$; Radloff, 1977), followed by the Depression Anxiety Stress Scales (short form [DASS-21]; $N_{\text{studies}} = 15$; Lovibond & Lovibond, 1995) Hospital Anxiety and Depression Scale (HADS-D; $N_{\text{studies}} = 3$; Zigmond & Snaith, 1983), and Beck Depression Inventory (BDI; $N_{\text{studies}} = 3$, Beck, 1967). In comparison, there was very little consistency in the standardised scales used to measure family functioning and social support (see Appendix J for full list). This included various versions of the Family Adaptability and Cohesion Evaluation Scale (FACES; $N_{\text{studies}} = 8$) and Dyadic Adjustment Scale (DAS; $N_{\text{studies}} = 2$).

Sample Characteristics

The pooled sample of 4,968 caregivers of persons with ASD were primarily female, married or in a partnership, and held secondary and tertiary education. The majority also identified as Caucasian and were in paid employment, although fewer studies reported this detail (see Table 1). Most of the individuals with ASD were male, consistent with the commonly reported 1:4 ratio of females:males diagnosed (APA, 2013; Fombonne, 2003, 2009). Of the 29 studies that reported the mean age of the individuals with ASD, 93% ($N_{\text{studies}} = 27$) reported a mean age of 18 years or less (range = 2.7 to 26.9 years).

Twenty-six studies reported a mean depression severity score for their caregiver sample. Regardless of whether a qualitative category or clinical cut-off score was used, depression ratings were generally high. In 38% of studies (i.e., 10 of 26 studies), the mean depression score could be classified as clinical/severe/extremely severe. In the 16 studies that reported cut-off scores, 33% of the pooled sample (i.e., 821 of 2,513 participants) were classified as depressed.

Table 1.

Caregiver and child characteristics for pooled sample ($N_{\text{studies}} = 34$, $N_{\text{caregivers}} = 4{,}968$, $N_{\text{children}} = 4{,}629$)

	N_{studies}	$N_{\text{participants}}$	%	*M*	*SD*
Caregiver					
Age (in years)	28	4,463		41.3	8.1
Gender	34				
Male		753	15.2%		
Female		4,201	84.8%		
		4,954[a]	100.0%		
Marital status	28				
Married/Partnered		3,430	87.0%		
Single		512	13.0%		
		3,942	100.0%		
Ethnicity	18				
White/Caucasian		2,005	76.4%		
Other		621	23.6%		
		2,626	100.0%		
Employment	14				
Employed		1,437	59.6%		
Unemployed		974	40.4%		
		2,411	100.0%		
Education	25				
≤ High school		782	22.5%		
> High school		2,688	77.5%		
		3,469	100.0%		
Child					
Age (in years)	27	3,958		10.6	7.0
Gender	27				
Male		2,821	80.9%		
Female		666	19.1%		
		3,487[a]	100.0%		
Diagnosis	30				
ASD		3,140	72.9%		
Autistic disorder		902	20.9%		
Asperger's syndrome		149	3.5%		
PDD-NOS		118	2.7%		
		4,309[b]	100.0%		
Caregiver depression					
Classification/severity (sample mean score)	26				
Normal/minimal		2,151	54.7%		
Mild/moderate		100	2.5%		
Clinical/severe/extremely severe		1,683	42.8%		
		3,934	100.0%		
Clinical cut-off	16				
Depressed		821	32.7%		
Not depressed		1,692	67.3%		
		2,513	100.0%		

N_{studies} = number of studies providing these data; $N_{\text{participants}}$ = number of participants from studies providing these data. [a] In Zhou, Yiting & Chunli (2018), responses were missing for gender (*n* = 14 caregivers, *n* = 5 children). [b] In Clifford & Minnes (2013), responses were not mutually exclusive as some children had multiple diagnoses.

Risk of Bias Assessment

The average QualSyst score was .88 (*SD* = .06, range = .75 - .95; see Figure 3 and Appendix G). All studies therefore met the conservative threshold for inclusion (i.e., met more than 75% of items; Kmet et al., 2004). Specifically, studies provided a clear description of their objective(s) (Criterion 1: 100% fulfilled), although study design and/or sample selection methods were not made explicit (Criteria 2 and 3: 29% and 12% fulfilled, respectively). Caregiver characteristics (e.g., age, gender) and depression (as a primary or secondary outcome) were generally well reported (Criteria 4 and 5: 85% fulfilled). Most studies were sufficiently powered to detect significant associations (i.e., $N = 26$, $\alpha = .05$, power = .80, $r = .50$; Cohen, 1992; Criterion 6: 94% fulfilled). Statistical analyses (Criterion 7: 97% fulfilled), and estimates of variance (e.g., confidence intervals, *SD*s; Criterion 8: 85% fulfilled) were provided, and statistical results sufficiently explained to allow replication (Criterion 9: 100% fulfilled). Conclusions also carefully considered study limitations, including the generalisability of the findings (Criterion 10: 97% fulfilled). Overall, the studies included in this review provided adequate information regarding potential sources of methodological bias, and no studies were excluded based on quality scores.

Effect Size Estimates

Effect estimates for the six family functioning and social support domains are grouped according to the relevant ecological system and presented in Tables 2 to 7. Each domain is reviewed in detail in the following sections, beginning with the *microsystem*, and followed by the *mesosystem*.

Marital relationship quality. Seven studies examined the association between marital relationship quality and caregiver depression, contributing to a pooled, medium effect size (Table 2): caregivers who endorsed more symptoms of depression also reported poor quality

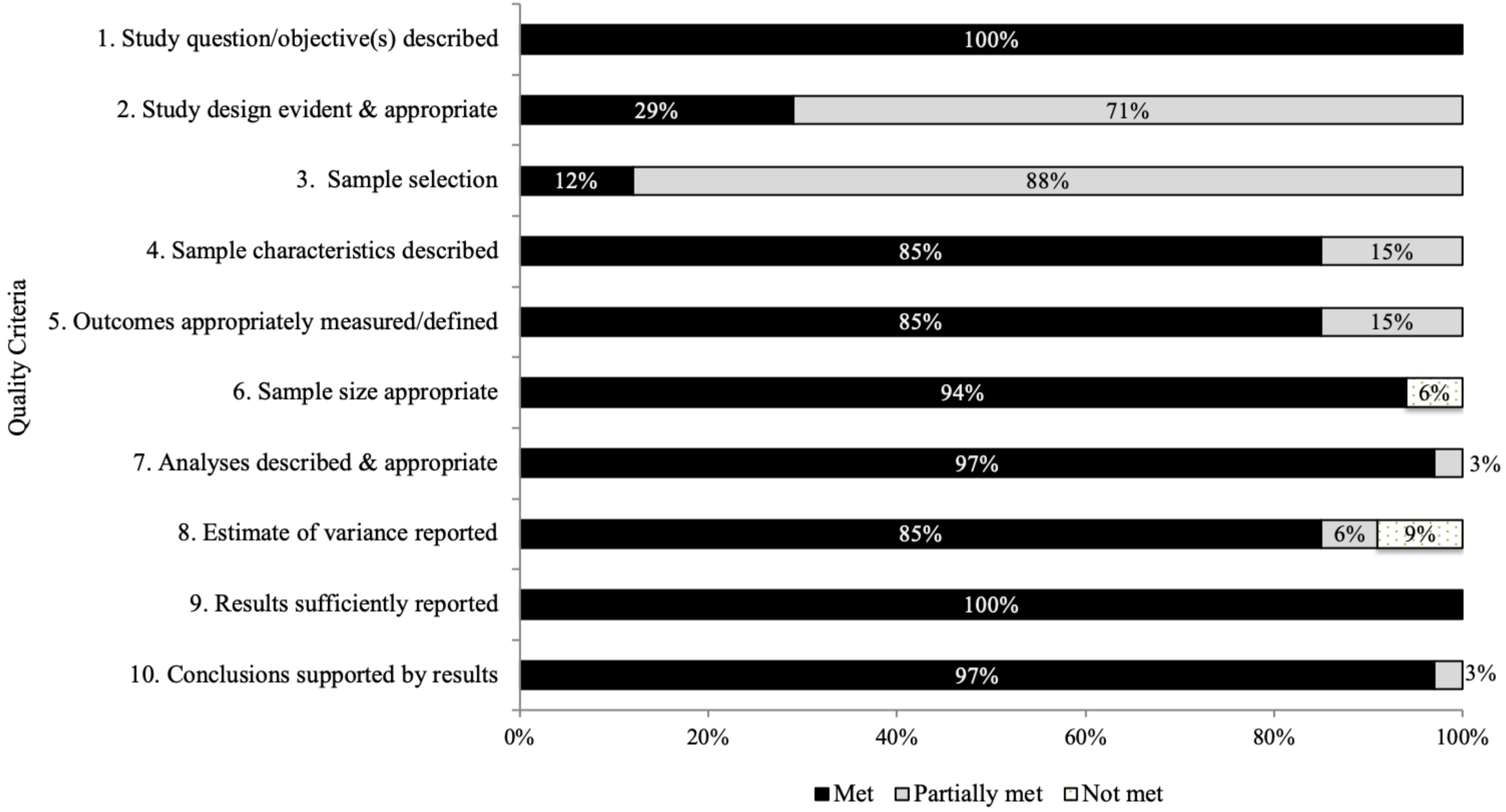

Figure 3. Proportion of included studies meeting each criterion on the QualSyst tool (Kmet et al., 2004).

Table 2.

Microsystem correlate of caregiver depression: marital relationship quality

Correlate	Marital relationship quality		Depression measure	$N_{studies}$	N	Effect size			95% CI			Heterogeneity				Author (year)
	Measure	Subscale				r_w	r	p	LL	UL	N_{fs}	Q	p	$\mathcal{T}$	I^2	
Marital quality	DAS-7		CES-D-7	1	96		-.460	.000	-.605	-.286	4					Benson (2011)
Marital satisfaction	MSS		BDI	1	48		-.458	.001	-.657	-.200	4					Kim (2009)
Marital satisfaction	DAS		CES-D	1	70		-.400	.001	-.580	-.182	3					Weitlauf (2014)
Marital satisfaction	CSI		CES-D	1	98		-.380	.000	-.538	-.196	3					Pruitt (2018)
Marital satisfaction	RSQ		IDS	1	90		-.369	.000	-.535	-.175	3					Da Paz (2018)
Marital satisfaction	ENRICH		PHQ-A	1	253		-.333	.000	-.438	-.219	3					Shtayermman (2013)
Relationship happiness	-		CES-D	1	70		-.390	.001	-.573	-.171	3					Timmons (2016)
Harmony	-		PHQ-9	1	375		-.340	.000	-.427	-.247	3					Chan (2018)
Harmony	-		CES-D	1	70		-.160	.186	-.381	.078	1					Timmons (2016)
			Total	**7**	**1030**	**-.360**		**.000**	**-.413**	**-.305**	**22**	**2.76**	**.838**	**.00**	**0**	

Note. (-) denotes a purposely designed, rather than a standardised measure of informal support. $N_{studies}$ = number of studies providing these data; N = number of participants (caregivers) from studies providing these data; r_w = weighted mean correlation; r = correlation coefficient; p = significance level; CI = 95% confidence interval for r/r_w, where LL = lower limit, UL = upper limit; N_{fs} = fail-safe N statistic; Q = significance test of heterogeneity; $\mathcal{T}$ = estimate of variance in r_w; I^2 = proportional estimate of true effect variance over sampling error observed.

