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► **To cite this version:**

Gwendoline Desquenne Godfrey, Naomi Downes, Emilie Cappe. A Systematic Review of Family Functioning in Families of Children on the Autism Spectrum. *Journal of Autism and Developmental Disorders*, 2023, 10.1007/s10803-022-05830-6 . hal-04421780

HAL Id: hal-04421780

<https://hal.science/hal-04421780v1>

Submitted on 28 Jan 2024

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A systematic review of family functioning in families of children on the autism spectrum

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Abstract

This article aims to review the literature on family functioning in the field of autism. The search was conducted in August 2021 in PubMed, PsycINFO, and PubPsy and sixty-two articles were included. Studies were published in English between 1980 and 2021 and provided quantitative data from validated measures of family functioning in families with an official diagnosis of autism. Results showed that family functioning appeared more problematic for families of autistic children than non-autistic ones. Difficulties were correlated with more caregiver demand and less resources. Interventional results varied. The findings highlight the importance of considering family functioning when providing care for autistic children and their families. Limitations and implications for future research are discussed.

Prospero registration number: CRD42022297696

Key words: Family functioning; Autism spectrum; Children; Systematic review

The autism spectrum¹ is characterised by a persistent deficit of communication and social interactions as well as repetitive behaviours and restricted interests (APA, 2013). Its impact on the family is well recognised internationally. For instance, studies in South Africa and Spain showed that the severity of autism was negatively associated with satisfaction regarding family quality of life (Pozo et al., 2014; Schlebusch et al., 2017). Similarly, studies in the USA and China indicated that higher levels of stress were linked to having a child on the autism spectrum and had a negative impact on family quality of life (Hsiao et al., 2017; Wang et al., 2020).

The *APA Dictionary of Psychology* (n.d.) defines family as “a kinship unit consisting of a group of individuals united by blood or by marital, adoptive, or other intimate ties”. Family systems theory posits that a family is a group of people with a set organisation (a system) recognised via interactions between family members. This approach allows a comprehension of how the family operates i.e., “family functioning” and can be used for family assessments and interventions (Crosbie-Burnett & Klein, 2009). In the field of autism, reviewing current knowledge on family functioning meets several clinical and research needs.

First, evolutions in considerations around autistic children and their families impact clinical and research settings. Indeed, the care has been shifting from professional-based to partnership-based interventions with parents, thus involving the family more (Borelle, 2019). In addition, the recurring changes in nosological classifications such as the DSM show a change of perception of autism (e.g., APA, 1980, 2013), and allow more distinctions within the spectrum. Therefore, it appears relevant to review descriptive characteristics of the literature on family functioning and autism, to contextualise the knowledge and encourage broader future research.

Secondly, family functioning has been conceptualised through a broad range of theories

¹ According to the recommendations of *Autisme France* and *Autisme Europe*, and in conformity with the recommendations of the United Nations Convention on the Rights of Persons with Disabilities, the term “autistic person” or “person on the autism spectrum” is used in order to avoid the negative connotation of the term disorder

resulting in a variety of definitions and assessment tools. For instance, the Circumplex Model (Olson, 2011), the McMaster Model (Epstein et al., 1983), or the Beavers Systems Model (Beavers & Hampson, 1990) all conceptualise family functioning but include different dimensions and refer to different assessment instruments (Favez, 2010). This diversity allows a complementarity of approaches, but also leads to challenges when collecting information on family functioning and communicating clearly on the topic. To improve current knowledge around family functioning in the field of autism and what it implies in clinical settings, it would be relevant to identify theories and tools being used in research in this specific domain.

Finally, considering the increasing interest for family involvement and well-being, several literature reviews have focused on families of autistic children but not on family functioning. In 2012, Karst and Van Hecke published a non-systematic review about the impact of having a child with autism on family relationships and well-being but not family functioning. In 2014, Cridland et al. also published a non-systematic review in which they referred to the concepts of boundaries, ambiguous loss, resilience, and traumatic growth, but again, not family functioning per se. The following reviews were both systematic. In 2016, Tint and Weiss aimed to review family well-being and included the term “family functioning” in the search. However, family functioning was not reviewed as a separate entity from family well-being. Finally, Greenlee et al.’s review published in 2018 focused on the association between family processes and the behavioural, social, and emotional development of autistic individuals. It addressed family functioning in the field of autism, but only targeted individual outcomes relating to the autistic child. The limits of the existing reviews highlight the need for a more general systematic review on family functioning which would allow for a better understanding by considering a broad range of variables associated with family functioning and its potential evolution.

Therefore, the aim of this article is to collate scientific knowledge on family functioning in families of autistic children. Specifically, the following objectives are addressed:

- Objective 1: report descriptive characteristics of the existing literature
- Objective 2: identify tools and models used to assess family functioning
- Objective 3: identify variables related to family functioning in the field of autism
- Objective 4: identify possible evolutions of family functioning

Method

In order to conduct and report this systematic review, the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines were followed (Page et al., 2020). The protocol was registered through the Prospero open access database (CRD42022297696) produced by the Centre for Reviews and Dissemination at the University of York (England).

Eligibility criteria

To be included in the review, articles had to have been published (1) in a peer reviewed journal (2) between 1980 and 2021 as autism first appeared in the DSM-III in 1980 as a separate diagnosis from schizophrenia (APA, 1980) (3). Only articles in French or English were considered as these are the languages spoken by the authors (4). Study participants had to be relatives or caregivers of autistic children (under 18) with an official diagnosis (5). The articles had to provide quantitative data from a research protocol (6) and from a validated measure of family functioning (7). Studies were excluded if instead of measuring family functioning, they measured the impact on the family as the tools were not based on a theory of family functioning.

Information sources and search strategy

For this review, an electronic search was conducted by the first author (GDG) in August 2021 in the databases PubMed, PsycINFO, and PubPsych respectively through the platforms *National Center for Biotechnology Information*, *EBSCOhost* and *PubPsych*. These databases were selected as significant international resources in the field of psychology and psychiatry. Filters were applied to ensure that the results would be articles from academic journals (1),

published between 1980 and 2021 (2), and written in either English or French (3). The search algorithm linked the terms autism and family functioning through Boolean operators: (autis* OR ASD) AND (“family functioning”). To include a broad range of terms relating to autism, the truncation “autis*” was used as well as the acronym “ASD” which stands for autism spectrum disorder in the DSM-5 (APA, 2013). In addition, to avoid unintentionally excluding articles by referring to a specific theory, the term “family functioning” was solely used.

Selection process

With the results from the databases, a two-step screening process was conducted by the first two authors (GDG and ND) independently. Firstly, the titles and abstracts were assessed using the eligibility criteria. Secondly, the preselected articles were fully read and reassessed. The agreement rate between the two authors was 95.3%. Disagreements were resolved through discussion. Once the screening process was completed, the bibliographies of the selected articles were searched for additional studies referring to autism and family functioning.

Data collection process

To collect the data from the articles the *Data collection form for intervention reviews: RCTs and non-RCTs* from the Cochrane Developmental, Psychosocial and Learning Problems Review Group (2014) was adapted by the first author (GDG). The information sought matched the objectives of the review. Regarding publication, the country of the research and the year of publication were collected (objective 1). Concerning methodology, information on the population (sample size, autism characteristics, age, gender), study design, and on the family functioning measure and its dimensions were extracted (objectives 1 and 2). Regarding the results (objective 3 and 4), data were only collected if there was a link with family functioning (variables and their relationship to family functioning). Any missing information was mentioned during the process. The extraction of data was conducted by the first author (GDG) and verified by the second author (ND) to avoid any risk of error.

Study quality and risk of bias assessment

Two assessments were conducted to analyse the quality and risk of bias across articles. First, the *Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies* from the National Heart, Lung, and Blood Institute (2013) was used. It focuses on the aim of the study, sample characteristics, inclusion and exclusion criteria, statistical power, variables, and study design. The assessment was conducted independently by the first two authors (GDG and ND). The inter-rater agreement rate was 87,1%. Secondly, to specifically assess the risk of bias, the Cochrane Collaboration's tool, *RoB2*, adapted from Higgins and Altman (2008) by Higgins et al. (2011) helped determine which biases to assess. The recruitment and participant biases, detection bias, performance bias, and attrition bias were thus estimated by the first author and checked by the second author. For each tool, disagreements were resolved through discussion.

Results

Study selection

Figure 1 displays the selection process. Overall, the search yielded 495 articles, including 200 duplicates. Therefore, 295 titles and abstracts were screened using the eligibility criteria. Among these, 181 were excluded, leading to the full text screening of 114 articles. As a result, 49 articles were included. Their bibliographies were checked for other articles meeting the criteria, consequently adding 13 articles. A total of 62 articles were thus included in the review. It should be noted that the same sample was used in some articles (five samples each led to two articles and two samples each led to three articles). Therefore, the 62 articles resulted from 53 samples. The primary reasons for exclusion were: the type of report (qualitative or non-academic), the lack of specificity in the diagnosis (inclusion of neurodevelopmental disorders as a group or lack of a validated diagnosis), or the absence of a satisfying assessment of family functioning (absent or non-validated assessment, or assessment of a different construct).

