Parental experience of parent-mediated intervention for children with ASD: A systematic review and qualitative evidence synthesis

Lucie Jurek, Kathy Leadbitter, Bruno Falissard, Cyrille Colin, Sandrine Touzet, Marie-Maude Geoffray

Original Article

autism

Autism
1–20

DOI: 10.1177/13623613221112204
journals.sagepub.com/home/aut
SAGE

Parental experience of parent-mediated intervention for children with ASD: A systematic review and qualitative evidence synthesis

Lucie Jurek[1,2], Kathy Leadbitter[3], Bruno Falissard[4], Cyrille Colin[2,5], Sandrine Touzet[5,6] and Marie-Maude Geoffray[1,2]

Abstract

While the effectiveness of parent-mediated interventions in the field of autism spectrum disorder is well documented, information on the experience of parents involved in parent-mediated interventions is limited. We performed a systematic review with qualitative evidence synthesis to explore the experience of parent-mediated interventions in parents of children with autism spectrum disorder. PubMed, Scopus, PsycINFO, CINAHL, and Sociology Collection were searched from the date of their creation until 25 February 2022. Qualitative studies reporting parents' experience of parent-mediated interventions were included. Two independent reviewers assessed the risk of bias. The findings of the selected studies were extracted and synthesized using the meta-aggregation method. The results are reported according to PRISMA and ENTREQ guidelines. A total of 23 studies were synthesized representing 345 participants. We found 34 categories that were summarized in four synthesized themes: barriers to implementation and logistical issues, feeling overwhelmed and stressed (a need for support), facilitators of implementation, and empowerment in the parent and improvement in the child. Parents' experience of parent-mediated interventions in autism spectrum disorder is balanced between positive outcomes for them and their child, emotional struggles, and some difficulties in implementing parent-mediated interventions. Based on these results, we propose new ways to improve implementation of parent-mediated interventions and research in the field.

Lay abstract

The effectiveness of parent-mediated interventions in the field of autism spectrum disorder is well documented but information on the experience of parents involved in parent-mediated interventions is limited.

This study is the first synthesis of evidence concerning the experience of parents involved in parent-mediated interventions. It synthesizes the voice of 345 parents across the world into four general themes: barriers to implementation and logistical issues, feeling overwhelmed and stressed (a need for support), facilitators of implementation, and empowerment in the parent and improvement in the child.

The findings of our study provide evidence that parent-mediated interventions should be adapted to the needs of each family. Specific care and support should be offered to parents in addition to parent-mediated interventions. Our study, however, highlights which outcomes are important to parents and should be considered in future studies.

Keywords

autism spectrum disorder, parent-mediated intervention, qualitative research

[1]Centre Hospitalier Le Vinatier, France
[2]RESHAPE, Research on Healthcare Performance, U1290, Claude Bernard Lyon 1 University (CBL1), France
[3]University of Manchester, UK
[4]Centre de Recherche en Epidémiologie et en Santé des Populations, INSERM U1018, Université Paris-Saclay, France
[5]Hospices Civils de Lyon, France
[6]Unité Mixte de Recherche Epidémiologique et de Surveillance Transport Travail Environnement (UMRESTTE) UMR T9405, Université Claude Bernard Lyon 1, France

Corresponding author:
Lucie Jurek, Pôle de psychiatrie de l'enfant et de l'adolescent, Centre Hospitalier Le Vinatier, 95 bd Pinel, 69500, Bron, France.
Email: Lucie.JUREK@ch-le-vinatier.fr

Introduction

As identification and diagnosis of autism spectrum disorder (ASD) in early childhood are now more common, several early interventions targeting core impairments of ASD have been developed and evaluated (Dawson, 2008; Pickles et al., 2016).

Boyd et al. (2010) highlighted in their review that the most promising intervention methods involve components of naturalistic interventions for teaching pivotal skills in natural environments and parent-implemented approaches (Boyd et al., 2010). In such interventions, a trained practitioner shares therapeutic strategies with the parent, either in one-to-one sessions or within a group, and the parent is then encouraged to use these strategies with their child outside the session (Bearss et al., 2015). Since then, many models of parent-mediated intervention (PMI) have been developed and evaluated.

The model of PMI allows intervention to begin early, with the aim that parent interaction strategies help enhance children's earliest social relationships. Increased parental skills allow for continual opportunities for child learning in a range of situations and increase the intensity of the intervention (Koegel et al., 2001; Oono et al., 2013). It is also proposed that these methods could increase parent empowerment and self-efficacy (Schertz et al., 2011), leading to a reduction in parental stress (Oono et al., 2013).

Nevertheless, recent studies have documented a disconnect between parent and professional perspectives and goals concerning children with disabilities, with professionals focusing more on impairment reduction and parents prioritizing their child's well-being (Leadbitter et al., 2018). Increased understanding could improve the implementation of interventions within community settings. Engaging families could begin with examining their individual intervention priorities at this pivotal time in the life of their child and their family (Wainer et al., 2017). Understanding their experiences is critical because it provides a glimpse into daily family realities and the ways that ASD can affect parent–child dynamics (DePape & Lindsay, 2015) and can allow intervention practitioners to be sensitive and responsive to family circumstances and priorities.

In the case of PMI in ASD, randomized controlled trials (RCTs) are a good tool to evaluate the efficacy of the treatment but do not usually assess the impact of the treatment on the family system. Qualitative evidence allows researchers to analyze the human experience and has a particular role in exploring and explaining why interventions are or are not effective from a person-centered perspective (Bali, 2014). To date, no qualitative evidence synthesis (QES) review has examined this topic.

The primary objective of this review was to identify, appraise, and synthesize qualitative research evidence on the barriers and facilitators for parents participating in PMI for children with ASD.

Method

The review protocol is available on PROSPERO CRD42020178743 and is reported according to PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses; Moher et al., 2009) and ENTREQ (Enhancing Transparency in Reporting the Synthesis of Qualitative Research; Tong et al., 2012) statements (checklists can be found in Supplemental Material).

Search strategy

As recommended, a combination of electronic databases (PubMed, Scopus, PsycINFO, CINAHL, and Sociology Collection) was searched from the date of their creation until 7 April 2020. An initial limited search of PubMed was undertaken to identify articles on the topic and create the search algorithm. Keywords describing autism and PMI were combined. Filters were used to exclude review articles. The search strategy for the different databases is provided in the Supplemental Material. The reference list of each identified record was reviewed to identify additional relevant studies. The searches were updated before the final analysis was performed on 25 February 2022 and any additional studies that were identified were included.

Only studies published in English and in French were considered for inclusion in this review, with no publication date restrictions.

Selection

We screened titles and abstracts of identified studies for eligibility, followed by full-text review where indicated. For the titles and abstracts screening, studies that presented a PMI for children with ASD were included regardless of the type of study. This first step was time-consuming but necessary to avoid excluded qualitative research that was not clearly indicated in the abstract (Booth, 2016).

For the full-text review, we considered studies as eligible if (1) the population included caregivers with a child below 18 years of age diagnosed with ASD according to an international classification manual (including a diagnosis of autism, Asperger's syndrome, pervasive developmental disorder (PDD), and PDD not otherwise specified (PDD NOS)); (2) those parents had been invited to a parent-implemented intervention, defined as skill-focused intervention where the parent is the agent of change and the child is the direct beneficiary of treatment (Bearss et al., 2015). These interventions could focus on core features of ASD or maladaptive behavior; (3) a qualitative methodology (based on a semi-structured interview or focus group) was used to describe the experiences of parents concerning the intervention. Experiences could relate to parent expectations about the intervention, their support requirements

and involvement (or lack of), but also the perceived barriers and facilitators to their participation in this kind of intervention.