Marital relationship quality measures: DAS-7 = Dyadic Adjustment Scale (short form); MSS = Marital Satisfaction Scale; DAS = Dyadic Adjustment Scale; CSI = Couples Satisfaction Index; RSQ = Relationship Satisfaction Questionnaire; ENRICH = Evaluating & Nurturing Relationship Issues, Communication, Happiness scale. **Depression measures:** CES-D-7 = Center for Epidemiologic Studies Depression Scale–7 item short form; BDI = Beck Depression Inventory; CES-D = Center for Epidemiologic Studies Depression Scale; IDS = Inventory of Depressive Symptoms; PHQ-A = Patient Health Questionnaire modified for adolescents; PHQ-9 = 9-item Patient Health Questionnaire.

relationships. The associated N_{fs} suggests that this finding is unlikely to be characterised by publication bias. This finding was relatively consistent across studies, resulting in low heterogeneity for this domain. However, a single study reported a non-significant relationship, based on a purposely designed scale of daily relationship harmony (Timmons et al., 2016).

Parent-child relationship. Of the nine studies that contributed data to this meta-analysis, only four reported significant effects (Table 3): warmth, functional interaction (i.e., the extent to which parents are satisfied with their parent-child interactions [Abidin, 1990]), reduced caregiver criticism of the child, and belief that the child with ASD has a positive family impact, were associated with lowered ratings of caregiver depression (Davis & Carter, 2008; Hastings et al., 2005; Hickey et al., 2019; Neff & Faso, 2015). The overall weighted effect was small but highly significant, precise (i.e., small CI) and robust to publication bias ($N_{fs} > N_{studies}$). Although the associated I^2 value indicated a small-to-moderate amount of variance across effect estimates, the non-significant Q and small tau (T) values suggest that there was no real variance among the effects (i.e., the dispersion may be due to random error; Borenstein et al., 2009).

Informal support. Ten studies examined the association between various sources of support from *family and friends* and caregiver depression (Table 4). The overall effect was significant and negative with good N_{fs}: social support buffered the impact of depression. Notably, studies varied greatly in their effect estimates (i.e., r range: -.62 to .16; $I^2 > 80\%$). In particular, strong associations were reported by studies which examined perceptions of support received from others (Ingersoll et al., 2011; Kim et al., 2009: Sawyer et al., 2010). Of the three studies that operationalised support in terms of network size, two reported significant findings: having a greater number of people who provided social support was associated with lowered levels of depressive symptoms (Benson, 2012; Smith et al, 2012). The pooled associations

Table 3.

Microsystem correlate of caregiver depression: parent-child relationship

	Parent-child relationship					Effect size			95% CI			Heterogeneity				
Correlate	Measure	Subscale	Depression measure	N_{studies}	N	r_w	r	p	LL	UL	N_{fs}	Q	p	τ	I^2	Author (year)
Belief that child has positive impact	KPP	PC	HADS-D	1	89		-.382	.000	-.546	-.188	3					Hastings (2005)
Functional interaction	PSI-SF	PCDI	CES-D	2	159	-.323		.000	-.457	-.175	6					Davis (2008), Neff (2015)
Reduced frustration	-		CES-D	1	83		-.210	.057	-.407	.006	1					Pruitt (2016)
Reduced inhibited attachment	DAI		DASS-21	1	29		-.210	.277	-.535	.170	1					Teague (2018)
Warmth	FMSS		CES-D	1	300		-.192	.001	-.298	-.080	1					Hickey (2019)
Reduced criticism	FMSS		CES-D	1	300		-.191	.001	-.298	-.080	1					Hickey (2019)
Belief that child is source of strength and family closeness	KPP	PC	HADS-D (Sp.)	1	152		-.154	.059	-.305	.006	1					García-López (2016)
Perceived closeness	PAI		CES-D	1	149		-.150	.068	-.303	.011	1					Baker (2011)
Cognitive engagement	PCIRS		CES-D	1	63		-.130	.311	-.366	.122	0					Wachtel (2008)
Reduced disinhibited attachment	DAI		DASS-21	1	29		-.130	.505	-.474	.248	0					Teague (2018)
Engaged interaction	PCIRS		CES-D	1	63		-.090	.485	-.330	.161	0					Wachtel (2008)
Belief that child is source of happiness	KPP	PC	HADS-D (Sp.)	1	152		-.055	.503	-.212	.105	0					García-López (2016)
Belief that child is source of personal growth/maturity	KPP	PC	HADS-D (Sp.)	1	152		-.051	.533	-.209	.109	0					García-López (2016)
Supportive engagement	PCIRS		CES-D	1	63		-.030	.816	-.276	.219	0					Wachtel (2008)
Positive interaction	-		CES-D	1	83		-.020	.858	-.235	.197	0					Pruitt (2016)
Reduced conflict	CPRS		DASS-21	1	29		-.020	.919	-.384	.349	0					Teague (2018)
Closeness	CPRS		DASS-21	1	29		.170	.381	-.210	.505	3					Teague (2018)
			Total	**9**	**1,024**	**-.199**		**.000**	**-.282**	**-.113**	**10**	**14.13**	**.078**	**.086**	**43.4**	

Note. (-) denotes a purposely designed, rather than a standardised measure of informal support. N_{studies} = number of studies providing these data; N = number of participants (caregivers) from studies providing these data; r_w = weighted mean correlation; r = correlation coefficient; p = significance level; CI = 95% confidence interval for r/r_w, where LL = lower limit, UL = upper limit; N_{fs} = fail-safe N statistic; Q = significance test of heterogeneity; τ = estimate of variance in r_w; I^2 = proportional estimate of true effect variance over sampling error observed.

Parent-child relationship measures: KPP = Kansas Inventory of Parental Perceptions; PC = Positive Contributions subscale; PSI-SF = Parenting Stress Index – short form; PCDI = Parent-Child Dysfunctional Interaction; DAI = Disturbances of Attachment Interview; FMSS = Five Minute Speech Sample; CPRS = Child-Parent Relationship Scale; PAI = Positive Affect Index; PCIRS = Parent-Child Interaction Rating Scales. **Depression measures:** HADS-D = Hospital Anxiety and Depression Scale – Depression subscale; CES-D = Center for Epidemiologic Studies Depression Scale; DASS-21 = Depression, Anxiety Stress scales (short form) – Depression subscale; HADS-D (Sp.) = Hospital Anxiety and Depression Scale – Depression subscale (Spanish language version).

Table 4.

Microsystem correlate of caregiver depression: informal supports

	Informal support					Effect size			95% CI			Heterogeneity				
Correlate	Measure	Subscale	Depression measure	N_{studies}	N	r_w	r	p	LL	UL	N_{fs}	Q	p	τ	I^2	Author (year)
Family and friend support																
Perceived interpersonal support	ISEL		CES-D	1	216		-.620	.000	-.696	-.530	7					Sawyer (2010)
Perceived interpersonal support	ISEL		BDI	1	60		-.244	.060	-.469	.010	2					Gill (1991)
Perceived social support	MOSS-SSS		CES-D	1	149		-.540	.000	-.645	-.415	5					Ingersoll (2011)
Perceived social support	SSI		BDI	1	48		-.483	.000	-.675	-.230	5					Kim (2009)
Perceived social support	MSPSS[a]	Family & Friend	CES-D-7	1	96		-.360	.000	-.523	-.172	3					Benson (2012)
Perceived social support	-		DASS-21	1	479		-.305	.000	-.384	-.221	2					Falk (2014)
Perceived helpfulness	FSS	Informal[a]	CES-D-7	1	90		-.390	.000	-.552	-.199	3					Benson (2009)
No. reducing interpersonal strain	-		CES-D-7	1	106		-.314	.001	-.476	-.131	2					Benson (2012)
Perceived positive support	-		CES-D	1	269		-.260	.000	-.368	-.145	2					Smith (2012)
Perceived positive support	-		CES-D	1	269		.090	.141	-.030	.207	2					Smith (2012)
Social support quantity	SSQ6	Network size	DASS-21	1	47		-.200	.179	-.461	.092	1					Pakenham (2005)
No. providing instrumental support	-		CES-D-7	1	106		-.193	.047	-.370	-.002	1					Benson (2012)
Perceived economic support	-		DASS-21	1	479		-.190	.000	-.275	-.102	1					Falk (2014)
Perceived quality	SSQ6	Satisfaction	DASS-21	1	47		-.190	.202	-.452	.103	1					Pakenham (2005)
No. providing emotional support	-		CES-D-7	1	106		-.187	.055	-.365	.004	1					Benson (2012)
Support network size	-		CES-D	2	670	-.167		.000	-.240	-.092	2					Lin (2011), Smith (2012)
Support network size	-		CES-D-7	1	106		-.139	.156	-.321	.053	0					Benson (2012)
Geographic proximity of network	-		CES-D-7	1	106		.101	.304	.092	.286	2					Benson (2012)
Frequency of contact	-		CES-D-7	1	106		-.040	.685	-.229	.152	0					Benson (2012)
Strong support connections	-		CES-D	1	20		-.040	.869	-.474	.410	0					Kuhn (2018)
No. of close connections	-		CES-D-7	1	106		-.034	.730	-.223	.158	0					Benson (2012)
No. of females in network	-		CES-D-7	1	106		.019	.847	-.172	.209	1					Benson (2012)
No. of parents with ASD child	-		CES-D	1	106		.163	.095	-.029	.343	3					Benson (2012)
			Total	**10**	**1,795**	**-.302**		**.000**	**-.432**	**-.160**	**21**	**77.38**	**.000**	**.217**	**88.4**	

	Informal support		Depression measure			Effect size			95% CI			Heterogeneity				
Correlate	Measure	Subscale		N_{studies}	N	r_w	r	p	LL	UL	N_{fs}	Q	p	$\mathcal{T}$	I^2	Author (year)
Family support																
Perceived support	PSS	Family	CES-D	1	94		-.310	.002	-.482	-.115	2					Ekas (2016)
Perceived support	MSPSS	Family	CES-D	2	166	-.298		.000	-.431	-.152	4					Pruitt (2018), Singh (2017)
Perceived support	SSSS[a]	Family	CES-D	1	119		-.280	.002	-.438	-.105	2					Ekas (2010)
Strong family connections	-		CES-D	1	20		-.209	.382	-.596	.257	1					Kuhn (2018)
No. of kin in network	-		CES-D	1	106		-.146	.136	-.328	.046	0					Benson (2012)
Perceived helpfulness	FSS		BDI-II	1	239		.089	.170	-.038	.213	2					Tudor (2018)
			Total	**6**	**650**	**-.184**		**.030**	**-.339**	**-.018**	**6**	**19.80**	**.001**	**.175**	**74.7**	
Friend support																
Perceived support	SSSS[a]	Friend	CES-D	1	119		-.330	.000	-.481	-.159	2					Ekas (2010)
Perceived support	MSPSS	Family	CES-D	2	166	-.187		.016	-.330	-.035	2					Pruitt (2018), Singh (2017)
Perceived support	PSS	Friend	CES-D	1	94		-.120	.250	-.315	.085	0					Ekas (2016)
			Total	**3**	**285**	**-.224**		**.001**	**-.349**	**-.091**	**3**	**2.64**	**.267**	**.060**	**24.3**	
Partner support																
Perceived support	SSSS[a]	Partner	CES-D	1	119		-.400	.000	-.541	-.237	3					Ekas (2010)
Perceived support	MSPSS	Other	CES-D	1	70		-.320	.007	-.516	-.092	2					Singh (2017)
Daily support	-		CES-D	1	70		-.160	.186	-.381	.078	1					Timmons (2016)
			Total	**3**	**259**	**-.310**		**.000**	**-.440**	**-.167**	**6**	**2.92**	**.232**	**.076**	**31.6**	

Note. (-) denotes a purposely designed, rather than a standardised measure of informal support. N_{studies} = number of studies providing these data; N = number of participants (caregivers) from studies providing these data; r_w = weighted mean correlation; r = correlation coefficient; p = significance level; CI = 95% confidence interval for r/r_w, where LL = lower limit, UL = upper limit; N_{fs} = fail-safe N statistic; Q = significance test of heterogeneity; $\mathcal{T}$ = estimate of variance in r_w; I^2 = proportional estimate of true effect variance over sampling error observed.