INSERT FIGURE 1

Study characteristics

The first objective of this review was to report descriptive characteristics of the literature on family functioning in the field of autism. Despite the language eligibility criteria, the articles that were included were all published in English, none in French. Out of the 62 articles, 52 were published between 2011 and 2021 (83.9%), reflecting an increasing interest in the topic over the past ten years (Figure 2). In addition, 29 of the studies were conducted in the USA (46.8%) and the rest in 13 other countries (Figure 3). This distribution supports the idea of a growing international interest, even though the research currently comes primarily from the USA.

INSERT FIGURE 2

INSERT FIGURE 3

Table 1 summarises the individual study characteristics of the 62 included articles. Among them, 41 had a cross-sectional design, and 21 had a longitudinal one. Moreover, 60 relied on caregiver reports of family functioning, one relied on a sibling report, and two relied on both. For caregivers, the mean age ranged from 32.6 (SD = 7.6) (Ji et al., 2014a) to 49.3 (SD = 5.8) (O'Brien, 2016). For siblings, the mean age was 12.3 (SD = 3.6) in Chan and Lai's article (2016) and 16.7 (SD = 3.8) in Laghi et al.'s (2018). Regarding gender, the percentage of female caregivers ranged from 50 to 100%. Rodrigue et al.'s article from 1992 only reported results from male caregivers, but the results from female caregivers had already been published in another report from the same study in 1990. For siblings, the percentages of female participants varied from 43% (Laghi et al., 2018) to 61,2% (Chan & Lai, 2016). Concerning the diagnosis, most studies included families of children on the autism spectrum without specification or at least analysed as one entity. Only four articles reported specific results. Heiman and Berger (2008), Pisula and Porębowicz-Dörsmann (2017), Rao and Beidel (2009) focused on autism

without an intellectual disorder including Asperger syndrome or high functioning autism. On the contrary, Chan and Lai (2016) focused on autism associated with a learning disability.

The second objective was to identify tools and models used to assess the functioning of families with an autistic child. Figure 4 shows that the most used tool was the FACES (Family Adaptability and Cohesion Evaluation Scale), all versions mixed, with a preference for the latest version, FACES IV (Olson, 2011). This tool is based on the Circumplex model and its cohesion, flexibility/adaptability, and communication dimensions. Cohesion and adaptability assessed through balanced (considered healthy) and unbalanced (considered unhealthy) scales. The second most used tool was the FAD (Family Assessment Device) based on the McMaster Model (Epstein et al., 1983). It includes affective involvement, problem solving, communication, role, affective responsiveness, and behavioural control. Studies in this review only used it for general functioning, except Temelturk et al. (2021). The other tools were the FES (Family Environment Scale) (Moos & Moos, 1994) with three groups of subscales, relationships (cohesion, expressiveness, conflict), personal growth (independence, achievement, intellectual cultural orientation, active recreational orientation), and system maintenance (organisation, control); the FAM III (Family Assessment Measure) (Skinner et al., 1995) with general family functioning, dyadic relationship, and self-rating subscales; the FFFS (Feetham Family Functioning Survey) (Feetham & Humenick, 1982) used as a general family functioning scale; and the FFS (Family Functioning Scale) (Bloom, 1985) with relationships and system maintenance dimensions.

INSERT FIGURE 4

The included articles used all or only certain dimensions of the tools. To synthesise the results in the review, they were grouped into seven categories: (1) general family functioning, (2) cohesion including affection and relationship between members, (3) organisation including adaptability and role, (4) communication, (5) conflict management including problem solving, (6) system control with system maintenance and behaviour control, and (7) personal functioning

within the family including personal growth and self-rating in the family. Overall, cohesion, general family functioning, and organisation were the most researched dimensions, followed by communication, conflict management, personal functioning, and system control (Figure 5).

INSERT FIGURE 5

Certainty of evidence: quality and risk of bias assessment

Regarding the quality, of the 62 articles, 12.9% were considered to be of poor quality, 67.7% of fair quality, and 19.4% of good quality. Details are presented in Table 1.

More specifically concerning the risk of bias, 75.8% of the studies recruited participants via electronic mailing lists, research databases, blogs, or unspecific and unclear procedures, resulting in an unclear or high-risk recruitment bias. In 88.7% of articles, the sample lacked diversity regarding gender, ethnicity, education, and/or socioeconomic status. Thus, they were subject to an unclear or high-risk population bias. As for methodology, all studies used validated measures of family functioning. However, the tools were self-report instruments, thus inducing a response bias. Moreover, 64.5% of the articles showed an unclear or high risk of performance bias as the condition in which participants responded were unspecified or unstandardised. Finally, 21 of the articles had a longitudinal design and were at risk of attrition bias. Specifically, 10 of these lost more than 20% of their original sample or did not report their loss.

INSERT TABLE 1

Cross sectional study of family functioning

To fulfil objective 3 (identify variables related to family functioning) results were synthesised by groups of variables.

Diagnosis status

To specify the functioning of families with an autistic child, comparisons are relevant.

General family functioning was found more problematic in families of autistic children than in families of typically developing ones (Chan & Lai, 2016; O'Brien, 2016; Pisula & Porębowicz-Dörsmann, 2017; Temelturk et al., 2021; Walton, 2019). However, no differences were found with families of children with developmental difficulties (Duvekot et al., 2017; Herring et al., 2006; Temelturk et al., 2021). Only Samadi et al. (2014) found lower family functioning in families of children with autism compared to intellectual disability. In addition, although Altieri and Von Kluge (2009) found a general satisfaction with family functioning in parents of autistic children, Gau et al. (2012), Kostiukow et al. (2019), Sullivan et al. (2012), Walton (2019) and Xue et al. (2014) found less satisfaction compared to parents of non-autistic children.

Despite the consensus on general family functioning, inconsistencies appear on specific dimensions. Several articles found higher cohesion in families of autistic children than a control group (Koegel et al., 1983; Lei, 2018; Lei & Kantor, 2020, 2021; Manning et al., 2011) or families of children with Down syndrome (Rodrigue et al., 1990, 1992). Similarly, in Lei (2018) and Xue et al. (2014), most autistic group families were classed as connected or very connected. However, three studies found their cohesion to be lower than the non-autistic group (Higgins et al., 2005; Kostiukow et al., 2019; Walton, 2019). Finally, three studies found no differences for relationships in the family (Koegel et al., 1983; Pisula & Porębowicz-Dörsmann, 2017; Rao and Beidel, 2009). Using unbalanced scales, Kostiukow et al. (2019) found the autistic group higher than the control group on the unmeshed (unbalanced high cohesion) and disengaged (unbalanced low cohesion) scales. Nonetheless, using balanced and unbalanced scales, Altieri and Von Kluge (2009) found a similar distribution of cohesion types in both groups.

For family organisation, Heiman and Berger (2008) and Temelturk et al. (2021) noted more organisation in parents of children with autism than without. Likewise, lower adaptability, i.e., stricter organisation was found in six articles (Gau et al., 2012; Higgins et al., 2005; Lei, 2018; Lei & Kantor, 2020, 2021; Walton, 2019). On the contrary, Baker et al. (2011) and Xue

et al. (2014) classed these families as flexible or very flexible. In three studies, having an autistic child also predicted more adaptability and even chaos (unbalanced high adaptability) than having a non-autistic child (Altiere & Von Kluge, 2009; Kostiukow et al., 2019; Sullivan et al., 2012). Finally, three studies found no differences between the autism and non-autism groups for balanced adaptability, rigidity (unbalanced low adaptability), and organisation (Rodrigue et al., 1990; Kostiukow et al., 2019; Koegel et al., 1983). Comparing diagnoses, Rodrigue et al. (1990) and Heiman and Berger (2008) found more organisation and less adaptability in families of children with autism than with an intellectual disability or Down syndrome. Temelturk et al. (2021) found no differences compared to families of children with a developmental delay.

Regarding communication, Heiman and Berger (2008) found lower expressiveness among parents of children with Asperger syndrome than the control and intellectual disability groups. On the contrary, Temelturk et al. (2021) and Xue et al. (2014) found no differences with the intellectual disability group and higher levels of communication for the autism group than the non-autism group. Finally, in Koegel et al. (1983), Kostiukow et al. (2019), Manning et al. (2011), and Walton (2019), no differences with the non-autistic group appeared in communication or expressiveness.