Studies were excluded if (1) parents underwent a psychoeducational program without any skill learning; (2) no qualitative method was described (even if some quotations were reported, a method of analysis should be described with the different steps); and (3) the outcome of the qualitative study was not focused on the experience of parents concerning the intervention but was more about appraisal and development of specific aspect of the program and not about the general parental experience.

Appraisal of the methodological limitations

Relevant studies were critically appraised by two independent reviewers (L.J. and M.-M.G.) for methodological quality using the Critical Appraisal Skills Programme (CASP) Checklist for Qualitative Research. The 10-item checklist considers three categories: validity (clarity of research aims, appropriateness of qualitative methodology, research design, recruitment strategy, data collection, appropriate consideration of researcher reflexivity), results (ethical considerations, appropriateness of data analysis, clarity of findings stated), and utility (the value of the research). Disagreements were resolved by consensus or by referral to a third author (K.L.). As proposed by Cochrane guidelines, we decided to exclude studies with high risk of bias from the analyses (Carroll et al., 2012; Hannes, 2011). A score below 6 on the CASP was considered at high risk of bias (Butler et al., 2016).

Data extraction

One author (L.J.) extracted data from each included study on authors, year, title, aim, study design, context, participants, and analytical approach. Each finding, defined as the authors' interpretation of their results, was identified by a single author and entered in a spreadsheet (Microsoft Excel, Redmond, Washington, USA) for all studies. If studies included views other than those of parents of children with ASD, only the data relating to parents' views were included in the synthesis. Using the terminology employed in the Joanna Briggs Institute Reviewer's Manual, each finding was assigned a level of credibility based on illustrations in the form of supporting quotations or field observations (Lockwood et al., 2015).

Possible credibility levels were unequivocal (the illustration supported the finding beyond a reasonable doubt), credible (some association was present between the illustration and the finding, but it did not clearly support it, meaning that the finding was open to challenge), and unsupported (no illustration was presented). The credibility levels were assigned by L.J. and K.L.; discrepancies were resolved by M.-M.G.

Data synthesis

A meta-aggregative approach was used to synthesize the data. In this approach, authors' qualitative findings are inductively linked to a specific category that includes findings with similar meaning. Categories are then summarized to produce a comprehensive set of "synthetized findings" that provide a basis for identifying recommendations for action. This method does not seek to reinterpret the findings as do some other methods of QES but seeks to enable generalizable statements in the form of recommendations (Booth et al., 2018; Hannes & Lockwood, 2011).

Two authors, L.J. and K.L., collaboratively derived categories and synthesized findings by inductively grouping similar findings and identifying conceptual categories. To improve external validity, the categories and synthesized findings were discussed with a third author (M.-M.G.). Discrepancies between L.J. and K.L. were resolved by M.-M.G. Some categories were renamed to fit the data and improve comprehension, and findings were reclassified if needed until a consensus was reached among the three authors. Implications of the results and recommendations for future practice and studies were discussed with a group of experts (L.J., K.L., B.F., C.C., S.T., and M.-M.G.).

Reflexivity

As quoted below, we chose to work with a multidisciplinary team to provide a synthesis combining different points of view and decrease the risk of personal bias. Four members of the team are child and adolescent psychiatrists (L.J., M.-M.G., K.L., and B.F.) and some are trained in PMI (M.-M.G. and K.L.). S.T. is a senior physician in public health and has been working on RCTs assessing the efficacy of PMI models with L.J. and M.-M.G. C.C. and B.F. are professors of public health. Most of the members are trained in qualitative methodology (L.J., K.L., S.T., B.F., and C.C.). K.L. has conducted qualitative research focused on the experience of parents with PMI.

A summary of team members and their implications in this study can be found in the Supplementary Material.

Confidence in the results

Each category was assessed using the GRADE-CERQual (Confidence in the Evidence from Reviews of Qualitative Research) approach. CERQual is a method to assess how much confidence to place in findings from QES. It assesses to what extent a review finding (here, our categories) reasonably represents a phenomenon of interest (Lewin, Booth, et al., 2018). The CERQual approach includes four elements: (1) methodological limitations of the individual studies that were here assessed with the CASP, (2) coherence of each category (with the primary data and the other findings), (3) adequacy of data (richness of data, number of studies corresponding to

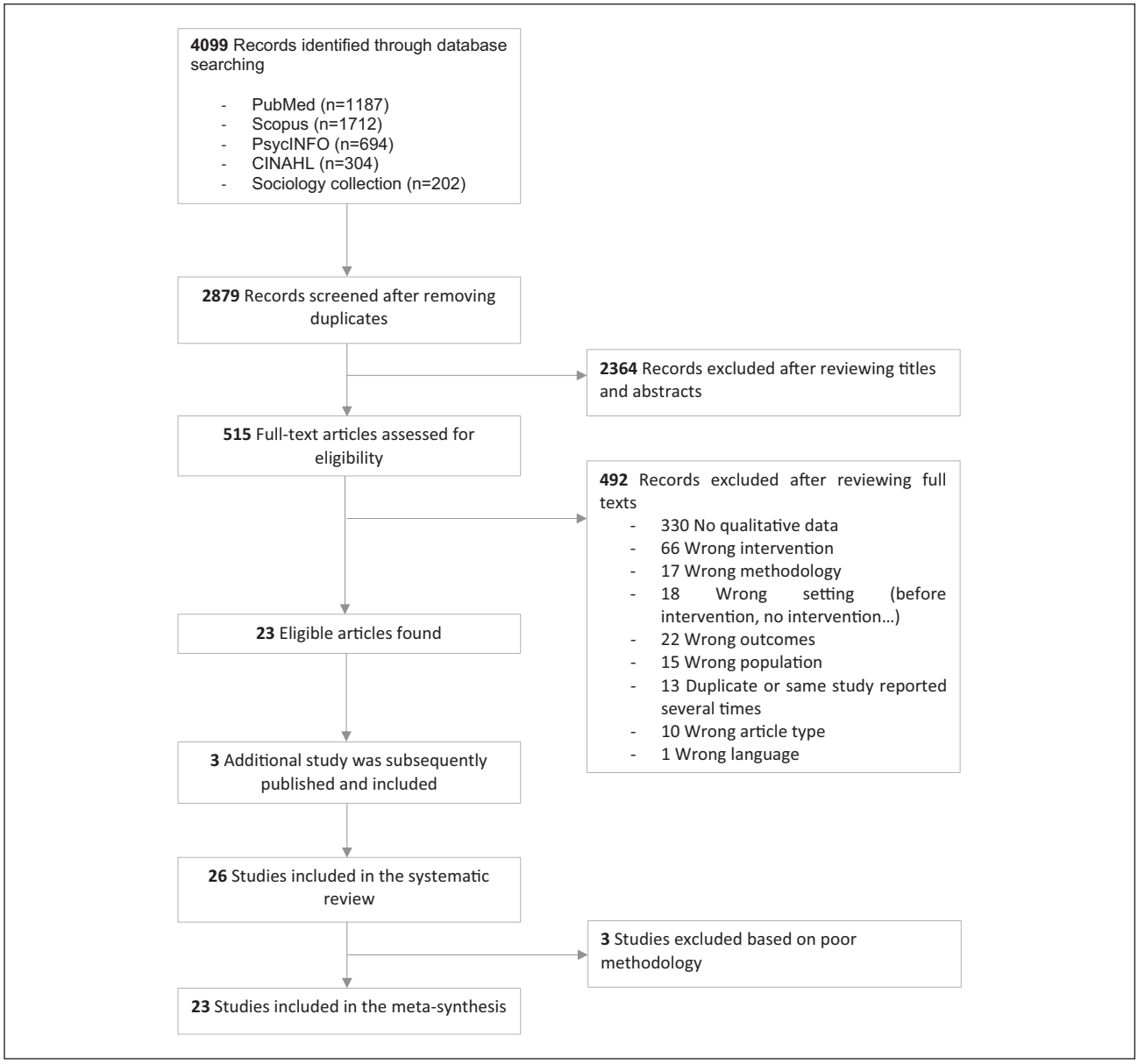

Figure 1. PRISMA flow-chart of included studies.

the finding, contexts of the different studies), and (4) relevance to the review question and context. We assessed each of these four components as having minor, moderate, or substantial concerns regarding the specific component. Based on an overall assessment of methodological quality, relevance, adequacy, and coherence, the confidence in the evidence for each review finding was assessed as high, moderate, or low (Lewin, Bohren, et al., 2018).