Informal support measures: ISEL = Interpersonal Support Evaluation List; MOSS-SSS = Medical Outcome Study – Social Support Survey; SSI = Social Support Index; MSPSS = Multidimensional Scale of Perceived Social Support; FSS = Family Support Scale; SSQ6 = Brief Social Support Questionnaire; PSS = Perceived Social Support scale; SSSS = Schuster Social Support Scale.

Depression measures: CES-D = Center for Epidemiologic Studies Depression Scale; BDI = Beck Depression Inventory; CES-D-7 = Center for Epidemiologic Studies Depression Scale – 7 item short form; DASS-21 = Depression, Anxiety, Stress Scales, short form – Depression subscale; BDI-II = Beck Depression Inventory – Second Edition.

[a] Scale or subscale has been modified.

between different sources of support – whether from *family*, *friends* or *partners* – and caregiver depression were all significant. However, these findings should be interpreted with caution as they were based on limited data ($N_{\text{fs}} = N_{\text{studies}}$; Table 4). There was also substantial between-study heterogeneity for *family support*. In particular, three independent studies reported that caregivers who perceived higher levels of family support reported lower levels of depression (Ekas et al, 2010, 2016; Pruitt et al., 2018; Singh et al., 2018). Family support was also identified as a non-significant correlate of parental depression (Benson et al., 2012; Kuhn et al, 2018; Tudor et al., 2018).

Formal support. Of the five studies that contributed data to this meta-analysis, only one reported significant, small to medium effects (Table 5; Taylor & Warren, 2012): caregivers who rated available ASD intervention services as both affordable and of higher quality reported lowered depression symptoms. Interestingly, this same study found that service accessibility was not a significant factor. The use of parent support groups and/or respite care was not directly related to caregiver depression (Clifford et al., 2013; Dyches et al., 2016; Ruiz-Robledillo et al., 2014). However, these individual results, along with the overall pooled finding, were susceptible to publication bias ($N_{\text{fs}} < N_{\text{studies}}$).

Family unit functioning. Ten studies examined family unit functioning contributing to a statistically significant, small-to-medium and robust r_w (Table 6). Some dispersion was evident, as indicated by the wide confidence interval and high I^2 value. The Questionnaire on Resources and Stress (QRS-F), used by three studies (Beer et al., 2013; Hastings et al., 2003, 2005), demonstrated the strongest association: greater harmony (i.e., fewer family problems) was associated with lower caregiver depression. Medium to large relationships between caregiver

Table 5.

Microsystem correlate of caregiver depression: formal supports

	Formal support					Effect size			95% CI			Heterogeneity				
Correlate	Measure	Subscale	Depression measure	$N_{studies}$	N	r_w	r	p	LL	UL	N_{fs}	Q	p	Ƭ	I^2	Author (year)
Affordable services	-	-	CES-D	1	75		-.330	.004	-.518	-.111	2					Taylor (2012)
Strong service connections	-	-	CES-D	1	20		-.274	.246	-.639	.192	2					Kuhn (2018)
Service quality	-	-	CES-D	1	75		-.240	.038	-.443	-.014	1					Taylor (2012)
Support use	-	-	BDI	1	24		-.209	.294	-.542	.182	1					Ruiz-Robledillo (2014)
Efficacy in accessing intervention	-	-	CES-D	1	75		-.110	.349	-.329	.120	0					Taylor (2012)
Support group use	-	-	CES-D	1	149		-.100	.221	-.255	.060	0					Clifford (2013)
Respite care	RCQ	-	CES-D	1	122		.070	.444	-.109	.245	1					Dyches (2016)
			Total	**5**	**390**	**-.099**		**.122**	**-.222**	**.027**	**3**	**25.52**	**.238**	**.075**	**27.5**	

Note. (-) denotes a purposely designed, rather than a standardised measure of informal support. $N_{studies}$ = number of studies providing these data; N = number of participants (caregivers) from studies providing these data; r_w = weighted mean correlation; r = correlation coefficient; p = significance level; CI = 95% confidence interval for r/r_w, where LL = lower limit, UL = upper limit; N_{fs} = fail-safe N statistic; Q = significance test of heterogeneity; Ƭ = estimate of variance in r_w; I^2 = proportional estimate of true effect variance over sampling error observed.

Formal support measure: RCQ = Respite Care Questionnaire. **Depression measures:** CES-D = Center for Epidemiologic Studies Depression Scale; BDI = Beck Depression Inventory.

Table 6.

Mesosystem correlate of caregiver depression: family unit functioning

	Family unit functioning					Effect size			95% CI			Heterogeneity				
Correlate	Measure	Subscale	Depression measure	N_{studies}	N	r_w	r	p	LL	UL	N_{fs}	Q	p	$\mathcal{T}$	I^2	Author (year)
Harmony	QRS-F	Parent & family problems	HADS-D	3	153	-.623		.000	-.724	-.495	22	2.41	.300	.071	17.0	Beer (2013), Hastings (2003, 2005)
Easy family life	FaMM	Family life difficulty	CES-D-10	1	234		-.510	.000	-.599	-.408	5					Kim (2016)
General functioning	FAD	General functioning	DASS-21	1	97		-.440	.000	-.588	-.264	4					Jellett (2015)
Adaptability	FACES-CV	Adaptability	CES-D	1	263		-.390	.000	-.488	-.282	3					Zhou (2018)
Adaptability	FACES [a]	Adaptability	CES-D	1	401		-.362	.000	-.444	-.274	3					Lin (2011)
Adaptability	FACES-II [b]	Adaptability	CES-D	1	149		-.190	.020	-.340	-.030	1					Baker (2011)
Cohesion	FACES-CV	Cohesion	CES-D	1	263		-.430	.000	-.524	-.326	0					Zhou (2018)
Cohesion	FACES [a]	Cohesion	CES-D	1	401		-.335	.000	-.419	-.245	3					Lin (2011)
Cohesion	FACES-IV	Balanced cohesion	CES-D	1	83		-.180	.104	-.381	.037	1					Pruitt (2016)
ASD child involvement	PROMIS®	Family involvement	PROMIS®	1	114		-.220	.018	-.388	-.038	1					Schwartz (2018)
Flexibility	FACES-IV	Balanced flexibility	CES-D	1	70		-.110	.366	-.336	.128	0					Timmons (2016)
Flexibility	FACES-IV	Rigidity	CES-D	1	83		-.010	.929	-.225	.206	1					Pruitt (2016)
			Total	**10**	**1,494**	**-.406**		**.000**	**-.501**	**-.302**	**39**	**41.56**	**.000**	**.163**	**78.3**	

Note. $N_{studies}$ = number of studies providing these data; N = number of participants (caregivers) from studies providing these data; r_w = weighted mean correlation; r = correlation coefficient; p = significance level; CI = 95% confidence interval for r/r_w, where LL = lower limit, UL = upper limit; N_{fs} = fail-safe N statistic; Q = significance test of heterogeneity; $\mathcal{T}$ = estimate of variance in r_w; I^2 = proportional estimate of true effect variance over sampling error observed.

Family functioning measures: QRS-F = Questionnaire on Resources and Stress – Friedrich (short form); FaMM = Family Management Measure; FAD = Family Assessment Device; FACES-CV = Family Adaptability and Cohesion Evaluation Scale – Chinese version; FACES-II = Family Adaptability and Cohesion Evaluation Scale – second edition; FACES-IV = Family Adaptability and Cohesion Evaluation Scale – fourth edition; PROMIS® = Patient-Reported Outcomes Measurement Information System. **Depression measures:** HADS-D = Hospital Anxiety and Depression Scale – Depression subscale; CES-D-10 = Center for Epidemiologic Studies Depression Scale – Boston (short form); DASS-21 = Depression, Anxiety, Stress Scales (short form) – Depression subscale; CES-D = Center for Epidemiologic Studies Depression Scale; PROMIS® = PROMIS Adult Depression measure.

[a] 81% of sample (n = 325) completed FACES-II and 19% (n = 72) completed FACES-CV. [b] Scale has been modified.

depression severity, positive general family functioning, adaptability and cohesion were also reported (Kim et al, 2016; Jellett et al., 2015; Lin et al., 2011; Zhou et al., 2018). In comparison, one independent study reported non-significant findings (Pruitt, Willis, Timmons, & Ekas, 2016; Timmons, Willis, Pruitt, & Ekas, 2016).

Sibling functioning. Variable findings were reported by the two studies that contributed to this domain, resulting in a pooled estimate that was small and non-significant (Table 7). Meyer et al. (2011) reported small-to-medium and negative associations: behavioural adjustment (including functional peer relationships, social behaviour and conduct) and positive sibling relationships were both significantly associated with reduced depression in caregivers. Tudor et al. (2018) reported a weak but significant association: caregivers with lower depression reported providing more equal attention to their children, with and without ASD. However, in the same study, sibling relationship quality was not a significant correlate (Tudor et al., 2018).

Sensitivity Analyses

Sensitivity analyses were conducted to examine the potential influence of outlier effects. Meaningful results were obtained for the *family support* meta-analysis: the removal of Tudor et al's (2018) study of 239 American mothers reduced the observed heterogeneity (from $I^{2} =$ 74.7% to 0%) and increased the magnitude of the relationship between caregiver depression symptoms and family support from a negligible to a small association ($r_{w} = -.253$, $p < .001$, 95% CI [-.34, -.16]); a finding that was robust to publication bias ($N_{fs} > N_{studies}$).

Table 7.

Mesosystem correlate of caregiver depression: sibling functioning

	Sibling functioning					Effect size			95% CI			Heterogeneity				
Correlate	Measure	Subscale	Depression measure	N_{studies}	N	r_w	r	p	LL	UL	N_{fs}	Q	p	Ƭ	I^2	Author (year)
Behavioural adjustment	SDQ		CES-D	1	70		-.380	.001	-.565	-.159	3					Meyer (2011)
Positive impact	FIQ	Impact on siblings	CES-D	1	70		-.340	.004	-.532	-.114	3					Meyer (2011)
Equal parental attention	WDW [a]		BDI-II	1	239		-.155	.016	-.276	-.029	1					Tudor (2018)
Relationship quality	SIB [a]		BDI-II	1	239		.064	.325	-.063	.189	2					Tudor (2018)
			Total	**2**	**309**	**-.193**		**.235**	**-.476**	**.127**	**2**	**5.72**	**.017**	**.213**	**82.5%**	

Note. N_{studies} = number of studies providing these data; N = number of participants (caregivers) from studies providing these data; r_w = weighted mean correlation; r = correlation coefficient; p = significance level; CI = 95% confidence interval for r/r_w, where LL = lower limit, UL = upper limit; N_{fs} = fail-safe N statistic; Q = significance test of heterogeneity; Ƭ = estimate of variance in r_w; I^2 = proportional estimate of true effect variance over sampling error observed.

Sibling functioning measures: SDQ = Strengths and Difficulties Questionnaire; FIQ = Family Impact Questionnaire; WDW = the Who Does What? questionnaire; SIB = Sibling Inventory of Behavior. **Depression measures:** CES-D = Center for Epidemiologic Studies Depression Scale; BDI-II = Beck Depression Inventory – Second Edition.