Concerning conflict management, Temelturk et al.'s (2021) results indicated more problem-solving behaviours in families of autistic children than non-autistic children and no differences with the developmental delay group. However, Koegel et al. (1983) and Manning et al. (2011) found no differences compared to a control group regarding expression of conflict.

Regarding personal functioning within the family, in Pisula and Porębowicz-Dörsmann (2017) and Kissel and Nelson (2016), parents of autistic children had lower self-rating scores than the non-autistic group. Similarly, Rao and Beidel (2009) and Sanders and Morgan (1997) found a trend towards significantly lower personal growth. Moreover, both these studies found lower active-recreation and intellectual-cultural orientation scores in families of the autistic

group than in a control and a Down syndrome group. Although most studies found lower levels of personal functioning, Koegel et al. (1983) found no differences with a non-autistic group.

Regarding system control, in Rao and Beidel (2009) and Koegel et al. (1983), families of autistic and non-autistic children did not differ on system maintenance. Similarly, Temelturk et al. (2021) found no differences for behaviour control. Only Heiman and Berger (2008) found higher system maintenance in the autism group than in intellectual disability and control groups.

Sociodemographic variables in families of autistic children

Firstly, regarding caregiver gender, although Gau et al. (2012) and Johnson et al. (2011) found lower satisfaction with family functioning in mothers than fathers of autistic children, three studies found they agreed (Altiere & Von Kluge, 2009; Pisula & Porębowicz-Dörsmann, 2017; Samadi & McConkey, 2014). Two studies also found similar patterns for both parents: lower personal functioning and higher cohesion than typically developing and Down syndrome groups (Sanders & Morgan, 1997; Rodrigue et al., 1990, 1992). However, Rodrigue et al. (1990, 1992) found lower adaptability than the Down syndrome group in mothers but not fathers. Gau et al. (2012) found lower cohesion for mothers than fathers, and the differences between mothers of the autism and control groups were not found in fathers. On the contrary, Temelturk et al. (2021) found similarities between groups of mothers whereas fathers of autistic and non-autistic children differed on general functioning, problem solving, roles, and communication.

Few articles focused on ethnicity. Ekas et al. (2016) found no differences regarding cohesion between Hispanic and Non-Hispanic mothers in the USA. On the other hand, Lin et al. (2011) found lower adaptability and cohesion for USA mothers than for Taiwanese mothers.

In married and unmarried mothers of autistic children, Johnson and Simpson (2013) found a low level of satisfaction with family functioning for daily practical support for family tasks. Only unmarried mothers reported dissatisfaction with partner relationship and child

school attendance. Baker et al. (2011) found no links between marital status and adaptability. Family composition was not linked to family functioning (Baker et al., 2011; Jellett et al., 2015).

Regarding social status, Lei and Kantor (2020) and Manning et al. (2011) found a higher perceived status to be associated with better family functioning. Similarly, Zaidman-Zait et al. (2018) found a link between a lower score on the index of socio-economic risk and better family functioning. In Lei and Kantor (2020), better employment status, household income, and educational level were associated with higher cohesion and adaptability. On the contrary, Baker et al. (2011), Benson (2015), and Jellett et al., (2015) found no link between family functioning and socioeconomic status (educational attainment, employment status, and household income).

Regarding child and care characteristics, six studies found no links between family functioning and age, gender, intervention or education of the child (Baker et al., 2011; Benson, 2015; Herring et al., 2006; Jellett et al., 2015; Walton, 2019; Xue et al., 2014). Nevertheless, Yusuf et al. (2020) found better family functioning correlated with higher perceived utility for biological testing of the child, which can be considered to be part of the child's care.

Autism characteristics and comorbidities

Few articles referred to specific entities within the autism spectrum or the pervasive developmental disorders and no comparison between them was made. Regarding severity of autism, no links were found with family functioning (Kelly et al., 2008; Samadi & McConkey, 2014). However, all articles studying behaviour problems showed that severe behaviours had more impact on family functioning (Baker et al., 2011; Brown et al., 2019; Di Nuovo & Azzara, 2011; Herring et al., 2006; Jellett et al., 2015; Khanna et al., 2011; Kissel & Nelson, 2016; Manning et al., 2011; O'Brien, 2016; Szatmari et al., 2021; Zaidman-Zait et al., 2018). Specifically, Brown et al. (2019) found less cohesion and adaptability in caregivers of children displaying physical and mixed aggression (physical and verbal) than in a non-aggressive group.

Regarding developmental characteristics, Herring et al. (2006) found no link between family functioning and the degree of developmental delay. However, Di Nuovo and Azzara (2011) found correlations with specific domains: developmental age for communication was positively associated with balanced cohesion, balanced adaptability, communication in the family, and satisfaction with family functioning, and negatively correlated with disengaged cohesion. Developmental age for motor skills was positively linked with balanced adaptability.

Concerning the intellectual disability comorbidity, Di Nuovo and Azzara (2011) found a positive link between the level of intelligence and cohesion, communication, and satisfaction with family functioning. It is also worth noting that in Zaidman-Zait et al. (2018), lower family functioning was associated with lower adaptive behaviour and academic achievement.

Finally, Van Steensel et al. (2017) found the style of family functioning to impact anxiety symptoms. Autistic children from “authoritarian families” (low family relation and high system maintenance) had higher levels anxiety compared to other families. In addition, a trend towards significance showed that children of “uninvolved families” (low family relation and low system maintenance) tended to have lower levels of anxiety.

Family adjustment

In 2014, Xue et al. grouped adjustment variables by category: “Demands” referred to mental and physical health variables, requiring an adjustment; and “Capabilities and resources” referred to variables supporting or hindering adjustment. These categories correlated with family functioning. A similar classification was used to present the results of the review.

Family adjustment - Demands

For families of autistic children, poorer family functioning was associated with lower quality of life (Pisula & Porębowicz-Dörsmann, 2017). Precisely, in three studies, caregivers reporting higher levels of cohesion and adaptability also reported greater satisfaction with their

family quality of life. No correlation with conflict was found (Lei, 2018; Lei & Kantor, 2020; McStay et al., 2014). Regarding specific domains of quality of life, family functioning seems to have a particularly strong effect on mental and physical health and social relationships (Ji et al., 2014b; Khanna et al., 2011; Khanna et al., 2013; Pisula & Porębowicz-Dörsmann, 2017).

Besides in quality of life, general health scores and fatigue did not correlate with family functioning in Jellett et al. (2015) and Samadi and McConkey (2014). However, higher levels of alexithymia, lower emotional well-being and lower mental health correlated with difficulties in family functioning in Johnson et al. (2011), Samadi et al. (2014), and Temelturk et al. (2021). More specifically, less optimal family functioning, lower family cohesion and adaptability, and more conflict were associated with more depressive symptoms among caregivers (Baker et al., 2011; Ekas et al., 2016; Jellett et al., 2015; Kelly et al., 2008, Zaidman-Zait et al., 2018; Zhou et al., 2018). Similarly, for siblings, lower adjustment scores seemed to correlate with a more problematic family functioning (Chan & Lai, 2016). In addition, in Walton and Tiede (2020), higher unbalanced scores of family functioning (enmeshment, disengagement, chaos but not rigidity) were predictive of more depression and less happiness in parents. Nevertheless, enmeshment was only related to less happiness for parents of typical children, not autistic ones.

Regarding parental stress around autism, only Samadi and McConkey (2014) found no correlation with family functioning. Indeed, higher parental stress was generally associated with poorer family functioning (Johnson et al., 2011; Kissel and Nelson, 2016; Manning et al., 2011; O'Brien, 2016; Pisula and Porębowicz-Dörsmann, 2017; Samadi et al., 2014; Zaidman-Zait et al., 2017, 2018) and specifically lower cohesion and expression (Benson, 2015; McStay et al., 2014). It was also positively linked with conflict for fathers. Considering, unbalanced scales, disengagement and chaos correlated with higher levels of family stress (Walton & Tiede, 2020).

Several studies focused on emotional variables related to the role of caregiver of an autistic child. Higher satisfaction with caring and lower levels of caregiver burden and caregiver

strain were associated with better family functioning (Ji et al., 2014b; Khanna et al., 2011, 2012; Samadi et al., 2014). In addition, according to O'Brien (2016), feelings of uncertainty regarding autism and the future were associated with less family adaptation. Finally, in Zhou et al. (2018), affiliate stigma (linked to an autistic child) negatively correlated with cohesion and adaptability.

Family adjustment - Capabilities and resources

Several articles focused on family relationships as part of the adjustment around autism. Regarding partner relationship, Timmons et al. (2016) found family adaptability to predict daily relationship quality on the partner support scale but not on the partner conflict or relationship happiness scales. Concerning parent-child relationship, an avoidant attachment style correlated with poorer family functioning in Temelturk et al. (2021). Similarly, reports of more positive affiliative, attachment and caregiving behaviours in parents were associated with better family functioning and satisfaction in Laghi et al. (2018) and specifically better cohesion in Pruitt et al. (2016). On the contrary, negative interactions were associated with lower family satisfaction (Laghi et al., 2018) and higher family rigidity (Pruitt et al., 2016). Finally, higher satisfaction regarding family leisure time was related to higher cohesion and adaptability in Walton (2019).