Community involvement statement

No community member was involved in this study, but community members (parents) were involved in every reviewed study.

Results

Description of included studies

Our search identified 2879 articles after duplicates were removed. After screening on title and abstracts, 515 articles were assessed for eligibility and 23 articles were included in the systematic review. Three additional studies were retrieved from the second search (Figure 1).

Methodological quality

The methodological quality of the 26 included articles was assessed. Twenty-three were considered at low risk of bias (Table 1) and three were considered at high risk of bias and

Table 1. Assessment of bias using Critical Appraisal Skills Programme tool for quality appraisal in qualitative evidence synthesis.

	Was there a clear statement of the aims of the research ?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research ?	Was the recruitment strategy appropriate to the aims of the research ?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?	Total	Risk of bias
Amsbary et al. (2020)	1	1	1	1	1	1	1	1	1	1	10	LOW
Blake et al. (2017)	0	1	0	1	0	0	0	0	0	1	3	HIGH
Carr & Lord (2016)	1	1	0	1	0	0	0	1	1	1	6	LOW
Chandler et al. (2002)	1	1	0	0	1	0	0	0	1	1	5	HIGH
Chlebowski et al. (2018)	1	1	1	1	1	1	1	1	1	1	10	LOW
Dababnah & Parish (2016)	1	1	1	1	1	0	1	0	1	1	8	LOW
de Korte et al. (2022)	1	1	1	1	1	1	1	1	1	1	10	LOW
Divan et al. (2015)	1	1	1	1	1	0	1	1	1	1	9	LOW
Donaldson et al. (2011)	1	1	0	1	1	0	1	0	1	1	7	LOW
Furukawa et al. (2018)	0	1	1	0	0	1	1	1	0	1	6	LOW
Hodgetts et al. (2013)	1	1	1	1	1	1	1	1	1	1	10	LOW
Hodgson et al. (2018)	1	1	1	1	0	1	1	1	1	1	9	LOW
Leadbitter et al (2020)	1	1	1	1	1	1	1	0	1	1	9	LOW
Manohar et al. (2020)	1	1	1	1	1	0	1	0	1	1	8	LOW
Nilses et al. (2019)	1	1	1	1	1	1	1	1	1	1	10	LOW
Ong et al. (2021)	1	1	1	0	1	0	1	0	1	1	7	LOW
Palmer et al. (2020)	1	1	1	1	1	0	1	1	1	1	9	LOW
Parson et al. (2019)	1	1	1	1	1	1	1	1	1	1	10	LOW
Patterson & Smith (2011)	1	1	1	0	1	0	0	1	1	1	7	LOW
Peckett et al. (2016)	1	1	1	0	1	1	1	0	1	1	8	LOW
Pickard et al. (2016)	1	1	1	1	1	0	1	1	1	1	9	LOW
Rogerson	1	1	1	1	1	1	1	1	1	1	10	LOW
Schertz et al. (2020)	1	1	1	1	1	1	1	1	1	1	10	LOW
Stadnick et al. (2012)	1	1	1	0	1	0	1	1	1	1	8	LOW
Stahmer et al. (2017)	1	1	1	1	1	0	1	1	1	1	9	LOW
Zand et al. (2018)	1	1	0	0	1	0	1	0	0	1	5	HIGH

1 = yes, 0 = no or can't/tell, a score below six was considered a high risk of bias.

were excluded from the synthesis (Blake et al., 2017; Chandler et al., 2002; Zand et al., 2018).

Studied population

The experience of 345 parents was described in the studies. The characteristics of each study are presented in Table 2. The mean age of parents was 36.7 ($SD = 3.4$) years and most of the interviewed parents were women (81%). Concerning the educational level, 49% of the parents had a college-level education, 33% completed high school, and 8% had a primary school–level education.

Children of parents included in the studies had a mean age of 62.7 (range = 15–133) months and mainly were boys (81%).

Interventions targeted social communication skills in most of the studies ($n = 17$), but also disruptive behavior ($n = 4$) or both ($n = 2$). Individual parent training was most frequent ($n = 17$). The mean number of sessions guided by a professional or an application was 13.5 ($SD = 7.9$). Parents were asked to regularly practice the intervention at home in most of the studies.

Eleven studies were from North America, six were from Europe, four from Asia, and two from Australia.

Concerning qualitative methodology, thematic analysis was used in 19 studies, framework analysis in three studies, and Kawakita Jiro method (KJ-method) in one study (a qualitative analysis method developed in Japan that pursues the core themes in a dialogue and explores them from a new angle by grouping them and labeling the groups according to common themes, then illustrating them by a diagram).

Synthesis

We extracted 208 findings from the 23 studies (see Supplemental Material). Concerning the level of credibility, 149 findings were considered unequivocal, 32 as credible, and 26 as unsupported (by the data presented in the article).

These findings were grouped into 34 categories summarized in four synthesized findings: barriers to implementation and logistical issues, feeling overwhelmed and stressed (a need for support), facilitators of implementation, and empowerment in the parent and improvement in the child (Figure 2).

As a sensitivity analysis, findings rated as unsupported (by the data) were removed. This did not affect the categories and the synthesized findings.

Confidence in the findings is reported in Table 3, along with quotes supporting the results. Twenty-one categories were assessed with high confidence, nine with moderate confidence, two with low confidence, and two with very low confidence (advocacy and importance of early intervention).

The details of the GRADE quotation are available in the Supplemental Material.

Synthesized Finding 1: barriers to implementation and logistical issues. Among the different studies, parents reported some barriers to implementing the intervention. They emphasized how challenging finding time for the intervention implementation was and how the recommended homework was challenging to organize in their planning. This barrier was described in nearly half the included studies.

Along with this barrier, parents had some concerns about logistics, particularly about the schedule and location of the sessions. Parents acknowledged that the session had to be close to their home participate. They also described the need to occupy the child during the intervention sessions with the therapist. Some other environmental barriers to the intervention's implementation were described, such as the presence of the siblings.

For some parents, integrating intervention into routines or daily activities was a challenge. Parents described challenges in implementing due to child factors. Because of ASD symptoms, such as a lack of flexibility in the child, parents experienced difficulties implementing the intervention at home. Parent-related factors in engagement were also described. Parents indicated that they sometimes felt unconfident about their parenting skills or overwhelmed by the situation, which led to difficulties in implementing the intervention. Conversely, some parents thought that the child could be more responsive to them than to the therapist because of the established child–parent relationship.

ASD is a large spectrum and parents share concerns about their child's individuality. They reported the need for personalization of the approach with different groups based on children's characteristics (verbal or nonverbal, with or without intellectual disability).

Some parents felt stressed by the therapist and sometimes undervalued with therapists presenting as experts and being directive, with no space for the parent to express their feelings.

Another limitation to implementation was parents' ambivalence concerning effectiveness. They mentioned their doubt about the causal relationship between the intervention and improvements in the child, which could have reduced the motivation to continue the intervention.

Synthesized Finding 2: feeling overwhelmed and stressed (a need for support). Even if parents underlined the importance of early intervention, they reported feeling overwhelmed and stressed throughout the process and advocated for more support. The difficulty in accepting the diagnosis and the fact that the postdiagnosis phase is difficult were well described by the parents.