[a] Scale has been modified

Moderator Analyses

There were a sufficient number of studies to enable subgroup comparisons between perceived support correlates ($N_{studies}$ = 13), received support ($N_{studies}$ = 3), and network characteristics ($N_{studies}$ = 3; Fu et al., 2010; Higgins & Altman, 2008). Between-group differences were not statistically significant (Q_B (2) = 4.31, p = .116; see Table 8). Notably, the 12 instruments that measured perceived support, contributed to significant heterogeneity (I^2 = 88.6%), in comparison to objective indices of received (actual) support (I^2 = 0%) and network characteristics (I^2 = 0%).

Table 8.

Moderator analyses for informal support

			Effect size		95% CI		Heterogeneity	
Subgroup	N_{studies}	N	r_w	p	LL	UL	Q	p
Perceived support	13	1,920	-.297	.000	-.421	-.161		
Received support	3	251	-.111	.103	-.241	.023		
Network characteristics	3	776	-.156	.000	-.224	-.086		
	19	**2,947**	**-.171**	**.000**	**-.226**	**.115**	**4.31**	**.116**

Note. N_{studies} = number of studies providing these data; N = number of participants (caregivers) from studies providing these data; r_w = weighted mean correlation; p = significance level; CI = 95% confidence interval for r_w, where LL = lower limit, UL = upper limit; Q = between subgroups heterogeneity (based on ANOVA).

Chapter 4

Discussion

Key Findings

Thirty-four studies, comprising 4,968 caregivers of persons with ASD, were meta-analysed to examine the impact of family and social support systems on caregiver depression severity. Results were structured within Bronfenbrenner's Ecological Systems Theory (1977, 1986), focussing specifically on the *micro-* and *mesosystems*. Informal social support, parent-child and marital relationship quality, and family unit functioning were all significantly associated with caregiver depression severity. In comparison, formal support and sibling functioning were not. These findings will be critically evaluated and discussed in this chapter, together with their implications for research and clinical practice.

Microsystem.

Marital relationship quality. Studies demonstrated relatively consistent, moderate associations: caregivers who experience more depressive symptoms also report poor quality relationships. This is consistent with previous meta-analytic data (Sim et al., 2016). Importantly, the larger sample size of the current meta-analysis ($N = 1,030$) allows for more robust conclusions. The causal nature of this relationship, along with potential mediating variables, should be a focus of future longitudinal regression research. One possible interpretation is that the relationship between caregiver mental health and marital relationship quality is bidirectional, as has been demonstrated in the general population (e.g., Mead, 2002). Furthermore, depression symptoms in one partner (e.g., flat affect, less positive interactions) can lead to relationship dissatisfaction in the other partner (Gau et al., 2012; Mead, 2002). Additionally, this association could be mediated by child factors: despite ASD typically being associated with lower levels of social awareness, marital conflict has been shown to negatively impact child ASD symptomatology (e.g., sensory sensitivity, behavioural rigidity) and challenging behaviour (Hartley et al., 2012; Kelly et al., 2008), which, in turn, could exacerbate depressive symptoms in caregivers. Finally, social support has been found to play a protective role in marital relationships within this caregiver group (Sim et al., 2016), hence access to appropriate supports could buffer potential negative effects of poor marital quality on caregiver depression symptoms.

Parent-child relationship. This meta-analysis synthesised the inconsistent effects reported in the literature, to produce an overall weighted effect that was small, yet highly significant, precise and robust. That is, parents who experience higher quality relationships and more positive interactions with their child with ASD are likely to experience fewer depression symptoms. More specifically, it appears that parent-child relationships characterised by warmth and reduced caregiver criticism, along with caregiver satisfaction regarding parent-child interactions, and caregivers’ belief about the child’s role in the family, may be important for protecting against depressive symptoms in caregivers.

This relationship may also be bidirectional: depressed parents have consistently reported greater irritability and hostility toward their child, thus causing strain in the parent-child relationship (Lovejoy, Craczyk, O’Hare, & Neuman, 2000; Maletic et al., 2007). Furthermore, child behaviour could play a mediating role: caregiver depression has been found to increase challenging behaviour (e.g., aggression) in children with ASD (Baker et al., 2011), which, in turn, could negatively impact on the parent-child relationship. Future research should investigate possible differences between parents’ perceptions of the relationship (e.g., perceived closeness, belief that the child is a source of happiness) and observed interactions (e.g., warmth, conflict), in order to ascertain whether caregivers' internal psychological processes or external parent/child behaviours have a greater impact on caregivers' mental health outcomes.

Informal support. Informal support appears to be a protective factor for depression in caregivers of persons with ASD, regardless of the source of this support (i.e., *family and friends, family, friends,* and *partners*). This aligns with previous research which has found that access to informal support can help to reduce feelings of helplessness, isolation, and psychological distress (Bromley et al., 2004; Cooley, 1994). Although based on limited data, support from partners appeared to have the greatest impact on caregiver depression symptoms. This is consistent with a previous review which found spousal support to be the most effective buffer against stress for mothers of children with ASD (Boyd, 2002). Notably, much of the available data has focused on female caregivers. Future research should seek to address this gap in the literature by investigating the impact of partner support on mental health outcomes in male or mixed caregiver samples.

Previous research has suggested that perceived, but not received, support is linked to reduced depressive symptoms in caregivers (Benson, 2012; Ingersoll & Hambrick, 2011; E. S. Kim, & B. S. Kim, 2009; Pakenham et al., 2005; Sawyer et al., 2010; Timmons et al., 2016). Although subgroup analyses found weighted effects that were consistent with these previous findings (i.e., significant effects for perceived support and network characteristics, but not received support), between-group differences were not statistically significant. It may be that the quantity of support received is just as important as the perceived quality and availability of supports. As such, simply increasing informal supports may be of benefit to caregivers. Further research is, however, needed to confirm this finding.

The substantial between-study heterogeneity noted for *family support* was primarily due to an outlier effect (Tudor et al., 2018). This particular study assessed mothers' perceptions of how helpful various sources of family support had been over the previous six month period. Future studies can extend on these findings by examining the potential impact of perceived support and how it is conceptualised (i.e., perceived availability vs. perceived helpfulness/quality) on caregiver depression.

Formal support. The pooled effect for this domain did not yield a significant relationship – although absence of evidence for an association does not necessarily provide evidence for no association, particularly in the context of relatively few studies (Ruopp, Collins, Whitcomb & Schisterman, 2009). Nonetheless, one possible explanation for the lack of a direct relationship between formal supports and caregiver depression could be the potential mediating effects of caregivers' psychological processes. Indeed, there is evidence that the relationship between respite care usage and caregiver depression may be mediated by caregivers' cognitive appraisals of daily experiences (i.e., positive perceptions of the tasks achieved while their child was in respite care contributed to decreased depressive symptoms; Dyches et al., 2016).

Mesosystem.

Family unit functioning. The strongest association observed in the current review was between caregiver depression symptom severity and family unit functioning. Specifically, greater family harmony, adaptability, cohesion, and more positive family functioning were all associated with lower caregiver depression, consistent with previous research (Beer et al., 2013; Hastings et al., 2005). This is concerning, given that families of children with ASD are likely to experience poorer functioning in each of these domains compared to families with typically developing children (Gau et al., 2012; Hartley et al., 2010; Higgins et al., 2005). Furthermore, there are likely to be transactional effects of family functioning on the child with ASD. That is, disruptions to family unit functioning can have reciprocal negative effects on child behaviour which may, in turn, disrupt family functioning and caregiver mental health (Baker et al., 2011; Hastings et al., 2005). Notably, the substantial heterogeneity observed in this analysis may be an artefact of the different instruments that studies used to measure various aspects of family functioning, rather than reflecting true differences in effect estimates between studies.

Sibling functioning. The overall effect size estimate for this domain was small and non-significant. Taken at face value, this could be interpreted as sibling functioning having little impact on caregiver depression symptom severity. The potential relationship between sibling functioning and caregiver depression does, however, remain under-investigated. Moreover, the few significant associations reported (i.e., between sibling behavioural adjustment, positive sibling relationships and equal caregiver attention; Meyer et al., 2011; Tudor et al., 2018) make this a key area for future research. Importantly, previous findings have indicated that parents tend to have more negative perceptions of sibling relationships than the siblings themselves (Macks & Reeve, 2007; Rivers & Stoneman, 2003). For this reason, future research on caregiver depression might consider utilising both parent- and sibling-reported measures of sibling functioning, to ensure that both perspectives are taken into account.

Clinical Implications and Future Research

The results of this meta-analysis have important clinical and theoretical implications. In particular, the findings highlight the need to address the entire family and social system when targeting caregiver depression, rather than focusing interventions exclusively on management of the child’s behaviour or solely on caregiver symptoms. For example, involving caregivers and other family members in interventions has been found to improve mental health outcomes for families and the dyadic relationships within them (Karst & Van Hecke, 2012; Rogers, 2000; Schertz & Odom, 2007; Schreiber, 2011; M. S. Smith & Elder, 2010). Indeed, there is evidence that multi-component interventions which involve a combination of child- (e.g., behavioural training) and caregiver-focused (e.g. individual counselling) services are more effective in reducing caregiver depressive symptoms than interventions that focus on child or caregiver outcomes alone (Singer et al., 2007). Possible treatment components could include: (a) psychoeducation, to improve understandings of ASD symptomatology; (b) parent skills training (e.g., Positive Behaviour Support strategies), to teach caregivers how to manage behaviours of concern in their child with ASD; and (c) individual or family counselling (e.g., cognitive behavioural therapy, mindfulness training) to help family members adjust to the ASD diagnosis, reduce stress, and improve family functioning. More specifically, interventions that aim to increase warmth and reduce criticism in parent-child interactions, address caregiver beliefs about the child's role within the family, or to increase marital satisfaction, may be effective in preventing or reducing depression symptoms in caregivers. These family-level interventions could be combined with social networking opportunities including: (d) support groups for parents or siblings, for seeking advice and reducing feelings of isolation; and (e) guidance around accessing financial and legal resources (e.g., the use of case managers to assist caregivers in selecting appropriate service providers or in accessing funding under the National Disability Insurance Scheme [NDIS]; Ruiz-Robledillo et al., 2014).

The current findings also suggest that clinicians consider assessing the informal social supports available to parents, in order to identify those caregivers who may not have access to sufficient levels of support, and therefore may be at greater risk of developing depressive symptoms (Lin et al., 2011; Twoy et al., 2007). In particular, social support from a partner appears to be a substantial protective factor (Ekas et al., 2010; Singh et al., 2017). Notably, the only included study with a sample of single mothers, reported the highest prevalence estimate of depression (77% depressed; Dyches et al., 2016). Indeed, previous research has found that single mothers access less social support than those who live with a partner (Bromley et al., 2004). This may not only be due to the absence of partner support, but also to the associated lack of support from a partner's family and friends, and the added time and financial constraints which may prevent lone caregivers from accessing support in other social settings (McIntyre & Brown, 2018). Interventions designed to support non-partnered parents and potentially buffer against depression therefore warrant attention.