Regarding involvement with the autistic child, for mothers, home-based involvement was positively associated with family cohesion (Benson, 2015). To go further, Sullivan et al. (2012) found that higher enmeshment predicted more grandmother involvement and less frustration. Also, a chaotic family style predicted higher grandmother need for information.

When a dog was present in the autistic child's home, Hall et al. (2016) found no links between family functioning and attachment to the dog. However, Hall et al. (2016) and Wright et al.'s (2015) results indicated an improvement in family functioning since acquiring a dog.

Regarding social support, for Ji et al. (2014b), Khanna et al. (2011), Samadi et al. (2014), Zaidman-Zait et al. (2018) families of autistic children with less social support also had poorer

family functioning. Precisely, Lei and Kantor (2020, 2021) and O'Brien (2016) found a positive association between social support and cohesion and adaptability. Lin et al. (2011) agreed on adaptability but not cohesion for USA mothers. No link was found for Taiwanese mothers. In Timmons et al. (2016), considering family support, adaptability was positively linked to partner support. On the contrary, Altieri and Von Kluge (2009) found rigid and structured families to perceive more family support than flexible and chaotic ones. For cohesion, in Ekas et al. (2016) and Heiman and Berger (2008), higher levels correlated with more family and partner support. Similarly, Altieri and Von Kluge (2009) found that disengaged families perceived lower family support than separated and enmeshed ones. Friends were perceived as more supportive by enmeshed families than separated and disengaged ones. Ekas et al. (2016) found a positive link between cohesion and friend support only for Hispanic USA mothers (not non-Hispanic ones).

Concerning coping around autism, a problematic family functioning appears to correlate with more maladaptive coping strategies and vice versa for adaptive strategies (Ji et al., 2014b; Khanna et al., 2011). Specifically, parents in enmeshed families used more coping strategies than in disengaged, separated, or connected ones in Altieri and Von Kluge (2009). In O'Brien (2016), adaptability was also positively linked with use of coping strategies. Considering coping strategy categories, Lin et al. (2011) and Zaidman-Zait et al. (2018) noted that more adaptability and cohesion in USA mothers was associated with more problem-focused and less emotion-focused coping strategies. For Taiwanese mothers, higher adaptability was also linked with problem-focused strategies, but no link was found for cohesion (Lin et al., 2011). Furthermore, for Manning et al. (2011), the social support seeking strategy was positively associated with family functioning. In addition, Altieri and Von Kluge (2009) showed that enmeshed families used more social support seeking strategies and that disengaged families used more avoidance and less reframing strategies than other families. In Ekas et al. (2016), optimism and benefit finding coping strategies, were associated with higher cohesion. Only Higgins et al. (2005)

found no link of family adaptability and cohesion with optimism and spousal support seeking.

Longitudinal study of family functioning

To answer objective 4 (identify possible evolutions of family functioning), results were synthesised in two groups: non-interventional and interventional longitudinal results.

Non-interventional longitudinal results

Among the included articles, only two focused on evolution of family functioning over time, with no reference to a specific intervention. Benson (2015) studied change in family functioning between age 7 and 14 of the autistic child. Results showed a significant increase in family cohesion among mothers. On the other hand, Herring et al. (2006), found no difference in parents' ratings between the time of diagnosis and 12 months later.

Interventional longitudinal results

Hall et al. (2016) and Wright et al. (2015) assessed the benefits of owning a dog in families of autistic children. An improvement of general family functioning was observed and maintained 2.5 years later in the dog-owning group. No changes occurred in the control group.

Considering the needs of parents of autistic children, interventions were created to help them navigate the care system. Crossman et al. (2020) found no changes in family functioning between baseline before the navigation intervention and follow-up 60 days later. Similarly, the Colorado Parent Mentoring program aimed to provide parents with information on autism and existing services, as well as provide emotional support (Moody et al., 2019). While the control group's rigidity increased, the intervention group remained low on rigidity. No changes in family functioning were noted. On the contrary, McConkey and Samadi (2013) and Samadi et al. (2013) used a training programme to inform on autism, coping, parents' emotional well-being, and social support. The intervention brought improvements in family functioning up to 12 months post baseline. Similarly, Ji et al. (2014a) assessed a multidisciplinary parent

education programme focused on family functioning, social support, and coping strategies as well as information on autism. An improvement of family functioning was observed for the intervention group a week after the last session but not for the control group.

Considering the specificity of autism, some interventions focusing on children's skills were beneficial for families. In 2014, Samadi and Mahmoodizadeh developed the "Omid Resource Kit" to provide information on autism and suggest play activities and communication aids. An improvement in family functioning was observed for the intervention group at the 12-month follow up. No changes were observed for the control group. Similarly, Okuno et al. (2016) assessed a social skills enhancement programme to help autistic children. A significant improvement in family relationships was observed within one month.

Regarding child behaviour problems, Zand et al. (2018) assessed "Primary Care SS Triple P", a one-on-one programme targeting maladaptive behaviours. Only the intervention group reported improvements in family functioning 4-8 weeks post baseline. Similarly, Wagner et al. (2019) assessed the effectiveness of multisystemic therapy (MST) (an intensive family and community-based program) on behaviour problems in autistic children. Family adaptability had increased for caregivers in the MST group at the 12-month follow-up and decreased for caregivers in the control condition. In addition, a trend towards significance showed an increased cohesion for the MST group and a decreased cohesion for the control group.

Discussion

In this systematic review on family functioning in families concerned with autism, 62 quantitative articles published in English between 1983 and 2021 in peer reviewed journals were included. The first objective was to report descriptive characteristics of the literature. While geographical diversity is increasing, most studies were published in the USA over the past decade. This recent interest in the topic provides a greater understanding, but more research is needed to generalise the results worldwide. Two thirds of the studies were cross-sectional,

and the rest were longitudinal. The autism spectrum was mainly considered as an entity without specification, thus not reflecting its heterogeneity. Participants were mostly female caregivers with little diversity and very few articles included siblings. This data could imply a lack of representativeness when reporting family functioning (only one member) and when recruiting families from various backgrounds. Indeed, although satisfaction with autism care is linked with maternal education and family income (Hidalgo et al., 2015), autism affects all cultural and socioeconomic backgrounds, which should therefore be included in the research samples.

The second objective was to identify the tools and models used in the field of autism to assess family functioning. Six tools were used overall, the most common ones being the FACES based on the Circumplex Model and the FAD based on the McMaster Model. The dimensions of the tools were grouped into seven categories, the most studied ones being cohesion, general functioning, and organisation. The variety of tools supports the validity of consistent results across studies. On the other hand, similarly named dimensions can refer to different definitions, thus possibly explaining inconsistent results. Using a metamodel-based tool could clarify these discrepancies. For instance, Pauzé et al. (2017) created a multi-dimensional integrative model based on several valid models to reflect the complexity of family functioning. In addition, using an observation tool like the Clinical Rating Scale based on the Circumplex model (Thomas & Olson, 1994) instead of self-reports could help validate and complement the existing literature.

The third objective was to identify variables related to family functioning around autism. Regarding diagnosis status, general functioning appears more problematic and less satisfying for families of autistic children compared to families of typically developing children, but not necessarily compared to families of children with other developmental difficulties. Results on specific dimensions are contradictory. Therefore, autism impacts family functioning, but precise dimensional conclusions cannot be drawn. The discrepancies could result from the variety of evaluations of family functioning, but also from the heterogeneity within the autism

spectrum (APA, 2013). Although no link was found between autism severity and family functioning, associated difficulties in behaviour, anxiety, and intelligence seem to correlate with poorer general family functioning, and lower cohesion and adaptability. As a result, family functioning is to be considered in relation to the comorbidities. Besides, participant factors such as sociodemographic or medical/psychological variables (e.g., history of depression) (Herr et al., 2007) influence family functioning and should be considered in inconsistencies.

Regarding sociodemographic variables, besides mothers being less satisfied with family functioning than fathers, results on caregiver gender, marital status, and socioeconomic status were incoherent. Family composition and child characteristics did not seem to impact family functioning but were tested in few studies. Differences between simplex and multiplex families were not studied. Finally, ethnicity seemed linked with family functioning but requires broader research in autism. Besides for description, sociodemographic factors should systematically be analysed in relation with family functioning to provide data on family profiles to support them, and contextualise the findings. For instance, Turkdogan et al. (2019) validated the Circumplex Model in Turkey. However, a positive link between enmeshment (unbalanced high cohesion) and satisfaction with family functioning was found because of their collectivist culture.