They mentioned feeling overwhelmed and emphasized the need to go slow at the beginning, as a great deal of new information is presented to them. Parents explained they went through many conflicting feelings: between hope and

Table 2. Characteristics of the studies included in the meta-synthesis.

Author (date)	Setting and location	Population (*N*)	Age (*SD*)	Women ratio	Educational level (*N*)	Intervention type *Name*	Intervention frequency (total number of sessions)	Children age (*SD*)	Children gender (girls)	qualitative method	qualitative analysis framework	Results main themes
Amsbary et al. (2020)	USA	6	35.8 (2.9)	100%	Under high school: 1 High school completion: 0 College level:5	Individual Therapist-Assisted PMI targeting social skills, using video-feedback *NA*	Weekly with home practice between sessions (*n* = 32)	24.5 (4.2)*	20%[a]	Semi-structured interview	Thematic analysis	Effective training approach/process Feeling overwhelmed Daily implementation challenges Mixed feelings integrating into routines and activities Overall satisfaction
Carr & Lord (2016)	USA	8	31.4 (4.8)	100%	Under high school: 0 High school completion: 3 College level: 5	Individual Therapist-Assisted PMI targeting social skills *ESI*	Twice weekly with home practice between sessions (*n* = 25)	28.4 (5.2)	0%	Semi-structured interview	Thematic analysis	Understanding child's impairment, advocacy and empowerment, negative aspects of the project, and positive aspects of the project
Chlebowski et al. (2018)	USA	29	40 (7.4)	93%	Under high school: 12 High school completion: 9 College level: 8	Individual Therapist-Assisted PMI targeting disruptive behaviors *AIM HI*	No info on frequency, home practice between session (*n* = 13)	117.6 (24.7)	10%	Semi-structured interview	Thematic analysis	Limited ASD knowledge Expectations of parental involvement Influences on parent–therapist interactions
Dababnah & Parish (2016)	USA	17	NA	NA	Under high school: 0 High school completion: 2 College level: 15	Group PMI targeting social skills *The Incredible Years*	Weekly with home practice between sessions (*n* = 15)	44.4 (11)	30%	Semi-structured interview	Thematic analysis	Planning IY Setting the stage: the first session Optimizing parent learning throughout the program Thinking to the future: additional supports for ASD-specific groups
de Korte et al. (2022)	Netherlands	17	36.2 (6.1)	71%	Under high school or high school completion: 5 College level: 11 Unknown: 1	Group PMI Targeting social skills *PRT*	Weekly (*n* = 14)	60.12 (14.4)	0%	Semi-structured interview	Thematic analysis	Facilitators and barriers Perceived effects
Divan et al. (2015)	India	17	NA	94%	Under high school: 1 High school completion: 16 College level: 0	Individual Therapist-Assisted PMI targeting social skills, using video-feedback *PACT*	Fortnightly then monthly with home practice between session (*n* = 18)	133.2 (23.5)	NA	Semi-structured interview and focus groups	Framework analysis	Adaptation of content Mode of delivery
Donaldson et al. (2011)	USA	10	31 to 51	0%	Under high school: 0 High school completion: 0 College level: 10	Individual Therapist-Assisted PMI targeting social skills, using video-feedback *FDIT*	Twice weekly with home practice between sessions (*n* = 20)	57.6 (8.5)	10%	Semi-structured interview	NA	Sharing time Having a close relationship Accepting the diagnosis Concerns of, and hope for, the future Benefits of the program

(Continued)

Table 2. (Continued)

Author (date)	Setting and location	Population (*N*)	Age (*SD*)	Women ratio	Educational level (*N*)	Intervention type *Name*	Intervention frequency (total number of sessions)	Children age (*SD*)	Children gender (girls)	qualitative method	qualitative analysis framework	Results main themes
Furukawa et al. (2018)	Japan	21	38.4 (4.3)	100%	Under high school: 0 High school completion: 2 College level: 11	Individual Therapist-Assisted PMI targeting social skills *PCIT*	Weekly ($n = 8$)	62.9 (14.6)	19%	Semi-structured interview	KJ-method	Changes in the parent–child interaction Changes in the child Changes in the parent Others
Hodgetts et al. (2013)	Canada	10	NA	60%	NA	Individual Therapist-Assisted PMI targeting disruptive behavior *SSTP*	Weekly ($n = 10$)	93.6 (35.2)	33%	Semi-structured interview	Thematic analysis	Attribution of cause Who's the boss? Rewarding is rewarding!
Hodgson et al. (2018)	UK	14	NA	93%	Under high school: 6 High school completion: 0 College level: 7	Group and Individual Therapist-Assisted PMI targeting disruptive behaviors *MRB*	Weekly with home practice between sessions ($n = 8$)	60.4 (19.1)	25%	Focus group	Framework analysis	Limited knowledge of RRB Commitment needed to attend and gain from the intervention Benefits of a group-based intervention Homework
Leadbitter et al. (2020)	UK	18	35.6 (6.1)	67%	Under high school: 0 High school completion: 9 College level: 9	Individual Therapist-Assisted PMI targeting social skills, using video-feedback *PACT*	Fortnightly then monthly with home practice between session ($n = 18$)	44.4 (7)	8%	Semi-structured interview	Thematic analysis	The backdrop of the therapy: emotional starting point, hopes and expectations Therapeutic process Practical challenges of the therapy Therapeutic outcomes
Manohar et al. (2020)	India	54	NA	56%	Under high school: 0 High school completion: 27 College level: 27	Individual Therapist-Assisted PMI targeting social skills and disruptive behaviors *NA*	Fortnightly with home practice between session ($n = 5$)	41.5 (17.2)	20%	Semi-structured interview	Thematic analysis	Impact of the child's disorder Treatment impact and change process Validation and acceptance
Nilses et al. (2019)	Sweden	11	34.5 (7.4)	55%	Under high school: 1 High school completion: 8 College level: 3	Individual Therapist-Assisted PMI targeting social skills *P-ESDM or Intensive Learning for Young Children with Autism*	Twice weekly with home practice between sessions ($n = $ NA)	54.6 (8.3)	NA	Semi-structured interview	Thematic analysis	A overwhelming diagnostic Cooperating with the team Growing as a parent
Ong et al. (2021)	Malaysia	8	NA	75%	NA	Group PMI Targeting social skills *CFT*	Weekly with home practice between sessions ($n = 12$)	90 (6.1)	25%	Focus group	Thematic analysis	Fear and resistance Awareness, learning, and adjustment Change is hard Identifying support

(Continued)

Table 2. (Continued)

Author (date)	Setting and location	Population (*N*)	Age (*SD*)	Women ratio	Educational level (*N*)	Intervention type *Name*	Intervention frequency (total number of sessions)	Children age (*SD*)	Children gender (girls)	qualitative method	qualitative analysis framework	Results main themes
Palmer et al. (2020)	UK	9	35.3 (6.8)	82%	NA	Group and Individual Therapist-Assisted PMI targeting social skills and disruptive behaviors, using video-feedback *EarlyBird*	Weekly (*n* = 11)	52.1 (9.6)	24%	Semi-structured interview	Thematic analysis and framework analysis	Positive aspects of the intervention Challenges to the delivery of EarlyBird
Parson et al. (2019)	Australia	24	37 (5)	100%	Under high school: 0 High school completion: 20 College level: 4	Individual Self-Guided PMI targeting social skills (technology-based) *TOBY app*	No info on frequency, home practice between session (*n* = NA)	60 (18.9)	25%	Semi-structured interview	Thematic analysis	If you have met one child with autism, you have met one child with autism The Toby App is just one piece of the jigsaw
Patterson & Smith (2011)	USA	7	NA	NA	Under high school: 0 High school completion: 2 College level: 2	Group and Individual Therapist-Assisted PMI targeting social skills *MTW*	Weekly (*n* = 11)	31.8 (3.8)	25%	Semi-structured interview	Thematic analysis	Program as a good starting point for their learning Unmet emotional and information needs Parent-to-parent contact Individualized coaching and feedback Child-centered factors Special consideration for parents who worked outside the home
Peckett et al. (2016)	UK	5	41 (4.9)	100%	NA	Individual Therapist-Assisted PMI targeting social skills *Lego Therapy*	No info on frequency, home practice between session (*n* = 2)	122.4 (18)	20%	Semi-structured interview	Thematic analysis	Family-specific factors Child-specific factors Intervention-specific factors
Pickard et al. (2016)	USA	10	NA	100%	Under high school: 0 High school completion: 1 College level: 8	Individual Self-Guided or Therapist-Assisted PMI targeting social skills (technology-based) *ImPACT Online*	No info on frequency, home practice between session (*n* = 12)	46.7 (12.6)	30%	Semi-structured interview	Thematic analysis	Perceptions of acceptability Ease of learning ImPACT Online Relative advantage Parent and child outcomes Perceptions of barriers Parent suggestions for dissemination