The interrelated nature of the *micro-* and *mesosystems* examined in this review also has implications for future ASD research. In line with recommendations from Tint and Weiss (2016), there is a need for future research to consolidate current knowledge of environmental influences in family wellbeing. This can be achieved by using a framework such as Bronfenbrenner's ecological systems approach (1977, 1986). The present meta-analysis identified key relationships between caregiver depression, family functioning and social support domains within the *micro-* and *mesosystems* (see Figure 4). Although these two innermost systems combine to have the most direct impact upon caregiver functioning (Bronfenbrenner, 1995; Tint & Weiss, 2016), more distal systems not captured in this review may also be important. For example, caregiver depression symptoms may be influenced by: (a) exosystem factors, such as the child's school environment (e.g., the school's capacity to provide a modified curriculum, effective anti-bullying program, and teachers who are appropriately trained in behaviour support strategies); (b) macrosystem components, such as the broader cultural (e.g., cultural understandings of ASD, social stigma), economic (e.g., access to funding for interventions), and legal (e.g., anti-discrimination policies) contexts; and (c) changes in each of these ecological systems over time (i.e., as the child with ASD ages).

Additional research is needed to more thoroughly assess the relationships between caregiver depression, sibling functioning and formal supports, ideally using larger samples and investigating both child- and caregiver-focused support services. Finally, given the reciprocal relationships reported in the literature between child behaviour, various aspects of family functioning, and caregiver depression (Baker et al., 2011; Hartley et al., 2012; Hastings et al., 2005; Kelly et al., 2008), future research should incorporate measures of child behaviour in order to investigate possible interactions with caregiver depression, and social and family functioning.

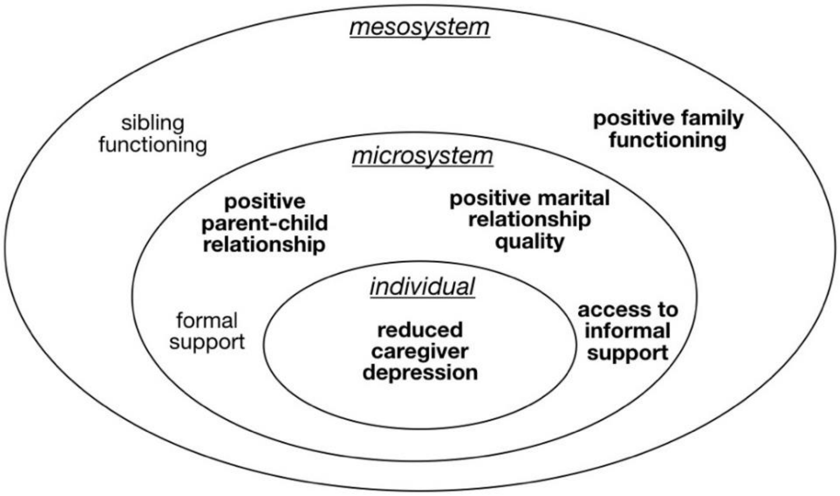

Figure 4. Relationships between caregiver depression, family functioning and social support from an ecosystems perspective. Bold text denotes significant correlates, as identified in this review. Normal text denotes correlates examined in this review, but not found to be significant.

Limitations

Several methodological limitations were encountered in the present review. First, the search criteria may have failed to capture all relevant studies. In an effort to minimise this limitation, broad search terms and multiple databases and search strategies (e.g., manual searches of reference lists, contacting authors) were adopted. Further, N_{fs} statistics were calculated in order to quantify the risk of publication bias (Zakznis, 2001), although the inclusion of this statistic does not fully alleviate the problem (Orwin, 1983). Despite these efforts, the relatively stringent eligibility criteria meant that some studies were excluded. In particular, limiting depression measures to validated, multi-item self-report scales reduced the number of eligible studies. This was done to ensure that the construct of depression was operationalised in a consistent way. Furthermore, very few identified studies used alternative measures of depression (e.g., structured clinician interviews, medical records indicating patient history of MDD). Nonetheless, given the tendency for self-ratings of depression severity to exceed observer-ratings (Möller, 2000), further research is warranted to investigate the possible impact of self-reported and clinician-based depression measures on noted associations in this review.

Second, the majority of participants in the pooled sample were female (84.8%) and married/partnered (87%). This limitation may be particularly problematic when it comes to understanding single mothers of persons with ASD, who have been found to be particularly at risk for depressive symptoms (Dyches et al., 2016). That both children and adults with ASD were considered in the present review may have also impacted the findings. There is evidence that the family and social implications of caring for an adult or child with ASD can differentially impact on caregiver mental health, with both child behaviour and caregiver psychological adaptation improving over time (Gray, 2006).

Finally, no causal inferences can be made regarding the relationships between caregiver depression, family functioning and social support, due to the cross-sectional and correlational nature of this meta-analysis (Knight, Fabes & Higgins, 1996). Further large-scale and longitudinal research will help to clarify causal relationships and assess the family functioning and social support domains that remain under-investigated.

Conclusion

The current meta-analysis provides an overview of how family and social systems interact to regulate the mental health of caregivers of children and adults living with ASD. The findings support an ecological systems-based approach to managing depression in this caregiver group, with suggestion that interventions be tailored to those who report low levels of social support or poor functioning within family, marital, or parent-child relationships. Future research can extend on these findings by focusing on the bidirectional and dynamic relationships between these family and social systems and their impact on caregiver functioning over time.

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Appendices

Appendix A: Logic Grids

Logic grids per database informing overall search strategy.

Table A1.

Logic grid for Embase

Caregivers AND	*Autism* AND	*Depression*
caregiver/de	autism/exp	depression/de
OR	OR	OR
“caregiver burden”/de	autis*:ti,ab	depression:ti,ab
OR	OR	OR
caregiver*:ti,ab	asperger*:ti,ab	depressed:ti,ab
OR	OR	OR
“care giver*”:ti,ab	ASD*:ti,ab	depressive:ti,ab
OR	OR	OR
carer*:ti,ab	“pervasive developmental disorder*”:ti,ab	“chronic depression”/de
OR		OR
parent/de	OR	“major depression”/de
OR	“PDD NOS”:ti,ab	OR
parent*:ti,ab	OR	“minor depression”/de
OR	“PDD-NOS”:ti,ab	OR
father/de		“mixed anxiety and depression”/de
OR		
father*:ti,ab		OR
OR		“organic depression”/de
mother/de		OR
OR		dysthymia/de
mother*:ti,ab		OR
OR		dysthym*:ti,ab
“adoptive parent”/de		OR
OR		melancholia/de
“divorced parent”/de		OR
OR		melanchol*:ti,ab
“separated parent”/de		OR
OR		“depression assessment”/exp
“single parent”/de		OR
OR		“mood disorder”/de
“child parent relation”/exp		OR
OR		“mood disorder*”:ti,ab
grandparent/exp		OR
OR		“major affective disorder”/de
grandparent*:ti,ab		OR

OR grandmother*:ti,ab OR grandfather*:ti,ab OR stepparent/exp OR stepparent*:ti,ab OR stepfather*:ti,ab OR stepmother*:ti,ab	“minor affective disorder”/de OR “affective disorder*”:ti,ab OR “mental health”/de OR “mental health”:ti,ab OR “mental illness*”:ti,ab OR “psychological distress”:ti,ab OR psychopatholog*:ti,ab OR “psychological adjustment”/de OR “psychological adjustment”:ti,ab OR “psychological adaptation”:ti,ab

Note: Search conducted on March 29, 2019. Filters applied for English language and publication dates from 1980 – 2019. Non-exploding index terms “parent”, “father” and “mother” were used in order to exclude unwanted narrower terms “adolescent parent”, “expectant parent”, “expectant father” and “expectant mother”. Search yielded 2,250 results.

Table A2.

Logic grid for PsycINFO

Caregivers AND	*Autism* AND	*Depression*
caregivers.sh	exp autism spectrum disorders	major depression.sh
OR		OR
caregiver burden.sh	OR	depression emotion.sh
OR	autis*.ti,ab	OR
caregiver*.ti,ab	OR	depression.ti,ab
OR	asperger*.ti,ab	OR
care giver*.ti,ab	OR	depressed.ti,ab
OR	ASD.ti,ab	OR
carer*.ti,ab	OR	depressive.ti,ab
OR	pervasive developmental disorder*.ti,ab	OR
exp parents		dysthymic disorder.sh
OR	OR	OR
parent*.ti,ab	PDD NOS.ti,ab	dysthym*.ti,ab
OR	OR	OR
parenting.sh	PDD-NOS.ti,ab	melanchol*.ti,ab
OR		OR
father*.ti,ab		mood disorder*.ti,ab
OR		OR
mother*.ti,ab		affective disorders.sh
OR		OR
parent child relations.sh		affective disorder*.ti,ab
OR		OR
grandparents.sh		mental health.sh
OR		OR
grandparent*.ti,ab		mental health.ti,ab
OR		OR
grandfather*.ti,ab		mental illness*.ti,ab
OR		OR
grandmother*.ti,ab		psychological distress.ti,ab
OR		OR
stepparent*.ti,ab		psychopathology.sh
OR		OR
stepfather*.ti,ab		psychopatholog*.ti,ab
OR		OR
stepmother*.ti,ab		psychological adjustment.ti,ab
		OR
		psychological adapatation.ti,ab

Note: Search conducted on March 29, 2019. Filters applied for English language and publication dates from 1980 – 2019. Search yielded 1,446 results.

Table A3.

Logic grid for PubMed

Caregivers AND	*Autism* AND	*Depression*
caregivers[mh] OR caregiver*[tiab] OR care giver*[tiab] OR carer*[tiab] OR parents[mh] OR parent*[tiab] OR parenting[mh] OR father*[tiab] OR mother*[tiab] OR parent-child relations[mh] OR grandparents[mh] OR grandparent*[tiab] OR grandmother*[tiab] OR grandfather*[tiab] OR stepparent*[tiab] OR stepfather*[tiab] OR stepmother*[tiab]	child development disorders, pervasive[mh] OR autis*[tiab] OR asperger*[tiab] OR ASD[tiab] OR pervasive developmental disorder*[tiab] OR PDD NOS[tiab] OR PDD-NOS[tiab]	depression[mh] OR depression[tiab] OR depressed[tiab] OR depressive disorder[mh] OR depressive[tiab] OR dysthym*[tiab] OR melanchol*[tiab] OR mood disorders[mh:noexp] OR mood disorder*[tiab] OR affective disorder*[tiab] OR mental health[mh] OR mental health[tiab] OR mental illness*[tiab] OR psychological distress[tiab] OR psychopathology[mh] OR psychopatholog*[tiab] OR psychological adjustment*[tiab] OR adaptation, psychological[mh:noexp]

Note: Search conducted on April 3, 2019. Filters applied for English language and publication dates from 1980 – 2019. Search yielded 1,425 results.

Appendix B: Systematic Reviews

Cridland, E. K., Jones, S. C., Magee, C. A., & Caputi, P. (2014). Family-focused autism spectrum disorder research: A review of the utility of family systems approaches. *Autism, 18*(3), 213–222.

Factor, R. S., Ollendick, T. H., Cooper, L. D., Dunsmore, J. C., Rea, H. M., & Scarpa, A. (2019). All in the family: A systematic review of the effect of caregiver-administered autism spectrum disorder interventions on family functioning and relationships. *Clinical Child and Family Psychology Review*, 1-25.

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Marshall, B., Kollia, B., Wagner, V., & Yablonsky, D. (2018). Identifying depression in parents of children with autism spectrum disorder: Recommendations for professional practice. *Journal of Psychosocial Nursing and Mental Health Services, 56*(4), 23-27. doi:10.3928/02793695-20171128-02

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Singer, G. H. S. (2006). Meta-analysis of comparative studies of depression in mothers of children with and without developmental disabilities. *American Journal on Mental Retardation, 111*(3), 155-169.