Lower family functioning appeared to be associated with higher parental demand. Precisely, lower quality of life, mental health, and emotional well-being were correlated with lower general functioning, cohesion, adaptability, and communication. Therefore, interventions targeting family functioning could be beneficial for psychological functioning. It is worth noting that Walton and Tiede (2020), found disengagement (unbalanced low cohesion) and chaos (unbalanced high adaptability) predicted more depression and less happiness in all parents, but enmeshment (unbalanced high cohesion) was only related to less happiness for parents of typical children, not autistic ones. This suggests that high enmeshment might not be negative for families of autistic children contrary to what is theorised in the Circumplex Model

(Olson, 2011). This should be explored via a comparison with other disorders. For example, Coe et al. (2018) found cohesion to act as a protector and enmeshment as a risk factor mediating the link between maternal relationship instability and child behaviour problems. Thus, enmeshment might be specific in families of autistic children. More research is required.

Regarding resources and capabilities, family relationships influence family functioning on several levels. First, the quality of relationships was positively linked with general family functioning, satisfaction, and cohesion. Secondly, home involvement with the autistic child was positively associated with cohesion for mothers and enmeshment for grandmothers. Finally, families can provide social support. General support but also specific support from friends and family seemed positively associated with general family functioning and cohesion. Since most family functioning models included a relationship dimension (often called cohesion), these correlations are not surprising. Meanwhile, results relating family relationships and adaptability diverged. Furthermore, the evaluations used did not distinguish family functioning in the nuclear and extended family while it is known that the extended family functioning influences the nuclear one and can increase support when there is openness (Klever, 2015). More research on the levels of family functioning would clarify the results on family resources around autism.

Regarding coping among parents of autistic children, family functioning was linked negatively to maladaptive coping strategies and positively to adaptive coping strategies. Although the terms are unclear, in a systematic review in the field of autism, Vernhet et al. (2018) define problem-focused strategies as protective and emotion-focused ones as detrimental. The current review also generally found a positive association of adaptability and cohesion with the use of problem-focused coping strategies. Nevertheless, Khanna et al. (2011) considered planning, positive reframing, or the use of emotional support as adaptive (problem and emotion-focused) and self-blame, avoidance, or substance use as maladaptive (emotion focused). Despite some discrepancies, coping by social support seeking, reframing, and benefit

finding seemed to correlate with more cohesion or even enmeshment whereas avoidance was linked to disengagement. Supporting a previous comment, enmeshment could be considered adaptative for families of autistic children. To test this hypothesis, family functioning should be studied as a mediator between resources and psychological demand. For instance, Lei and Kantor (2020) found that cohesion and adaptability mediated the relationship between social support and the quality of life in caregivers of autistic children. Further research is needed.

The fourth objective was to identify possible evolutions of family functioning in autism. Only two non-interventional longitudinal studies were found. One reported no change over a year, and another showed improvement over 7 years. Only a few articles assessed interventions. Programmes targeting information on autism, care system navigation, and parental adjustment produced inconsistent findings related to family functioning, which could be due to differences in the support provided by health care systems across countries (Ogloblin, 2011). On the other hand, interventions to improve children's skills and behaviour appeared beneficial for family functioning. This could be explained by the link between behaviour problems and family functioning. Acquiring a dog also seemed beneficial for improving family functioning. Considering the aim of the review, it is surprising that no article focused on family therapy. Similarly, no study met Spain et al.'s (2017) inclusion criteria in a systematic review on family therapy in autism. Future research on family functioning should focus on this type of therapy.

Limitations of the review protocol

Several limits should be noted. First, only articles in English and French were selected. Complementary results could be found in other languages. Secondly, qualitative data were not integrated in the review, and could have helped specify certain inconsistent findings. Thirdly, studies were selected if they used an assessment tool specific to family functioning. Other tools focusing on a particular dimension such as a subsystem of the family might have been used in studies without mentioning family functioning. Finally, in the results, associations between

family functioning and other variables were reviewed one at a time. Considering several variables together could potentially clarify family functioning in families of autistic children.

Clinical recommendations and implications for future research

The findings of this review suggest an association of family functioning with several resources and psychological demands among families of autistic children and should therefore be assessed by professionals to adapt the care provided. Indeed, its assessment would allow family functioning to be considered as a resource or a vulnerability factor when helping families face the challenges of autism. The review also highlights that interventions focusing on child behaviours impact family functioning and should thus consider this variable, either as a primary target or as a secondary benefit if needed after assessment.

Regarding future research, this review should be completed with a systematic review of qualitative findings on family functioning in autism for more clarity. Second, observation tools should be used to extend the quantitative findings of the current review more ecologically. Third, further research should aim to explore differences and similarities in nuclear and extended family functioning as well as in reports of various family members related to an autistic child. Assessment of family functioning concerns different generations and positions in the family which should therefore be considered. Fourth, creating profiles of families by linking family functioning to other variables would guide professionals in their interventions. In that sense, family functioning should be tested as a risk or protective mediator between resources and demands. Specifically, enmeshment should be addressed. Finally, considering the importance of family functioning in relation to psychological demands, the effectiveness of family therapy on family functioning should be tested in families of children with autism.

Conclusion

To conclude, this review shows the increasing interest for family functioning in the field

of autism. General family functioning appears more problematic and less satisfying for families of autistic children than families of non-autistic children. Findings focusing on specific dimensions are not consistent. Moreover, difficulties in family functioning seem associated with more parental demands and less resources but can be improved through interventions. Several limitations should be addressed though further research to specify the findings. Nevertheless, family functioning should be considered and targeted by professionals working to improve the well-being of children on the autism spectrum and their families.

Support and competing interests

The authors have no conflict of interest and financial support to declare for this review.

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TABLES AND FIGURES

Figure 1

Flow diagram of the selection process following the PRISMA guidelines (Page et al., 2020)