(Continued)

Table 2. (Continued)

Author (date)	Setting and location	Population (*N*)	Age (*SD*)	Women ratio	Educational level (*N*)	Intervention type *Name*	Intervention frequency (total number of sessions)	Children age (*SD*)	Children gender (girls)	qualitative method	qualitative analysis framework	Results main themes
Rogerson et al. (2019)	Australia	17	38.4 (4.9)	77%	Under high school: 0 High school completion: 0 College level: 17	Individual Self-Guided PMI targeting social skills (technology-based) *TOBY App*	No info on frequency, home practice between session (*n* = NA)	48 (0)	NA	Semi-structured interview	Thematic analysis	Preparation Support Activities Personal factors
Schertz et al. (2020)	USA	11	31.5 (5.3)	100%	NA	Individual Therapist-Assisted PMI targeting social skills, using video-feedback *Joint Attention Mediated Learning intervention*	No info on frequency, home practice between session (*n* = NA)	27.2 (3.7)	36%	Semi-structured interview	Thematic analysis	Autism-related early challenges to parent self-efficacy Parent/professional roles and PSE Manifestations and personal contributors to PSE Child autonomy as an extension of PSE
Stadnick et al. (2012)	USA	13	43.4 (6.3)	85%	Under high school: 0 High school completion: 6 College level: 7	Individual Therapist-Assisted PMI targeting disruptive behaviors *AIM HI*	No info on frequency, home practice between session (*n* = 11)	123.2 (27)	0%	Semi-structured interview	Thematic analysis	Therapy process Impression of therapy Outcomes/impact
Stahmer et al. (2017)	USA	9	34.9 (4)	100%	Under high school: 0 High school completion: 1 College level: 8	Individual Therapist-Assisted PMI targeting social skills *Project ImPACT*	Weekly with home practice between sessions (*n* = 12)	15 (3)	15%	Semi-structured interview	Thematic analysis	Parent coaching process Impression of the intervention Treatment planning process Homework Logistics of the intervention format Perceived effectiveness Improved child social communication Reduced parent stress

N: number; *SD*: standard deviation; PMI: parent-mediated intervention; ESI: early social interaction; AIM HI: An Individualized Mental Health Intervention for ASD; ASD: autism spectrum disorder; PRT: pivotal response treatment; PACT: Preschool Autism Communication Therapy; FDIT: Elder's Father-Directed In-Home Training; PCIT: Parent–Child Interaction Therapy; SSTP: Stepping Stones Triple P; MRB: Managing Repetitive Behaviors; P-ESDM: Parent-Early Start Denver Model; CFT: Children's Friendship Training; TOBY App: Therapeutic Outcomes by You application; MTW: More Than Words; RCT: randomized controlled trial.

[a]Data come from the total RCT population and not the subgroup in the qualitative study.

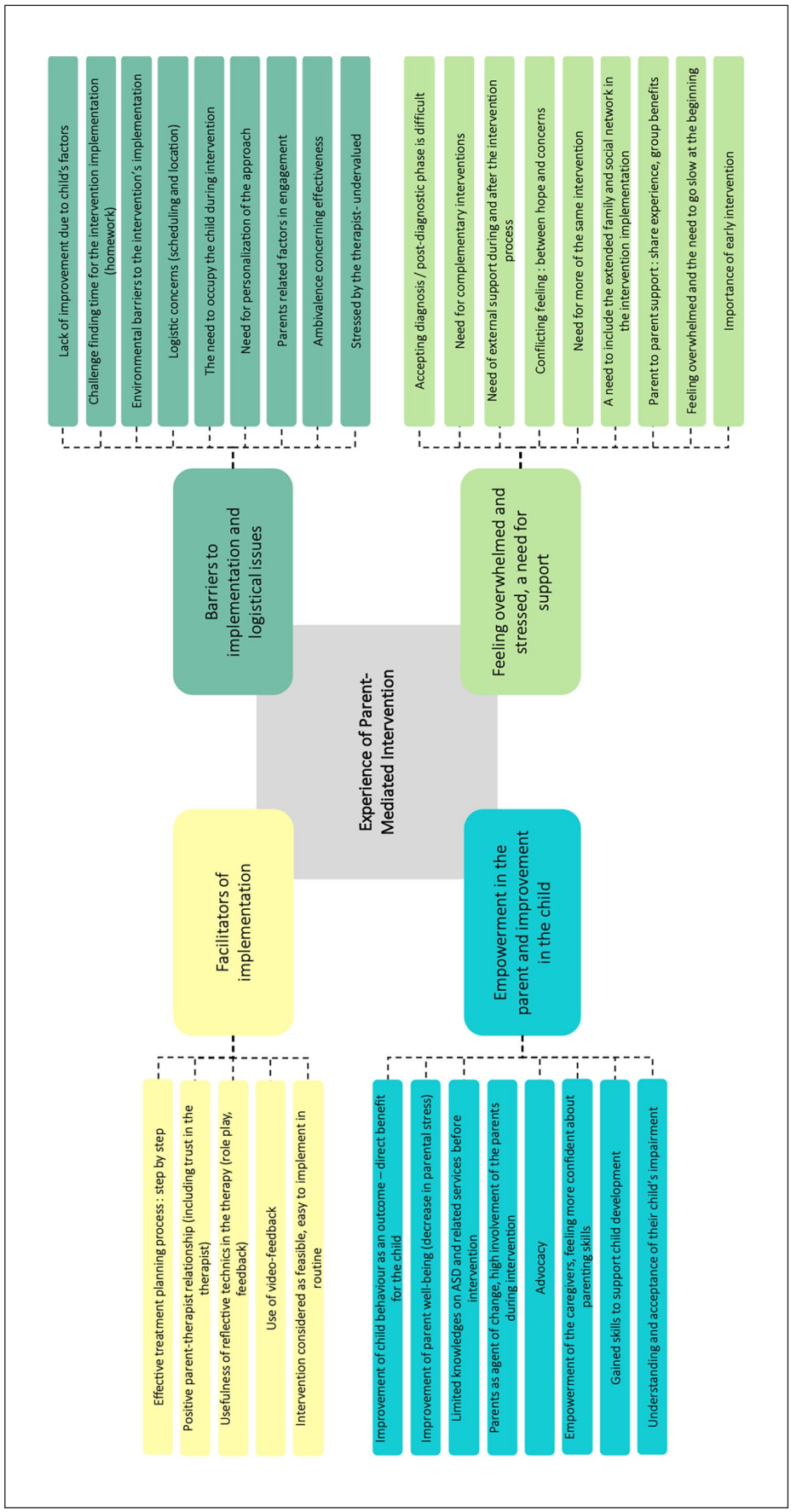

Figure 2. Results of the qualitative evidence synthesis of parent-mediated intervention in autism spectrum disorder.

Table 3. Summary of findings.