Smith, M. S., & Elder, J. H. (2010). Siblings and family environments of persons with autism spectrum disorder: A review of the literature. *Journal of Child and Adolescent Psychiatric Nursing, 23*(3), 189-195.

Tint, A., & Weiss, J. A. (2016). Family wellbeing of individuals with autism spectrum disorder: A scoping review. *Autism, 20*(3), 262-275.

Appendix C: Depression Measures

Table C1.

Included depression measures, severity classifications and clinical cut-off scores.

Measure	Abbreviation	Range	Classification	Clinical cut-off
Beck Depression Inventory	BDI	0–63	0–9: Minimal 10–19: Mild 20–30: Moderate-severe ≥ 31: Severe	10
Beck Depression Inventory – Second Edition	BDI-II	0–63	0–13: Minimal 14–19: Mild 20–28: Moderate-severe 29–63: Severe	16
Center for Epidemiologic Studies Depression Scale	CES-D	0–60	-	16
Center for Epidemiologic Studies Depression Scale – 7 item short form	0–60	0–21	-	8
Center for Epidemiologic Studies Depression Scale – Boston (short form)	CES-D-10	0–30	-	10
Depression Anxiety Stress Scales (short form) – Depression subscale	DASS-21	0–21	0–4: Normal 5–6: Mild 7–10: Moderate 11–13: Severe ≥ 14: Extremely severe	-
Hospital Anxiety and Depression Scale – Depression subscale	HADS-D	0–21	0–7: Normal 8–10: Borderline 11–21: Abnormal	11
Hospital Anxiety and Depression Scale – Depression subscale (Spanish language version)	HADS-D (Sp.)	0–21	0–7: Normal 8–10: Borderline 11–21: Abnormal	12
Inventory of Depressive Symptoms	IDS	0–84	0–11: None 12–23: Mild 24–36: Moderate 37–48: Severe ≥ 47: Very severe	-

Patient Health Questionnaire modified for adolescents	PHQ-A	0–27	0–4: None - minimal 5–9: Mild 10–14: Moderate 15–19: Moderately severe 20–27: Severe	-
9-item Patient Health Questionnaire	PHQ-9	0–27	0–4: None - minimal 5–9: Mild 10–14: Moderate 15–19: Moderately severe 20–27: Severe	10
PROMIS Adult Depression measure	PROMIS	41-79 (T-score)	40: 1 SD below the mean 50: mean 60: 1 SD above the mean	-
State Depression subscale of the State-Trait Depression Scales	STDS	0–80	-	39–40

Appendix D: PRISMA Checklist

Table D1.

Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) Checklist (Moher et al., 2009).

Section/topic	#	Checklist item	Reported on page
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	Title pg
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	iv
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	12
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	12-13
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	-
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	14-16
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	14
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	75-78
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	14-16
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	17-18
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	17-18
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	18
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	15
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	17-18

Section/topic	#	Checklist item	Reported on page
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	18
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	20-21
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	22-23
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	22, 24, 88-92
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	85-86
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	26, 28-37
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	26, 28-37
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	27
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	36, 38
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	39-43
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	47-48
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	44-47, 49
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	N/A

Appendix E: Data Extraction Sheet

Title:
Lead author:
Year:

Study characteristics
Country: ________________

Study design:
Cross-sectional/Longitudinal

Depression measure:
____

Family functioning measure:
____

Social support measure:
____

Effect size data
Outcome: _______________
r: ________
M: ________ *SD:* ________
F: ________

Caregiver demographics
Sample size: ________

Gender (% or *n*)
Male: ________
Female: ________

Age
M: ________ *SD:* ________

Ethnicity (% or *n*)
White/caucasian: ________
Other: ________

Marital status (% or *n*)
Married/partnered: ________
Single: ________

Employment status (% or *n*)
Employed: ________
Unemployed: ________

Education (% or *n*)
At/below high school: _____
Above high school: ________

Child demographics
Sample size: ________

Gender (% or *n*)
Male: ________
Female: ________

Age
M: ________ *SD:* ________

Diagnosis (% or *n*)
ASD: ________
Autistic disorder: ________
Asperger's syndrome: ______
PDD-NOS: ________

Caregiver depression characteristics
M: ________ *SD:* ________

Cut-off score: ________

Prevalence (% or *n*)
Depressed: ________
Not depressed: ________

Appendix F: QualSyst Reporting Quality Criteria

Criterion	**Yes (score 2)**	**Partial (score 1)**	**No (score 0)**
1. Question or objective sufficiently described	Study aims and/or research questions are easily identified in the Introduction (or first paragraph of Methods).	Vaguely/incompletely reported (e.g. "describe the effect of" or "examine the role of")	Study aims and/or research questions not reported.
2. Design evident and appropriate to answer study question	Explicit mention of study design (e.g. cross-sectional, longitudinal)	Design not clearly identified, but appears appropriate.	Design is not appropriate to answer study question.
3. Method of subject selection Is described and appropriate.	Sampling time frame and source explicitly stated (e.g., 'participants recruited over a XX period from (date) to (date)', or 'data obtained from Wave 1 of XXX longitudinal study')	Selection methods not completely described, but no obvious inappropriateness (e.g., recruitment source identified but not sampling time frame).	No information provided about the selection procedures.
4. Sample characteristics sufficiently described	Relevant demographic information of participants is provided (i.e. caregiver age & gender)	Poorly defined criteria (e.g. "healthy volunteers") or incomplete relevant demographic information (e.g. gender but not age)	No demographic information provided.
5. Outcome well defined and robust.	Detail relating to standardised questionnaire/ interview provided.	Definition of measures not reported in detail or purposely developed measure of social support/family functioning used.	No description of questionnaire/ interview content or response options.
6. Sample size appropriate	Some estimation of power provided and/or sample size sufficient to achieve a medium correlation: $N > 26$ (with power at 0.80, $\alpha = 0.05$; Cohen, 1992).	$N = 26$	$N < 26$.
7. Analysis described and appropriate	Statistical tests are named (e.g. "chi square"/ "t-tests"/ pearson *r* etc) and appropriate.	Statistical tests are not identified and have to be guessed, but are probably appropriate.	Statistical analyses are not described and cannot be determined or analyses are not appropriate (e.g., chi-square tests for continuous data etc.).
8. Some estimate of variance is reported for main outcomes	Appropriate variances estimate(s) is/are provided (e.g., range, distribution, confidence intervals, etc.).	Variance estimates provided for some, but not all main results/outcomes.	No information regarding uncertainty of the estimates.
9. Results reported in sufficient detail	Both primary and secondary outcomes reported (i.e. depression/social support/ family functioning).	Quantitative results reported only for some outcomes.	Quantitative results reported for a subsample, or results for some major or outcomes only qualitatively reported.
10. Results support the conclusions	Conclusions are supported by the data. Authors acknowledge limitations of study (e.g. generalisability of results to the target population).	Some of the conclusions are supported by the data, some are not (i.e. speculative interpretations or low response rate, limiting generalisability of findings).	No conclusions or negative findings (due to low power) are reported as definitive evidence.

Appendix G: Individual Risk of Bias Assessment

Table G1.

Reporting quality of included studies based on QualSyst ($N_{studies} = 34$)

Lead author (date)	**1: Question/objective**	**2: Study design**	**3: Sample selection**	**4: Sample characteristics**	**5: Outcome measurement**	**6: Sample size** [a]	**7: Analytic methods**	**8: Estimate of variance**	**9: Reporting of results**	**10: Conclusions supported**	**Sum Score**	**Total Sum ÷ Total Possible Sum**
Beer (2013)	2	1	2	2	2	2	2	2	2	2	19	.95
Benson (2012)	2	2	2	2	1	2	2	2	2	2	19	.95
Chan (2018)	2	2	1	2	2	2	2	2	2	2	19	.95
Clifford (2013)	2	1	1	2	1	2	2	2	2	2	17	.85
Da Paz (2018)	2	2	1	2	2	2	2	0	2	2	17	.85
Davis (2008)	2	2	1	2	2	2	2	2	2	2	19	.95
Dyches (2016)	2	1	1	2	2	2	2	2	2	2	18	.90
Ekas (2010)	2	1	1	2	2	2	2	2	2	2	18	.90
Falk (2014)	2	1	1	2	2	2	2	2	2	2	18	.90
García-López (2016)	2	1	1	2	2	2	2	2	2	2	18	.90
Gill (1991)	2	1	1	2	2	2	2	2	2	1	17	.85
Hastings (2003)	2	1	1	2	2	2	2	2	2	2	18	.90
Hastings (2005)	2	1	1	2	2	2	2	2	2	2	18	.90
Hickey (2019)	2	2	2	2	2	2	2	1	2	2	19	.95
Ingersoll (2011)	2	1	1	2	2	2	2	2	2	2	18	.90
Jellett (2015)	2	1	1	2	2	2	2	2	2	2	18	.90
Kim (2009)	2	1	1	1	2	2	2	2	2	2	15	.75
Kim (2016)	2	2	1	2	2	2	2	2	2	2	19	.95
Kuhn (2018)	2	1	1	1	2	0	2	2	2	2	16	.80
Lin (2011)	2	1	1	2	2	2	2	2	2	2	18	.90
Neff (2015)	2	1	1	2	2	2	2	2	2	2	18	.90
Pakenham (2005)	2	1	1	1	2	2	2	0	2	2	15	.75
Pruitt (2018)	2	1	1	2	2	2	2	2	2	2	18	.90

Lead author (date)	**1: Question/objective**	**2: Study design**	**3: Sample selection**	**4: Sample characteristics**	**5: Outcome measurement**	**6: Sample size [a]**	**7: Analytic methods**	**8: Estimate of variance**	**9: Reporting of results**	**10: Conclusions supported**	**Sum Score**	**Total Sum ÷ Total Possible Sum**
Ruiz-Robledillo (2014)	2	1	1	2	1	0	2	2	2	2	15	.75
Sawyer (2010)	2	1	1	1	2	2	2	2	2	2	17	.85
Schwartz (2018)	2	1	1	1	1	2	2	1	2	2	15	.75
Shtayermman (2013)	2	2	1	2	2	2	2	2	2	2	19	.95
Singh (2017)	2	1	1	2	2	2	2	0	2	2	16	.80
Smith (2012)	2	2	2	2	1	2	2	2	2	2	19	.95
Teague (2018)	2	1	1	2	2	2	2	2	2	2	18	.90
Tudor (2018)	2	1	1	2	2	2	2	2	2	2	18	.90
Wachtel (2008)	2	2	1	2	2	2	1	2	2	2	18	.90
Weitlauf (2014)	2	2	1	2	2	2	2	2	2	2	19	.95
Zhou (2018)	2	1	1	2	2	2	2	2	2	2	18	.90

Scoring note: 2 = criterion met; 1 = criterion partially met; 0 = criterion not met or unclear.

Appendix H: Overlapping Samples

Table H1.

Included studies and studies using overlapping samples.

Included studies	Studies using overlapping samples
Benson, 2012	Benson & Karlof, 2009 Benson & Kersh, 2011
Ingersoll & Hambrick, 2011	Meyer, Ingersoll, & Hambrick, 2011
Pruitt, Rhoden, & Ekas, 2018	Ekas, Pruitt, & McKay, 2016 Pruitt, Willis, Timmons, & Ekas, 2016 Timmons, Willis, Pruitt, & Ekas, 2016
Smith, Greenberg, & Seltzer, 2012	Baker, Seltzer, & Greenberg, 2011
Weitlauf, Vehorn, Taylor, & Warren, 2014	Taylor & Warren, 2012

Appendix I: Included Study Details

Table I1.

Study characteristics and caregiver demographics per study.