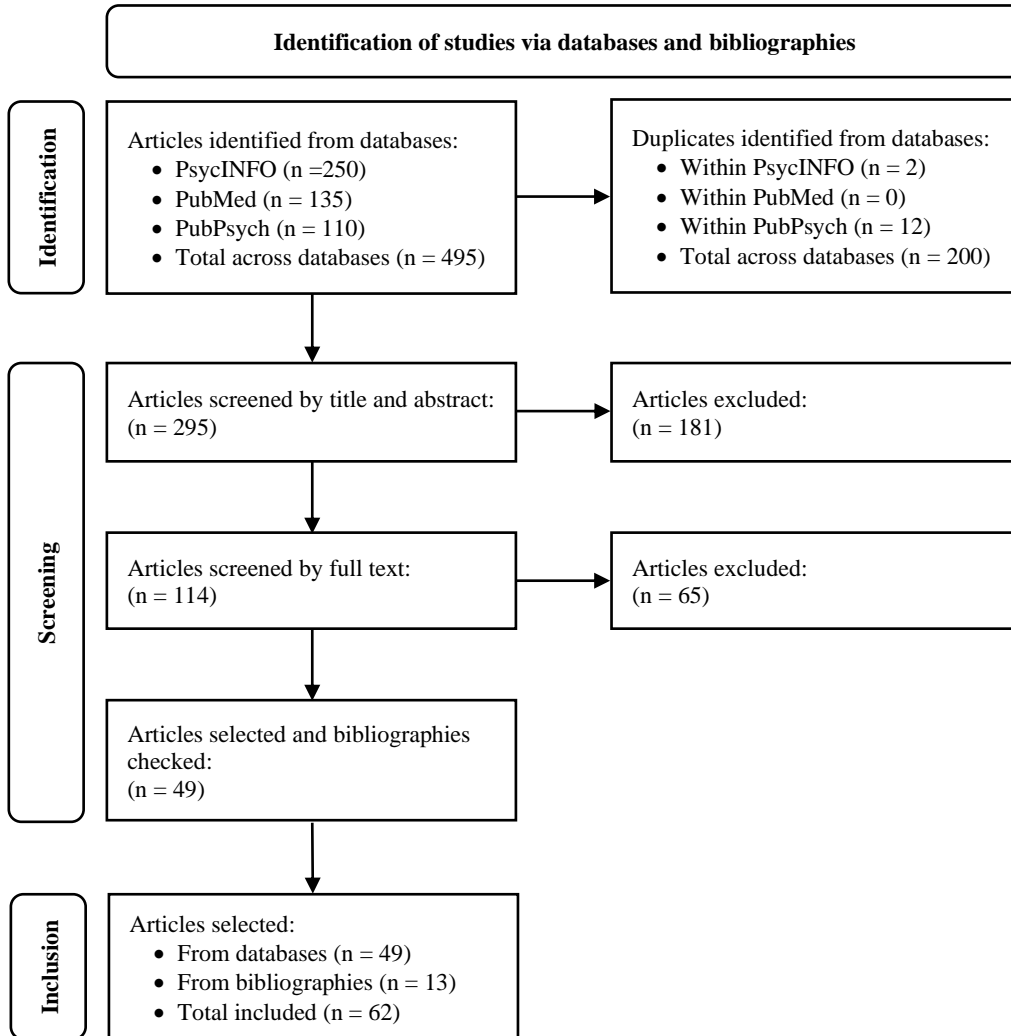


Figure 2

Distribution of the included articles by year of publication

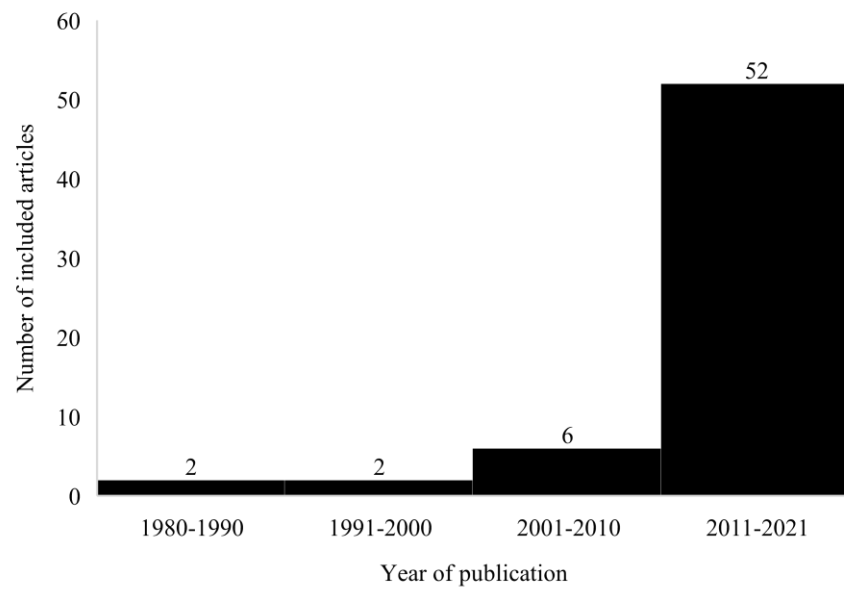
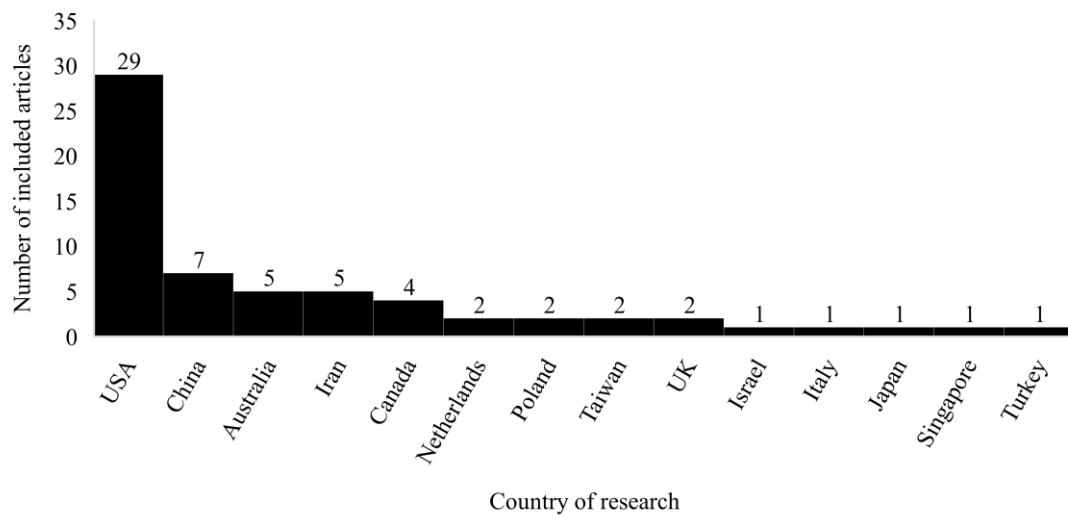


Figure 3

Distribution of the included articles by country of research



Note. The study by Lin et al. (2011) was conducted in the USA and in Taiwan and was therefore counted twice

Figure 4

Distribution of the included articles by family functioning assessment tool

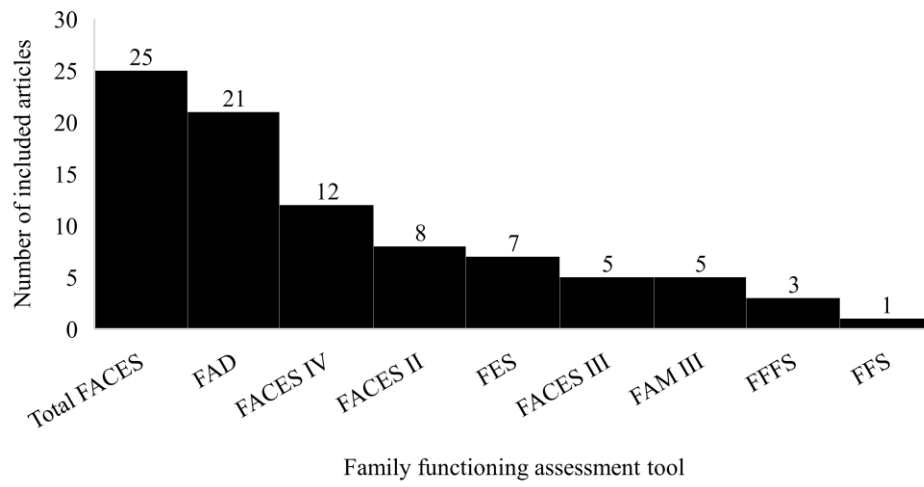


Figure 5

Number of included articles assessing each family functioning dimension

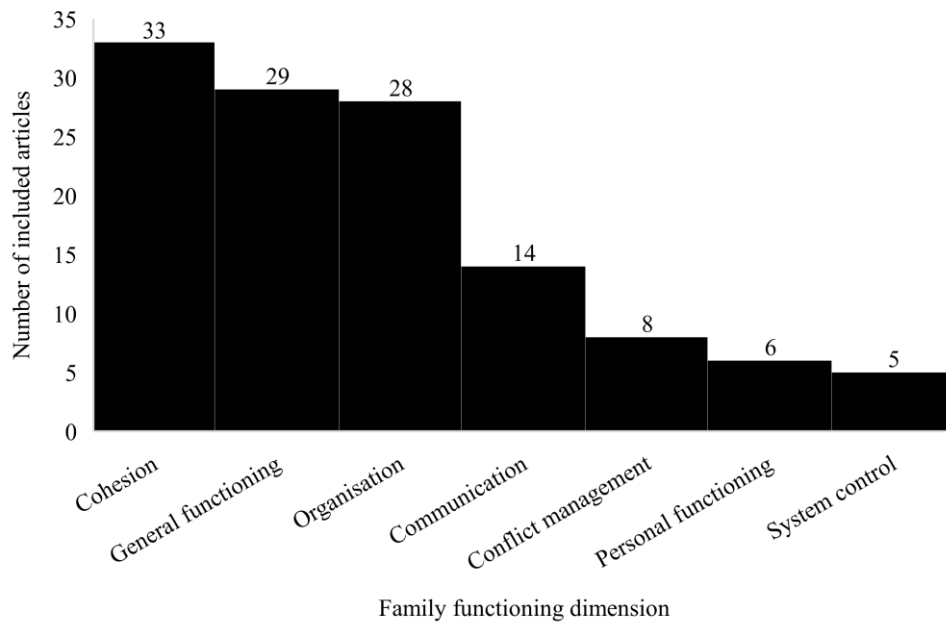


Table 1*Individual studies' characteristics*

| Citation | Country | Population | | | Autism characteristics | Study design | Measure of family functioning | | Quality |
|---------------------------|---------|--|---|---|--|-----------------|-------------------------------|--------------------------|---------|
| | | Sample size | Age (years (SD)) | Gender (female %) | | | Tool | Dimensions | |
| Altiere & Von Kluge, 2009 | USA | 52 caregivers | - | 50.0% | Asperger syndrome, autism, PDD-NOT | Cross-sectional | FACES III | Cohesion Adaptability | Fair |
| Baker et al., 2011 | USA | 149 caregivers | 44.4 (SD = 5.2) | 100% | Autism spectrum | Longitudinal | FACES IV | Adaptability | Good |
| Benson, 2015 | USA | 113 caregivers | 42.0 (SD = 5.2) | 100% | Asperger syndrome, autism, PDD-NOT | Longitudinal | FACES II | Cohesion | Fair |
| Brown et al., 2019 | USA | 120 caregivers | - | - | Autism spectrum | Cross-sectional | FACES II | Cohesion Adaptability | Fair |
| Chan & Lai, 2016 | China | 116 caregivers 116 siblings | 45.0 (SD = 5.4) 12.3 (SD = 3.6) | - 61.2% | Autism spectrum with intellectual disorder | Cross-sectional | FAD | General functioning | Fair |
| Crossman et al., 2020 | USA | Target group: 96 caregivers Control group: 164 caregivers | Target group: 35.4 (SD = 5.8) Control group: 35.7 (SD = 7.2) | Target group: 83.9% Control group: 91.6% | Autism spectrum | Longitudinal | FAD | General functioning | Fair |