Categories	CerQUAL confidence	Related quote	Studies
Facilitators of implementation			
Positive parent–therapist relationship (including trust in the therapist)	High confidence	"We had a relationship of trust, it is as if I was talking with a friend, she made me feel as a friend, as someone who I could trust, as someone who listens to me and is not criticizing or watching to see what I'm going to say" (Chlebowski et al., 2018)	Amsbary et al. (2020), Carr & Lord (2016), Chlebowski et al. (2018), Divan et al (2015) Leadbitter et al. (2020), Nilses et al. (2019), Stadnick et al. (2012), de Korte et al. (2022)
Use of video-feedback	High confidence	"You can't think of everything and you don't see all the little things that go right or wrong or anything, so it is so very, very good to watch yourself back on it." (Leadbitter et al., 2020)	Amsbary et al. (2020), Divan et al (2015), Leadbitter et al. (2020), de Korte et al. (2022)
Usefulness of reflective techniques in the therapy (role-play, feedback)	High confidence	"the time that we spent together working in the therapy setting was great, because I could watch [the therapist] do the strategies and then she gave me time and real-time feedback on how to do things and then she'd always ask me how it was going." (Stahmer et al., 2017)	de Korte et al. (2022), Divan et al (2015), Leadbitter et al. (2020), Manohar et al. (2020), Stadnick et al. (2012), Stahmer et al. (2017)
Intervention considered as feasible, easy to implement in routine	High confidence	"So, I just did it in different scenarios during the day" (Amsbary et al., 2020)	Amsbary et al. (2020), de Korte et al. (2022), Divan et al (2015), Hodgson et al. (2018), Manohar et al. (2020), Nilses et al. (2019), Ong et al. (2021), Pickard et al. (2016), Stahmer et al. (2017)
Effective treatment planning process: step by step	Low confidence	"I think the part that worked best for us was breaking things down into the smaller goals"	Amsbary et al. (2020), Stahmer et al. (2017)
Barriers to implementation and logistical issues			
Challenge finding time for the intervention implementation (homework)	High confidence	"Sometimes I am lazy, means the half an hour practice session is the most difficult to tell you the truth." (Divan et al., 2015)	Amsbary et al. (2020), Divan et al (2015), Furukawa et al. (2018), Leadbitter et al. (2020), Palmer et al. (2020), Peckett et al. (2016), Pickard et al. (2016), Rogerson et al. (2019), Stahmer et al. (2017), Ong et al. (2021), de Korte et al. (2022)
Logistic concerns (scheduling and location)	High confidence	"We didn't have to go all the way across the city to see the team. Yeah . . . that was better for us. Otherwise it would have been hard, both for us, and for X too" (Nilses et al., 2019)	Carr & Lord (2016), Leadbitter et al. (2020), Nilses et al. (2019), Patterson & Smith (2011), Pickard et al. (2016), Stahmer et al. (2017)
Need of personalization of the approach	High confidence	"For me the PECS stuff wasn't useful because my child's verbal, but obviously it's a very wide spectrum. I don't know in the future if it may be better to group parents in terms of having a non-verbal group and a verbal group." (Palmer et al., 2020)	Amsbary et al. (2020), Dababnah & Parish (2016), de Korte et al. (2022), Palmer et al. (2020), Parson et al. (2019), Patterson & Smith (2011)
Environmental barriers to the intervention's implementation	Moderate confidence	"[My daughter]'s almost two years older and she was in pre-K and all that so I had to entertain her and then we had homework." (Amsbary et al., 2020)	Amsbary et al. (2020), Ong et al. (2021)
Challenge implementing due to child's factor	Moderate confidence	"It's hard to get him to sit for that long and do blocks. Besides, he likes to line them up and play different." (Carr & Lord, 2016)	Carr & Lord (2016), Peckett et al. (2016), Rogerson et al. (2019), Ong et al. (2021)

(Continued)

Table 3. (Continued)

Categories	CerQUAL confidence	Related quote	Studies
The need to occupy the child during intervention	Moderate confidence	"The only thing I found really hard, [child's name] found it stressful the fact that he couldn't get my attention afterwards, 'cos I had to try and watch the video and talk to [therapist's name] and I found it so hard and I think he did 'cos he mithered [pestered] to death, 'Mummy, mummy, mummy, mummy', and, er, I was torn between the two, trying to concentrate and him." (Leadbitter et al., 2020)	Dababnah & Parish (2016), Leadbitter et al. (2020)
Parent-related factors in engagement	Moderate confidence	"I spend more time with him so . . . maybe what I do sticks with him better just because I'm able to repeat it a lot more throughout the week." (Schertz et al., 2020)	Ong et al. (2021), Rogerson et al. (2019), Schertz et al. (2020)
Ambivalence concerning effectiveness	Moderate confidence	"I don't know whether that's just the Lego, I think it definitely has helped during the sessions, that we were calm and patient, obviously there was no frustration there, but it's just because Robert generally seems a lot happier, that obviously there is less friction anyway . . . it's probably a combination, yeah, probably a combination yeah of him generally being happier and also I think yeah, maybe the Lego."	Parson et al. (2019), Peckett et al. (2016), Stahmer et al. (2017)
Stressed by the therapist—undervalued	Low confidence	"I have never been more intimidated [than] by this team. . . You have professionals coming in. . . telling you what you should do. . . I wish I could be a part of the discussion. . . I have not felt an equal member of the team. They come over as, 'We're the experts.'" (Rogerson et al., 2019)	Carr & Lord (2016), Schertz et al. (2020)
Empowerment in the parent and improvement in the child			
Improvement of child behavior as an outcome—direct benefits on the child	High confidence	"He's got a lot more eye contact, a lot more communication, like verbally and non-verbally." (Carr & Lord, 2016)	Carr & Lord (2016), de Korte et al. (2022), Donaldson et al. (2011), Furukawa et al. (2018), Hodgson et al. (2018), Leadbitter et al. (2020), Palmer et al. (2020), Peckett et al. (2016), Rogerson et al. (2019), Stadnick et al. (2012), Stahmer et al. (2017)
Improvement of family relationships and interactions	High confidence	"Our relationship now is. . . actually very strong. . . I know how to reach him and how to interact with him and how to have fun with him. . . he seems to be coming along every day. . . just something new every day. He's coming out of his shell a little bit more and he does interact with us and it's. . . its good." (Donaldson et al., 2011)	Amsbary et al. (2020), Carr & Lord (2016), de Korte et al. (2022), Donaldson et al. (2011), Furukawa et al. (2018), Leadbitter et al. (2020), Nilses et al. (2019), Peckett et al. (2016)
Empowerment of the caregivers, feeling more confident about parenting skills	High confidence	"I was very insecure about myself and my parenting skills concerning [child's name], because I tried so much and nothing seemed to help. . . I became more self-confident and now I'm like 'I'm not doing anything wrong, but there are some adjustments possible.'" (de Korte et al., 2022)	Carr & Lord (2016), de Korte et al. (2022), Donaldson et al. (2011), Furukawa et al. (2018), Hodgetts et al. (2013), Hodgson et al. (2018), Pickard et al. (2016), Rogerson et al. (2019)
Parents as agent of change, high involvement of the parent during intervention	High confidence	"They [traditional early interventionists] write up a plan, they decide. . . When [the parent-mediated intervention professional] is here. . . we come up with a plan together. . . Because I come up with it, I'm more willing to do it" (Schertz et al., 2020)	Chlebowski et al. (2018), Divan et al (2015), Hodgson et al. (2018), Schertz et al. (2020), Stadnick et al. (2012), Stahmer et al. (2017)

(Continued)

Table 3. (Continued)