Author	*N*	Country	Study design	Age (*years*) *(mean ± SD)*	Gender *(% F)*	Marital status *(% married/ partnered)*	Ethnicity *(% white/ caucasian)*	Employment *(% employed)*[a]	Education *(high school)*	
									At/below	Above
Beer (2013)	28	Australia	Cross-sectional	43.2 ± 8.4	85.7%	60.7%	85.7%	-	32.2%	67.8%
Benson (2012)	106	USA	Longitudinal	42.1 ± 5.2	100.0%	80.0%	85.0%	40.0%	34.0%	66.0%
Chan (2018)	375	China	Cross-sectional	43.3 ± 8.3	86.1%	96.3%	-	37.9%	-	-
Clifford (2013)	149	Canada/USA	Cross-sectional	41.0 ± 7.1	96.0%	84.6%	-	-	5.0%	95.0%
Da Paz (2018)	90	USA	Cross-sectional	42.3 ± 5.7	100.0%	-	93.3%	-	18.9%	81.1%
Davis (2008)	108	USA	Cross-sectional	37.2 ± 5.6	50.0%	100.0%	88.0%	-	33.5%	66.5%
Dyches (2016)	122	USA	Cross-sectional	36.7 ± 7.0	100.0%	0.0%	71.3%	-	56.6%	43.4%
Ekas (2010)	119	USA	Cross-sectional	40.1 ± 7.2	100.0%	82.9%	95.0%	-	10.1%	89.9%
Falk (2014)	479	Australia	Cross-sectional	40.7 ± 6.7	52.2%	-	-	-	-	-
García-López (2016)	152	Spain	Cross-sectional	42.3 ± 5.3	50.0%	100.0%	-	66.0%	-	-
Gill (1991)	60	USA	Cross-sectional	38.8 ± -	100.0%	86.7%	-	58.3%	-	-
Hastings (2003)	36	UK	Cross-sectional	42.3 ± 4.9	50.0%	100.0%	-	-	75.0%	25.0%
Hastings (2005)	89	UK	Cross-sectional	36.1 ± 4.9	53.9%	96.6%	-	-	61.8%	38.2%
Hickey (2019)	300	USA	Longitudinal	39.7 ± 6.0	50.0%	100.0%	85.0%	73.3%	28.2%	71.8%
Ingersoll (2011)	149	USA	Cross-sectional	39.9 ± 6.7	91.3%	84.6%	84.6%	-	6.0%	94.0%
Jellett (2015)	97	Australia	Cross-sectional	36.1 ± 5.5	90.7%	89.7%	-	56.7%	21.6%	78.4%
Kim (2009)	48	Korea	Cross-sectional	-	100.0%	100.0%	-	0.0 %	-	-
Kim (2016)	234	USA	Cross-sectional	37.5 ± 7.1	100.0%	86.3%	69.2%	57.7%	16.2%	83.8%
Kuhn (2018)	20	USA	Cross-sectional	-	100.0%	70.0%	90.0%	-	25.0%	75.0%

Author	*N*	Country	Study design	Age (*years*) *(mean ± SD)*	Gender *(% F)*	Marital status *(% married/ partnered)*	Ethnicity *(% white/ caucasian)*	Employment *(% employed)*[a]	Education *(high school)*	
									At/below	Above
Lin (2011)	401	Taiwan/USA	Cross-sectional	47.3 ± 7.0	100.0%	83.0%	-	83.0%	25.9%	74.1%
Neff (2015)	51	USA	Cross-sectional	40.4 ± 6.4	78.4%	-	80.0%	-	6.0%	94.0%
Pakenham (2005)	47	Australia	Cross-sectional	-	100.0%	83.0%	-	-	46.8%	53.2%
Pruitt (2018)	98	USA	Cross-sectional	37.7 ± 5.5	100.0%	100.0%	82.7%	-	26.5%	73.5%
Ruiz-Robledillo (2014)	24	Spain	Cross-sectional	45.6 ± 3.3	66.7%	83.3%	-	-	37.5%	62.5%
Sawyer (2010)	216	Australia	Cross-sectional	-	100.0%	79.0%	-	63.0%	-	-
Schwartz (2018)	114	USA	Cross-sectional	-	93.9%	-	69.3%	-	10.5%	89.5%
Shtayermman (2013)	253	USA	Cross-sectional	42.2 ± 7.5	95.0%	100.0%	91.7%	-	6.1%	93.9%
Singh (2017)	70	India	Cross-sectional	35.3 ± 5.2	100.0%	95.7%	-	18.6%	-	-
Smith (2012)	269	USA	Longitudinal	52.4 ± 10.6	100.0%	78.1%	95.0%	66.0%	23.0%	77.0%
Teague (2018)	29	Australia	Cross-sectional	37.5 ± 6.4	96.6%	-	-	-	-	-
Tudor (2018)	239	USA	Cross-sectional	42.9 ± 5.6	100.0%	88.2%	86.6%	-	4.6%	95.4%
Wachtel (2008)	63	USA	Longitudinal	36.5 ± 3.7	100.0%	95.2%	87.3%	-	7.9%	92.1%
Weitlauf (2014)	70	USA	Cross-sectional	34.9 ± 6.1	100.0%	100.0%	-	50.0%	-	-
Zhou (2018)	263	China	Cross-sectional	34.6 ± 5.4	71.5%[b]	-	0.0%	-	32.7%	67.3%

Note. (-) data that were not reported and/or could not be obtained.

[a] Employment refers to paid employment (i.e., full-time, part-time or casual work) rather than unpaid work (i.e., volunteering), as per the definition provided by the International Labour Organization. See: International Labour Organization. *Guidelines concerning a statistical definition of employment in the environmental sector adopted by The Nineteenth International Conference of Labour Statisticians*, Geneva, 2013. Available at: http://www.ilo.org/global/statistics-and-databases/. [b] Responses were missing for 14 participants.

Table I2

Child characteristics per study.

				Primary diagnosis			
Author	*N*	Age (*years*) (*mean ± SD*)	Gender (*% M*)	ASD	Autistic disorder	Asperger's syndrome	PDD-NOS
Beer (2013)	28	9.0 ± 4.3	85.7%	100.0%			
Benson (2012)	106	8.6 ± 1.5	86.0%	24.0%	33.0%	14.0%	29.0%
Chan (2018)	375	10.2 ± 6.5	82.4%		94.4%	3.2%	2.4%
Clifford (2013)	149	9.0 ± 4.6	81.9%	29.0%[a]	52.0%[a]	23.0%[a]	15.0%[a]
Da Paz (2018)	90	-	-	100.0%			
Davis (2008)	54	26.9 ± 4.2	74.0%	100.0%			
Dyches (2016)	122	-	-	-	-	-	-
Ekas (2010)	119	9.5 ± 4.1	82.9%	100.0%			
Falk (2014)	479	8.4 ± 3.9	-	100.0%			
García-López (2016)	76	7.7 ± 3.4	-	100.0%			
Gill (1991)	60	9.9 ± -	78.3%	100.0%			
Hastings (2003)	18	11.8 ± 2.6	85.7%		100.0%		
Hastings (2005)	48	3.1 ± 0.4	85.4%		100.0%		
Hickey (2019)	150	8.0 ± 2.3	85.7%	100.0%			
Ingersoll (2011)	149	8.4 ± 4.1	77.9%	1.2%	53.3%	18.8%	26.7%
Jellett (2015)	97	4.3 ± 1.1	84.5%	18.5%	52.6%	12.4%	16.5%
Kim (2009)	48	-	-	-	-	-	-
Kim (2016)	234	7.1 ± 3.4	81.6%	100.0%			
Kuhn (2018)	20	15.7 ± 0.9	-	100.0%			
Lin (2011)	401	17.9 ± 5.2	75.6%	100.0%			
Neff (2015)	51	-	-	-	-	-	-
Pakenham (2005)	47	-	85.1%			100.0%	
Pruitt (2018)	98	8.3 ± 3.1	83.7%	100.0%			
Ruiz-Robledillo (2014)	24	15.3 ± 3.6	95.8%		100.0%		
Sawyer (2010)	216	11.0 ± 2.9	88.0%		100.0%		
Schwartz (2018)	114	7.9 ± 2.1	86.8%	100.0%			
Shtayermman (2013)	253	15.9 ± -	-	100.0%			
Singh (2017)	70	8.0 ± 2.8	68.6%	100.0%			
Smith (2012)	269	23.2 ± 9.8	74.7%	100.0%			
Teague (2018)	29	5.4 ± 2.3	79.3%	-	-	-	-
Tudor (2018)	239	11.7 ± 2.8	84.0%	100.0%			
Wachtel (2008)	63	2.7 ± 0.6	76.2%	100.0%			
Weitlauf (2014)	70	5.0 ± 1.8	88.6%	100.0%			
Zhou (2018)	263	5.4 ± 2.4	74.9%[b]	100.0%			

Note. (-) data that were not reported and/or could not be obtained. ASD = autism spectrum disorder; PDD-NOS = pervasive developmental disorder not otherwise specified. [a] Responses not mutually exclusive as some parents indicated that their children had received multiple diagnoses. [b] Responses missing for 5 participants.

Table I3

Caregiver depression characteristics per study.

		Mean score		Clinical cut-off	
Author	Depression measure	Mean ± SD	Severity classification	*N* depressed	% depressed
Gill (1991)	BDI	-	-	-	-
Kim (2009)	BDI	-	-	-	-
Ruiz-Robledillo (2014)	BDI	10.9 ± 7.4	mild	-	-
Tudor (2018)	BDI-II	12.0 ± 9.8	minimal	81	34.0%
Davis (2008)	CES-D	11.7 ± 9.8	normal	27	25.0%
Dyches (2016)	CES-D	46.3 ± 9.4	clinical	94	77.0%
Ekas (2010)	CES-D	33.6 ± 9.9	clinical	-	-
Hickey (2019)	CES-D	-	-	98	32.8%
Ingersoll (2011)	CES-D	21.4 ± 12.9	clinical	83	55.7%
Kuhn (2018)	CES-D	15.5 ± 11.3	normal	6	30.0%
Lin (2011)	CES-D	14.0 ± 10.6	normal	-	-
Neff (2015)	CES-D	1.73 ± 0.5	normal	-	-
Pruitt (2018)	CES-D	16.4 ± 11.1	clinical	47	48.0%
Sawyer (2010)	CES-D	16.5 ± 11.8	clinical	104	48.0%
Singh (2017)	CES-D	16.2 ± 12.5	clinical	33	47.1%
Smith (2012)	CES-D	12.2 ± 9.8	normal	67	24.9%
Wachtel (2008)	CES-D	-	-	-	-
Weitlauf (2014)	CES-D	29.7 ± 9.6	clinical	20	29.0%
Zhou (2018)	CES-D	20.6 ± 11.2	clinical	-	-
Benson (2012)	CES-D-7	-	-	-	-
Kim (2016)	CES-D-10	3.4 ± 2.9	normal	-	-
Falk (2014)	DASS-21	17.6 ± 12.0	extremely severe	-	-
Jellett (2015)	DASS-21	11.8 ± 8.7	severe	-	-
Pakenham (2005)	DASS-21	9.4 ± 9.1	moderate	9	20.0%
Teague (2018)	DASS-21	5.6 ± 4.9	mild	-	-
Beer (2013)	HADS-D	5.89 ± 4.3	normal	4	14.8%
Hastings (2003)	HADS-D	5.3 ± 3.6	normal	-	-
Hastings (2005)	HADS-D	7.2 ± 4.1	normal	-	-
García-López (2016)	HADS-D (Sp.)	5.3 ± 3.8	normal	-	-
Da Paz (2018)	IDS	-	-	-	-
Shtayermman (2013)	PHQ-A	-	-	31	13.7%
Chan (2018)	PHQ-9	7.2 ± 5.6	normal	111	29.6%
Schwartz (2018) [a]	PROMIS®	53.4 ± 8.6	-	-	-
Clifford (2013)	STDS	20.6 ± 6.7	normal	1	0.7%

Note. (-) data that were not reported. BDI = Beck Depression Inventory; BDI-II = Beck Depression Inventory – Second Edition; CES-D = Center for Epidemiologic Studies Depression Scale; CES-D-7 = Center for Epidemiologic Studies

Depression Scale – 7 item short form; CES-D-10 = Center for Epidemiologic Studies Depression Scale – Boston (short form); DASS-21 = Depression Anxiety Stress Scales (short form) – Depression subscale; HADS-D = Hospital Anxiety and Depression Scale – Depression subscale; HADS-D (Sp.) = Hospital Anxiety and Depression Scale – Depression subscale (Spanish language version); IDS = Inventory of Depressive Symptoms; PHQ-A = Patient Health Questionnaire modified for adolescents; PHQ-9 = 9-item Patient Health Questionnaire; PROMIS® = PROMIS Adult Depression measure; STDS = State Depression subscale of the State-Trait Depression Scales.