| | | | | | | | | | |
|-------------------------|-------------|---|---|---|---|-----------------|-----------|---|------|
| Di Nuovo & Azzara, 2011 | Italy | 40 caregivers | 42.9 (SD = 5.3) | 50.0% | Autism spectrum | Cross-sectional | FACES IV | Cohesion Adaptability Communication | Poor |
| Duvekot et al., 2017 | Netherlands | 239 caregivers | 38.1 (SD = 5.5) | 88.0% | Asperger syndrome, autism, PDD-NOT | Longitudinal | FAD | General functioning | Good |
| Ekas et al., 2016 | USA | Target group: 75 caregivers Control group: 41 caregivers | Target group: 37.6 (SD = 5.9) Control group: 39.9 (SD = 6.4) | Target group: 100% Control group: 100% | Autism spectrum | Cross-sectional | FACES IV | Cohesion | Fair |
| Gau et al., 2012 | Taiwan | Target group: 151 caregivers Control group: 113 caregivers | Target group: 38.8 (SD = 4.8) Control group: 39.2 (SD = 4.6) | Target group: 50.0% Control group: 50.0% | Autism spectrum | Cross-sectional | FACES III | Cohesion Adaptability | Fair |
| Hall et al., 2016 | UK | Target group: 22 caregivers Control group: 15 caregivers | - | Target group: 81.8% Control group: 85.7% | Asperger syndrome, autism spectrum, autism, autistic traits | Longitudinal | FAM III | General functioning | Good |
| Heiman & Berger, 2008 | Israel | Target group 1: 33 caregivers Target group 2: | Target group 1: 48.7 (SD = 9.9) Target group 2: | Target group 1: 81.8% Target group 2: | Asperger syndrome | Cross-sectional | FES | <u>Relationships</u> : cohesion, expressiveness, conflict <u>Personal growth</u> : independence, | Fair |

| | | | | | | | | | |
|-------------------------|-----------|--|---|---|---------------------------------------|---------------------|----------|--|------|
| | | 43 caregivers | 37.4 (SD = 3.4) | 83.7% | | | | achievement, intellectual | |
| | | Control group: 45 caregivers | Control group: 38.9 (SD = 6.6) | Control group: 86.7% | | | | cultural orientation, active recreational orientation | |
| | | | | | | | | <u>System maintenance:</u> organization, control | |
| Herring et al., 2006 | Australia | Target group: 151 caregivers Control group: 72 caregivers | - | Target group: 52.3% Control group: 52.8% | Autism spectrum, PDD-NOT | Longitudinal | FAD | General functioning | Good |
| Higgins et al., 2005 | Australia | 52 caregivers | - | 97.0% | Asperger syndrome, autism spectrum | Cross- sectional | FACES II | Cohesion Adaptability | Poor |
| Jellett et al., 2015 | Australia | 97 caregivers | 36.1 (SD = 5.5) | 90.7% | Asperger syndrome, autism, PDD-NOT | Cross- sectional | FAD | General functioning | Fair |
| Ji et al., 2014a | China | Target group: 22 caregivers Control group: 20 caregivers | Target group: 32.6 (SD = 7.6) Control group: 35.7 (SD = 8.7) | Target group: 90.9% Control group: 90.0% | Autism spectrum | Longitudinal | FAD | General functioning | Good |
| Ji et al., 2014b | China | 273 caregivers | 35.2 (SD = 9.6) | 84.2% | Autism spectrum | Cross- sectional | FAD | General functioning | Fair |
| Johnson et al., 2011 | USA | 128 caregivers | 40.6 (SD = 7.5) | 50.0% | Asperger syndrome, autism, PDD-NOT | Cross- sectional | FFFS | General functioning | Fair |

| | | | | | | | | | |
|-------------------------|-----------|---|-----------------|---|------------------------------------|-----------------|---------|---|------|
| Johnson & Simpson, 2013 | USA | 261 caregivers | 39.2 (SD = 7.2) | 100% | Asperger syndrome, autism, PDD-NOT | Cross-sectional | FFFS | General functioning | Poor |
| Kelly et al., 2008 | Australia | 285 caregivers | - | - | Asperger syndrome, autism, PDD-NOT | Cross-sectional | FES | Cohesion Conflict | Fair |
| Khanna et al., 2013 | USA | 326 caregivers | - | 93.7% | Asperger syndrome, autism, PDD-NOT | Cross-sectional | FAD | General functioning | Fair |
| Khanna et al., 2011 | USA | 304 caregivers | 38.9 (SD = 8.0) | 93.1% | Asperger syndrome, autism, PDD-NOT | Cross-sectional | FAD | General functioning | Fair |
| Khanna et al., 2012 | USA | 304 caregivers | 38.9 (SD = 8.0) | 93.1% | Asperger syndrome, autism, PDD-NOT | Cross-sectional | FAD | General functioning | Fair |
| Kissel & Nelson, 2016 | USA | Target group 1: 33 caregivers Target group 2: 15 caregivers Control group: 16 caregivers | - | Target group 1: 84.8% Target group 2: 86.7% Control group: 75.0% | Asperger syndrome, autism, PDD-NOT | Cross-sectional | FAM-III | General functioning Self-Rating | Poor |
| Koegel et al., 1983 | USA | 49 caregivers | - | - | Autism spectrum | Cross-sectional | FES | <u>Relationships</u> : cohesion, expressiveness, conflict <u>Personal growth</u> : independence, achievement, intellectual | Fair |

| | | | | | | | | | |
|---------------------------|-------------------|---|--|---|---------------------------------------|---------------------|-----------|---|------|
| | | | | | | | | cultural orientation, active recreational orientation <u>System maintenance:</u> organization, control | |
| Kostiukow et al., 2019 | Poland | Target group: 70 caregivers Control group: 70 caregivers | - | - | Autism spectrum | Cross- sectional | FACES IV | Cohesion Adaptability Communication | Poor |
| Laghi et al., 2018 | Italy | 86 siblings | 16.7 (SD = 3.8) | 43.0% | Autism spectrum | Cross- sectional | FACES IV | Cohesion Adaptability Communication | Fair |
| Lei, 2018 | China | 163 caregivers | - | - | Autism spectrum | Cross- sectional | FACES III | Cohesion Adaptability | Fair |
| Lei & Kantor, 2020 | China | 163 caregivers | - | - | Autism spectrum | Cross- sectional | FACES II | Cohesion Adaptability | Fair |
| Lei & Kantor, 2021 | China | 167 caregivers | - | - | Autism spectrum | Cross- sectional | FACES II | Cohesion Adaptability | Fair |
| Lin et al., 2011 | USA and Taiwan | Target group: 76 caregivers Control group: | Target group: 46.6 (SD = 5.9) Control group: | Target group: 100% Control group: | Asperger syndrome, autism, PDD-NOT | Cross- sectional | FACES II | Cohesion Adaptability | Fair |

| | | | | | | | | | |
|---|-----------|--|---|---|---|-----------------|----------|---|------|
| | | 325 caregivers | 47.5 (SD = 7.2) | 100% | | | | | |
| Manning et al., 2011 | USA | 195 caregivers | 40.9 (SD = 6.1) | 95.9% | Autism spectrum | Cross-sectional | FES | Cohesion Expressiveness Conflict | Fair |
| McConkey & Samadi, 2013 | Iran | 28 caregivers | - | 60.7% | Autism spectrum | Longitudinal | FAD | General functioning | Poor |
| McStay et al., 2014 | Australia | 196 caregivers | 43.0 (SD = 6.1) | 50.0% | Asperger syndrome, autism, PDD-NOT, autism spectrum, | Cross-sectional | FES | Cohesion Expressiveness Conflict | Fair |
| Moody et al., 2019 | USA | Target group: 33 caregivers Control group: 34 caregivers | Target group: 35.8 (SD = 5.9) Control group: 33.9 (SD = 6.2) | Target group: 91.0% Control group: 88.2% | Autism spectrum | Longitudinal | FACES IV | Cohesion Adaptability | Good |
| O'Brien, 2016 | USA | 103 caregivers | 49.3 (SD = 5.8) | 91.3% | Autism spectrum | Cross-sectional | FAD | General functioning | Fair |
| Okuno et al., 2016 | Japan | 26 caregivers | 42.2 (SD = 3.8) | 65.3% | Autism spectrum | Longitudinal | FFFS | General functioning | Fair |
| Pisula & Porębowicz- Dörsmann, 2017 | Poland | Target group: 98 caregivers Control group: 104 caregivers | Target group: 40.7 (SD = 5.3) Control group: 40.8 (SD = 6.5) | Target group: 50% Control group: 50% | Asperger syndrome, autism without intellectual disorder | Cross-sectional | FAM III | General functioning Dyadic relationship Self-rating | Fair |