Categories	CerQUAL confidence	Related quote	Studies
Gained skills to support child development	High confidence	"I also learnt. So, not just to bring, let him join. Then, we also have to guide. This is very important. To guide him. Tell him what to do, make, making a friend. That's very important" (Ong et al., 2021)	Amsbary et al. (2020), Ong et al. (2021), Parson et al. (2019), Peckett et al. (2016), Schertz et al. (2020), Stadnick et al. (2012)
Understanding and acceptance of the child's impairments	High confidence	"not only speech, his communication and interaction are equally important" (Manohar et al., 2020)	Carr & Lord (2016), de Korte et al. (2022), Hodgetts et al. (2013), Leadbitter et al. (2020), Manohar et al. (2020), Ong et al. (2021), Palmer et al. (2020), Peckett et al. (2016), Schertz et al. (2020)
Limited knowledges on ASD and related services before intervention	High confidence	"At first I thought he has to see a doctor to have an examination to sort out the problem. . .. It's something he has . . . somewhere he's in pain . . . or suffers from some kind of disease . . . but I was never aware of any autism . . . That didn't exist in my mind, those kind of diseases. . ." (Nilses et al., 2019)	Carr & Lord (2016), Chlebowski et al. (2018), Hodgson et al. (2018), Nilses et al. (2019), Ong et al. (2021), Patterson & Smith (2011)
Lack of improvement due to child's factors	Moderate confidence	"I was expecting that it would help more with social skills, I guess. . . He found it too slow, too boring and I guess that's because of his level of functioning compared to other children." (Rogerson et al., 2019)	Ong et al. (2021), Patterson & Smith (2011), Rogerson et al. (2019), Schertz et al. (2020)
Improvement of parent well-being (decrease in parental stress)	Moderate confidence	"I'm a lot calmer and I don't scream at him anymore. More in control" (Palmer et al., 2020)	Furukawa et al. (2018), Manohar et al. (2020), Palmer et al. (2020), Stahmer et al. (2017)
Advocacy	Very low confidence	"I try get awareness out as much as I can. . . people will ask me questions and I'm like okay, hold on let me make sure I'm giving you the right information." (Carr & Lord, 2016)	Carr & Lord (2016), de Korte et al. (2022)
Feeling overwhelmed and stressed: a need for support			
Need of external support during and after the intervention process	High confidence	"I think we would have been okay up to a point and then at the end it would have been really, really tough putting it together, because that is when I really relied on the coach." (Pickard et al., 2016)	Dababnah & Parish (2016), Furukawa et al. (2018), Nilses et al. (2019), Parson et al. (2019), Pickard et al. (2016), Rogerson et al. (2019), Ong et al. (2021)
A need to include the extended family and the social network in the intervention implementation	High confidence	"[My partner attending] would've helped me to feel more supported . . . [A] lot of the moms I met are the ones doing the up-front work [on ASD]. I feel like if the other spouse or partner was involved . . . it would lend some credence to some of the stuff on the autism front . . . I feel that sometimes that exposure to someone other than your spouse relaying all of this information . . . can be a nice way to bring couples closer together." (Dababnah & Parish, 2016)	Amsbary et al. (2020), Dababnah & Parish (2016), de Korte et al. (2022), Hodgson et al. (2018), Ong et al. (2021)

(Continued)

Table 3. (Continued)

Categories	CerQUAL confidence	Related quote	Studies
Feeling overwhelmed and the need to go slow at the beginning	High confidence	"Yeah, to me at times it seemed like you go over stuff each session, but then they give you time to ask questions and stuff but then, there were still questions that didn't get answered, sometimes I felt like I left without knowing something. . . I wanted to ask more about it but we didn't have time so I guess. . . maybe we need a longer period of time, cover less aspects in one night so you have more time to discuss it. . ." (Patterson & Smith, 2011)	Amsbary et al. (2020), Dababnah & Parish (2016), Patterson & Smith (2011)
Accepting diagnosis/ postdiagnostic phase is difficult	High confidence	"I already knew most of it so I wasn't shocked really. It was hard to take at first" (Carr & Lord, 2016)	Carr & Lord (2016), Donaldson et al. (2011), Nilses et al. (2019), Ong et al. (2021)
Conflicting feeling: between hope and concerns	High confidence	"We're not worried any more, never . . . We were before, when this whole thing started, but these past six months . . . this past year, our feelings have changed." (Nilses et al., 2019)	Carr & Lord (2016), de Korte et al. (2022), Donaldson et al. (2011), Furukawa et al. (2018), Leadbitter et al. (2020), Manohar et al. (2020), Nilses et al. (2019), Patterson & Smith (2011), Rogerson et al. (2019)
Parent-to-parent support: share experience, group benefits	High confidence	"It helped me to interact with the other families. It taught me that I wasn't alone, there are many people going through the same struggles. At the beginning, I thought I was basically by myself you know, dealing with this but actually it's nice to have a group setting and to have other people views and opinions. . ." (Patterson & Smith, 2011)	Dababnah & Parish (2016), de Korte et al. (2022), Hodgson et al. (2018), Ong et al. (2021), Palmer et al. (2020), Patterson & Smith (2011)
Need for parents self-care	High confidence	"Market [the program] as how to help your children. You'd have to trick us into [focusing on ourselves]! It feels so selfish, but . . . when you get on the scale and you gained 40 pounds, or when you realize you've been collecting records and you haven't listened to them in over a year . . . That's pretty depressing . . . Then for me, you get resentful of your life . . . when you see your partner doing something enjoyable, you're like, "How dare you?" Just all of this stuff, please include it more." (Dababnah & Parish, 2016)	Dababnah & Parish (2016), Nilses et al. (2019), Patterson & Smith (2011)
Need for complementary interventions	Moderate confidence	"Maybe not this particular intervention but the next step maybe, in some kind of social skills groups." (Amsbary et al., 2020)	Amsbary et al. (2020), Carr & Lord (2016), Parson et al. (2019)
Need for more of the same intervention	Moderate confidence	"More on helping to make friends and developing theory of mind. Social skills training would have been really helpful. The social stories were helpful and some of the books but there need to be more. We're working on theory of mind with my child now and there are things that you can do." (Palmer et al., 2020)	Dababnah & Parish (2016), Palmer et al. (2020)
Importance of early intervention	Very low confidence	"I read that it's better if you find out and get your child help when they're young because they actually may have signs of it at all time but they can be live to be productive normal people" (Carr & Lord, 2016)	Carr & Lord (2016), Pickard et al. (2016)

Categories have been classified by level of confidence inside each synthesized finding. ASD: autism spectrum disorder.

concerns, from the beginning to the end of the training. They described the need for parents' self-care to support the burden of their situation and evoked that parent-to-parent support, with the possibility of sharing experiences, was or could be helpful. For group intervention, parents described the benefits of sharing with other parents, as long as the group was not too big.

Along with the emotional struggles, parents described the need for support. First, they explained the need to include the extended family and social network in the intervention implementation. Parents, and notably mothers, reported that including the child's siblings, the partner, and/or the grandparents would help them feel supported and make it easier to implement the intervention. They also underlined the need for external support during and after the intervention process. Parents evoked that having regular contact with a professional was essential to respond to any questions and to feel supported. In studies where the intervention was self-guided through a tablet application, parents described the importance of having a coach to help them. Parents also pointed out the anxiety they felt at the end of the program, unsure they would be able to continue implementing the intervention without the therapist.

Along with these worries, parents indicated the need for more of the same intervention. Parents reported they would have enjoyed an "advanced program" in some situations. They felt the program was not covering every difficulty related to autism and that, for some families, additional content would be necessary. After going through different interventions (individual PMI or self-guided PMI), parents evoked the need for complementary interventions to focus on other aspects of ASD.

Synthesized Finding 3: facilitators of implementation. Parents described several factors that enhanced the implementation of the PMI in their daily life. They indicated that the positive parent–therapist relationship, and notably the trust in the therapist, was an essential factor in their adherence to the therapy. In most studies, the relationship between parents and the therapist was described as strong, personalized, and cheerful, with the feeling of being understood. As seen previously, some parents felt, on the contrary, stressed by the therapist. This variability could be explained by the heterogeneity in the included populations and the type of interventions.