[a] Approximately 20% of participants reported depression scores more than one standard deviation above the mean for the US standardisation sample mean of 50 (standard deviation of 10).

Appendix J: Standardised Measurement Scales

Table J1.

Standardised instruments used to measure depression symptoms, family functioning, and social support variables in included studies.

Abbreviation	Reference
Depression symptoms	
BDI	Beck, A. T. (1967). *Depression: Clinical, experimental and theoretical aspects*. New York: Harper and Row.
BDI-II	Beck, A. T., Steer, R. A., & Brown, G. K. (1996). *Manual for the beck depression inventory-II*. San Antonio, TX: Psychological Corporation.
CES-D	Radloff, L. S. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement, 1,* 385–401.
CES-D-7	Levine, S. Z. (2013). Evaluating the seven-item Center for Epidemiologic Studies Depression Scale short-form: A longitudinal US community study. *Social psychiatry and psychiatric epidemiology*, *48*(9), 1519-1526.
CES-D-10	Kohout, F. J., Berkman, L. F., Evans, D. A., & Cornoni-Huntley, J. (1993). Two shorter forms of the CES-D depression symptoms index. *Journal of Aging & Health, 5* (2), 179-193.
DASS-21	Lovibond, S., & Lovibond, P. (1995). *Manual for the Depression Anxiety Stress Scales* (2nd ed.). Sydney: Psychology Foundation.
HADS-D	Zigmond, A. S., & Snaith, R. P. (1983). The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica, 67,* 361–70. doi:10.1111/j.1600-0447.1983.tb09716.x.
HADS-D (Sp.)	Tejero, A., Guimera´, E. M., & Farre´, J. (1986). Uso clı´nico del HADS (Hospital Anxiety and Depression Scale) en poblacio´n psiquiátrica: Un estudio de su sensibilidad, fiabilidad y validez. *Revista del Departamento de Psiquiatrı´a de la Facultad de Medicina de Barcelona*, *13*, 233–238.
IDS	Rush, A. J., Giles, D. E., Schlesser, M. A., Fulton, C. L., Weissenburger, J., & Burns, C. (1986). The inventory for depressive symptomatology (IDS): Preliminary findings. *Psychiatry Research, 18,* 65–87.
PHQ-A	Johnson, J. G., Haris, E. S., Spitzer, R. L., & Williams, J. B. (2000). The patient health questionnaire for adolescents. *Journal of Adolescent Health, 30,* 196-204.
PHQ-9	Kroenke, K., Spitzer, R. L., & Williams, J. B. (2001). The PHQ-9: Validity of a brief depression severity measure. *Journal of General Internal Medicine, 16,* 606–613.
PROMIS	Pilkonis, P.A., Choi, S.W., Reise, S.P., Stover, A.M., Riley, W.T., & 6 Anger Cella, D. (2011). Item Banks for Measuring Emotional Distress from the Patient-Reported Outcomes Measurement Information System (PROMIS): Depression, Anxiety, and Anger. *Assessment, 18*(3), 263-283.
STDS	Spielberger, C. D., Ritterband, L. M., Reheiser, E. C., & Brunner, T. M. (2003). The nature and measurement of depression. *International Journal of Clinical and Health Psychology, 3,* 209–234.

Abbreviation	Reference
Marital relationship quality	
CSI	Funk, J. L., & Rogge, R. D. (2007). Testing the ruler with item response theory: Increasing precision of measurement for relationship satisfaction with the Couples Satisfaction Index. *Journal of Family Psychology, 21*, 572–583
DAS	Spanier, G. B. (1989) *Manual for the Dyadic Adjustment Scale*. North Tonawanda, NY: Multi-Health Systems.
DAS-7	Hunsley, J., Pinsent, C., Lefebvre, M., James-Tanner, S., & Vito, D. (1995). Construct validity of the short forms of the Dyadic Adjustment Scale. *Family Relations, 44*, 231–237.
ENRICH	Fowers, B. J., & Olson, D. H. (1993). ENRICH Marital Satisfaction Scale: A brief research and clinical tool. *Journal of Family Psychology 7*(2), 176-185
MSS	Yoo, E. H., & Park, S. Y. (1991). The developmental patterns of attachment and autonomy as related to young adults' marital satisfaction. *Journal of the Korean Home Economics Association, 29*(1), 139–158
RSQ	Burns, D., & Sayers, S. (1992). *Development and validation of a brief relationship satisfaction scale*. Philadelphia, PA: Unpublished manuscript, Department of Psychiatry, Presbyterian Medical Center of Philadelphia
Parent-child relationship	
CPRS	Driscoll, K., & Pianta, R. (2011). Mothers' and fathers' perceptions of conflict and closeness in parent-child relationships during early childhood. *Journal of Early Childhood & Infant Psychology*, 7, 1–24.
DAI	Zeanah, C. H., Smyke, A. T., Koga, S. F., & Carlson, E. (2005). Attachment in institutionalized and community children in Romania. *Child Development, 76*(5), 1015–1028.
FMSS	Magaña, A. B., Goldstein, M. J., Karno, M., Miklowitz, D. J., Jenkins, J., & Falloon, I. R. (1986). A brief method for assessing expressed emotion in relatives of psychiatric patients. *Psychiatry Research, 17*, 203–212. https://doi.org/10.1016/0165-1781(86)90049-1
KPP	Behr, S. K., Murphy, D. L., & Summers, J. A. (1992). *User's manual: Kansas Inventory of Parental Perceptions (KIPP).* Lawrence, KS: Beach Center on Families and Disability
PAI	Bengtson, V. L., Schrader, S. S., Mangen, D., & Peterson, W. (1982). Handbook of research instruments in social gerontology
PCIRS	Sosinsky, L. S., Marakovitz, S. & Carter, A. S. (2004) *Parent–Child Interaction Rating Scales (PCIRS).* Unpublished manual. University of Massachusetts Boston
PSI-SF	Abidin, R. R. (1990). *The parenting stress index—Short form—Test manual.* Charlottesville: Pediatric Psychology Press
Informal support	
FSS	Dunst, C., Jenkins, V., & Trivette, C. (1984). Family support scale: Reliability and validity. *Journal of Individual, Family, and Community Wellness, 1*(4), 45–52.
ISEL	Cohen, S., Mermelstein, R., Kamarck, T., & Hoberman, H. (1985). Measuring the functional components of social support. In I. G. Sarason & B. R. Sarason (Eds.), *Social support: Theory, research and application*. The Hague, Holland: Martinus Nijhoff

Abbreviation	Reference
MOSS-SSS	Sherbourne, C. D., & Stewart, A. L. (1991). The medical outcomes study social support survey. *Social Science and Medicine*, *32*, 705–714.
MSPSS	Zimet GD, Dahlem NW, Zimet SG, et al. (1988) The multidimensional scale of perceived social support. *Journal of Personality Assessment* 52(1): 30–41.
PSS	Procidano, M. E., & Heller, K. (1983). Measures of perceived social support from friends and from family: three validation studies. *American Journal of Community Psychology*, *11(1)*, 1–24. http://dx.doi.org/10.1007/BF00898416
SSI	Park, J. W. (1985). *A study to development a Scale of Social Support.* Unpublished doctoral dissertation, Yonsei University, Korea.
SSSS	Schuster, T. L., Kessler, R. C., & Aseltine, R. H. (1990). Supportive interactions, negative interactions, and depressed mood. *American journal of community psychology*, *18*(3), 423-438.
SSQ6	Siegert, R. J., Patten, m. D., & Walkey, F. H. (1987). Development of a brief social support questionnaire, *New Zealand Journal of Psychology*, *16*, 79–83
Formal support	
RCQ	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, 2604–2616. doi:10.1007/s10803-013-1812-0.
Family unit functioning	
FACES-II	Olson, D. H., Bell, R. Q., & Portner, J. (1982). *FACES II: Family adaptability and cohesion evaluation scales*. St. Paul, MN Family Social Science
FACES-IV	Olson, D. (2011). FACES IV and the circumplex model: Validation study. *Journal of Marital and Family Therapy, 37*, 64–80.
FACES-CV	Fei, L., Shen, Q., Zheng, Y., Zhao, J., Jiang, S., Wang, L., et al., 1991. Preliminary evaluation of FACES and FES: A case-control study between normal families and families with psychiatric patients. *Chinese Mental Health Journal, 5,* 198–202.
FAD	Epstein, N. B., Baldwin, L. M., & Bishop, D. S. (1983). The McMaster family assessment device. *Journal of Marital and Family Therapy, 9*(2), 171–180. doi:10.1111/j.1752-0606.1983.tb01497
FaMM	Knafl, K., Deatrick, J. A., Gallo, A., Dixon, J., Grey, M., Knafl, G., et al. (2011). Assessment of the psychometric properties of the family management measure. Journal of Pediatric Psychology, 36(5), 494–505
PROMIS	Reeve, B. B., Hays, R. D., Bjorner, J. B., Cook, K. F., Crane, P. K., Teresi, J. A., ... Cella, D. (2007). Psychometric evaluation and calibration of health-related quality of life item banks: Plans for the Patient-Reported Outcomes Measurement Information System (PROMIS). *Medical Care*, *45*(5 Suppl. 1), S22–S31.
QRS-F	Friedrich, W. N., Greenberg, M. T., & Crnic, K. (1983). A short-form of the questionnaire on resources and stress. *American Journal of Mental Deficiency, 88,* 41–48.

Abbreviation	Reference
Sibling functioning	
FIQ	Donenberg, G., & Baker, B. L. (1993). The impact of young children with externalizing behaviors of their families. *Journal of Abnormal Child Psychology, 21*, 179–198
SDQ	Goodman, R. (1997). The strengths and difficulties questionnaire: A research note. *Journal of Child Psychology and Psychiatry*, *38*, 581–586
SIB	McHale, S. M., & Gamble, W. C. (1988). Sibling relationships and adjustment of children with disabled brothers and sisters. *Journal of Children in Contemporary Society*, *19*(3–4), 131–158.
WDW	Cowan, C. P., & Cowan, P. A. (1990). Who does what. In J. Touliatos, B. F. Perlmutter & M. A. Straus (Eds.) *Handbook of Family Measurement Techniques* (pp. 447–448). Beverly Hills: Sage