| | | | | | | | | | |
|--------------------------|-----|---|--|---|----------------------------|---------------------|-----------|--|------|
| Pruitt et al., 2016 | USA | 83 caregivers | 38.6 (SD = 6.1) | 100% | Autism spectrum | Longitudinal | FACES IV | Cohesion Adaptability | Fair |
| Rao & Beidel, 2009 | USA | Target group: 15 caregivers and 7 siblings Control group: 14 caregivers and 8 siblings | - | Target group: 80.0% caregivers 57.1% siblings Control group: 85.7% caregivers 33.3% siblings | High functioning autism | Cross- sectional | FES | <u>Relationships</u> : cohesion, expressiveness, conflict <u>Personal growth</u> : independence, achievement, intellectual cultural orientation, active recreational orientation <u>System maintenance</u> : organization, control | Poor |
| Rodrigue et al., 1990 | USA | Target group 1: 20 caregivers Target group 2: 20 caregivers Control group: 20 caregivers | - | Target group 1: 100% Target group 2: 100% Control group: 100% | Autism spectrum | Cross- sectional | FACES III | Cohesion Adaptability | Fair |
| Rodrigue et al., 1992 | USA | Target group 1: 20 caregivers Target group 2: 20 caregivers | Target group 1: 40.3 (SD = 6.8) Target group 2: 40.9 (SD = 7.5) | Target group 1: 0% Target group 2: 0% | Autism spectrum | Cross- sectional | FACES III | Cohesion Adaptability | Fair |

| | | | | | | | | | |
|------------------------------------|------|---|--|---|-----------------|-----------------|-----|--|------|
| | | Control group: 20 caregivers | Control group: 36.6 (SD = 5.4) | Control group: 0% | | | | | |
| Samadi & McConkey, 2014 | Iran | 103 caregivers | - | 56.3% | Autism spectrum | Cross-sectional | FAD | General functioning | Fair |
| Samadi & Mahmoodizadeh, 2014 | Iran | 65 caregivers | - | 50.8% | Autism spectrum | Longitudinal | FAD | General functioning | Fair |
| Samadi et al., 2014 | Iran | Target group: 121 caregivers Control group: 115 caregivers | - | Target group: 57.0% Control group: 72.2% | Autism spectrum | Cross-sectional | FAD | General functioning | Fair |
| Samadi et al., 2013 | Iran | 37 caregivers | - | 64.9% | Autism spectrum | Longitudinal | FAD | General functioning | Fair |
| Sanders & Morgan, 1997 | USA | Target group 1: 18 caregivers Target group 2: 18 caregivers Control group: 18 caregivers | Target group 1: 36.9 (SD = 5.10) Target group 2: 42.9 (SD = 6.4) Control group: 38.7 (SD = 4.9) | - | Autism spectrum | Cross-sectional | FES | <u>Relationships</u> : cohesion, expressiveness, conflict <u>Personal growth</u> : independence, achievement, intellectual cultural orientation, active recreational orientation | Poor |

| | | | | | | | | <u>System maintenance:</u> | |
|------------------------------|-------------|-----------------|-----------------|-----------------|---------------------------------------|---------------------|----------|--|------|
| | | | | | | | | organization, control | |
| Sullivan et al., 2012 | USA | Target group 1: | | Target group 1: | Asperger syndrome, autism | Cross- sectional | FACES IV | Cohesion Adaptability Communication | Fair |
| | | 31 caregivers | | 100% | | | | | |
| | | Target group 2: | - | Target group 2: | | | | | |
| | | 19 caregivers | | 100% | | | | | |
| | | Control group: | | Control group: | | | | | |
| | | 34 caregivers | | 100% | | | | | |
| Szatmari et al., 2021 | Canada | 272 caregivers | - | - | Autism spectrum | Longitudinal | FAD | General functioning | Fair |
| Temelturk et al., 2021 | Turkey | Target group 1: | | | Autism spectrum | Cross- sectional | FAD | General functioning Problem solving Communication Roles Affective responsiveness Affective involvement Behaviour control | Good |
| | | 25 caregivers | | | | | | | |
| | | Target group 2: | - | - | | | | | |
| | | 23 caregivers | | | | | | | |
| | | Control group: | | | | | | | |
| | | 27 caregivers | | | | | | | |
| Timmons et al., 2016 | USA | 70 caregivers | 38.3 (SD = 6.0) | 100% | Autism spectrum | Longitudinal | FACES IV | Adaptability | Good |
| Van Steensel et al., 2017 | Netherlands | 135 caregivers | 43.7 (SD = 4.8) | 57.8% | Asperger syndrome, autism, PDD-NOT | Longitudinal | FFS | Relationships System maintenance | Good |

| | | | | | | | | | |
|-------------------------|-----------|----------------|-----------------|----------------|--|---------------------|----------|---|------|
| Wagner et al., 2019 | USA | Target group: | | Target group: | Autism spectrum | Longitudinal | FACES II | Cohesion Adaptability | Fair |
| | | 8 caregivers | - | 87.5% | | | | | |
| | | Control group: | | Control group: | | | | | |
| | | 5 caregivers | | 100% | | | | | |
| Walton, 2019 | USA | Target group: | Target group: | Target group: | Autism spectrum | Cross- sectional | FACES IV | Cohesion Adaptability Communication | Fair |
| | | 112 caregivers | 40.0 (SD = 9.3) | 76.8% | | | | | |
| | | Control group: | Control group: | Control group: | | | | | |
| | | 123 caregivers | 39.5 (SD = 9.1) | 86.2% | | | | | |
| Walton & Tiede, 2020 | USA | Target group: | Target group: | Target group: | Autism spectrum | Cross- sectional | FACES IV | Cohesion Adaptability Communication | Fair |
| | | 112 caregivers | 40.0 (SD = 9.3) | 76.8% | | | | | |
| | | Control group: | Control group: | Control group: | | | | | |
| | | 123 caregivers | 39.5 (SD = 9.1) | 86.2% | | | | | |
| Wright et al., 2015 | UK | Target group: | Target group: | Target group: | Asperger syndrome, autism spectrum, autism | Longitudinal | FAM III | General functioning | Good |
| | | 42 caregivers | - | 90.5% | | | | | |
| | | Control group: | Control group: | Control group: | | | | | |
| | | 28 caregivers | | 92.9% | | | | | |
| Xue et al., 2014 | Singapore | Target group: | Target group: | Target group: | Asperger syndrome, autism, PDD-NOT | Cross- sectional | FACES IV | Cohesion Adaptability Communication | Fair |
| | | 65 caregivers | 40.1 (SD = 4.5) | 70.8% | | | | | |
| | | Control group: | Control group: | Control group: | | | | | |
| | | 97 caregivers | 39.0 (SD = 7.7) | 92.8% | | | | | |
| Yusuf et al., 2020 | Canada | 97 caregivers | 39.0 (SD = 7.7) | 92.8% | Autism spectrum | Cross- sectional | FAM III | General functioning | Fair |

| | | | | | | | | | |
|---------------------------|--------|--|---|---|-----------------|-----------------|----------|--------------------------|------|
| Zaidman-Zait et al., 2017 | Canada | 191 caregivers | 35.4 (SD = 5.4) | 100% | Autism spectrum | Longitudinal | FAD | General functioning | Good |
| Zaidman-Zait et al., 2018 | Canada | 207 caregivers | - | - | Autism spectrum | Longitudinal | FAD | General functioning | Fair |
| Zand et al., 2018 | USA | Target group: 12 caregivers Control group: 9 caregivers | Target group: 36.6 (SD = 7.2) Control group: 34.8 (SD = 5.7) | Target group: 100% Control group: 100% | Autism spectrum | Longitudinal | FAD | General functioning | Good |
| Zhou et al., 2018 | China | 263 caregivers | 34.6 (SD = 5.4) | 71.5% | Autism spectrum | Cross-sectional | FACES II | Cohesion Adaptability | Fair |

Notes. USA = United States of America; UK = United Kingdom; SD = Standard Deviation; PDD-NOT = Pervasive Developmental Disorder-Not Otherwise Specified; FACES = Family Adaptability and Cohesion Evaluation Scale; FAD = Family Assessment Device; FAM III = Family Assessment Measure III; FES = Family Environment Scale; FFFS = Feetham Family Functioning Survey; FFS = Family Functioning Scale; - = Missing or incomplete information