Along with this, the content and tools used in the PMI were also described as facilitators. Parents reported that the treatment planning process was effective as it was systematic: one step at a time.

They enjoyed using reflective techniques in the therapy (role-play, feedback) and the use of video-feedback. They described the importance of watching themselves interact with their child to later adjust the interaction.

While some parents have described difficulties in finding time to implement the intervention, others considered the intervention as feasible and easy to implement in routine. Parents explained how they implemented the learned tools in their daily life and how they organized their day to be able to practice the intervention.

Synthesized Finding 4: empowerment in the parent and improvement in the child. While describing their global experience of PMI, the parents described several positive outcomes.

Parents reported that they had limited knowledge of ASD and related services before intervention; this was corrected by the intervention that gave them understanding and acceptance of their child's impairments and specific skills to support child development. They understood, for example, that interaction skills are as essential as language or that following the child's interests can lead to improvement in interaction. Parents developed a sense of ASD advocacy and used their new knowledge to help other families.

These new skills made them more confident about their parenting skills and brought a feeling of empowerment after the intervention. Parents acknowledged that their high involvement during the intervention was essential and described themselves as agents of change.

Even if the intervention was demanding for the parents, it improved parents' well-being and decreased parental stress. A general improvement of family relationships and interactions was described by the parents.

Concerning intervention outcomes, parents also described that interventions had direct benefits on their child with an improvement in child behavior. This improvement was noted in verbal and nonverbal communication, repetitive behavior, and challenging behavior. Unfortunately, for some families, improvement was not observed; this was sometimes attributed to the child's factors.

Discussion

Summary of main results and comparison with literature

By pooling the main findings of 23 studies, our study synthesized the voices of 345 parents who experienced PMI for their child with ASD. Many parents reported a global feeling of empowerment and improvements in their children. They described the PMI as feasible and underlined the facilitators of implementation. The parent–therapist relationship was described as an important factor for obtaining the full participation of parents in the intervention. Systematic intervention with a well-described process and a step-by-step approach was appreciated by the parents and the reflective techniques used by the therapists.

Besides those positive reports, many parents emphasized the emotional toll of the situation on themselves. They stated that PMI needs to be carried out alongside

support for parents' mental health and well-being. Parents highlighted some barriers to PMI interventions that could be addressed in practice and future studies.

Implication for practice

Recent implementation science studies suggest that evidence-based treatments for ASD often do not get appropriately transported to real-world practice settings (Wainer et al., 2017). Focusing on parent-level variables as meaningful outcomes and/or moderators could increase the effective implementation of evidence-based interventions in the "real world," as demonstrated in the disruptive behavior (Pickard et al., 2019). Therefore, parents' experience of PMI in ASD should be used to inform future intervention models and the main findings of our study could be used to inform future guidelines.

The findings of our study provide evidence that self-guided intervention needs to include an element of coaching from a professional as the relationship with the therapist is described as a key facilitator of intervention. There is a need to consider how PMI should be included in an individualized intervention plan using a stepped-care framework (Green, 2019). PMI should promote parents' self-efficacy and lead to parents' understanding of their abilities. This first step is essential to help them promote child engagement, which is the main objective of PMI.

Parents sometimes report feeling overwhelmed and stressed after the diagnosis of their child but also, during the intervention process, psychoeducation or "post-diagnosis" support could be recommended before the beginning of PMI. Offering systematic parent care or support along with the intervention program could also help decrease parental stress and promote resilience (Zhao et al., 2021). Support during the intervention can also come from peers and parent-to-parent support programs could be developed. It is important to remember the holistic needs of parents in the intervention process.

Balancing work, family, and demands associated with caring for a child with ASD can be challenging. In our study, parents described how difficult it could be to find time for the training and implementation of the intervention. An intervention should not require a parent to give up employment or personal interests. The clinician should propose the PMI when the timing is suitable for the family and subsequently adapt the PMI to the context of the family (McConnell et al., 2015). Personalization in the choice of intervention could lead to better implementation outcomes. Concerning group-based intervention, it seems important to consider the diversity in ASD and create intervention groups in which children share specific features, such as language or intellectual abilities.

Our review has brought to light the feeling of "empowerment" gained by parents participating in PMI. Empowerment is essential to shared decision-making in health care that often has the potential to enhance outcomes and to be cost-effective. While shared decision-making generally leads to improved outcomes, some individuals prefer to leave decision-making in the hands of professionals (Levinson et al., 2005). It is also important to note that empowerment does not mean putting responsibility in parents' hands but guiding them to make their own decisions.

Implications for research

Most research focuses on the effectiveness of PMI intervention in reducing autistic symptoms. Improving social communication skills is undoubtedly important; however, other intervention goals are also valuable. Parents' perceptions and experiences of an intervention should be sought using qualitative methods and this focus should be included alongside effectiveness studies. The ECO-Framework (Wainer et al., 2017) proposes a reflection on important outcomes for families in the field of early intervention in ASD and describes the need to assess different domains: immediate family outcome (knowing their rights and advocacy, understanding the child's strengths and special needs, helping their child to develop and learn, having support systems, and gaining access to desired services and activities), outcome (quality of life), and intermediate outcome (family interaction, parenting, and well-being).

Strengths and limitations

The strengths of our study are that we used a two-step robust systematic search strategy to identify studies with a sensitive approach conducted by two independent reviewers to ensure the inclusion of all relevant articles; recent guidelines informed our methodology on conducting a meta-synthesis and the quality of included studies was assessed with a validated tool. We used transparent and reproducible methods, including preregistration. Qualitative studies do not aim to be representative but can fill "gaps" in our understanding that are not resolved by the quantitative research (Sandelowski, 2004). Within the meta-synthesis approach, we deeply describe the population of the different studies to enable future comparison and external application of our results. An assessment of confidence in our results has been provided. Heterogeneity in the results has also been described.

Our work also has some limitations. The synthesis was limited to interview (semi-structured interview) and focus group studies only and did not include other qualitative methodologies, such as open-ended questions in questionnaires as they are less likely to generate a rich and detailed description of participant experience with context, personal experience, and social meaning. We chose to exclude survey-generated data to avoid great heterogeneity in the selected methodologies (LaDonna et al., 2018).

Two researchers conducted the synthesis collaboratively and discussed it with a third author rather than being operated independently. The discussion among the three researchers aimed to validate that the categories and synthesized findings were close to the original findings of the included articles and that findings were appropriately classified in the different categories. If the first authors misunderstood or misclassified findings, the third opinion enabled correction. A meta-synthesis is an analysis based on previously analyzed data and depends on the subjective interpretation of the original study's authors. This limitation was partly addressed by considering good quality qualitative research with the help of the CASP. Thus, it is still possible that the original interpretation was not informed by the context and did not necessarily reflect a deep understanding of the studied phenomenon.

The results and recommendations of meta-synthesis are interpretations made by a group of researchers with their assumptions and biases. To enable the reader to understand those interpretations better, a description of the team's background is described in the Supplemental Material. Results were discussed with a multidisciplinary team with diverse expertise in PMI.

A frequent criticism of meta-synthesis is the lack of contextual detail and the loss of original diversity of experiences. Meta-synthesis should be considered a tool to recognize the importance of qualitative studies and highlight shared opinions on a shared experience across a diverse population. Our work included studies focusing on different interventions across various countries and periods. It was striking how similar themes were presented across numerous studies, despite the diverse populations and interventions, and this provides confidence in the applicability of the results.

Conclusion

In this review, parental experiences of PMI for their child with ASD are deeply described. Parents highlight how PMI can lead to feelings of empowerment and positive outcomes for their children. They also raise critical questions about the implementation (barriers and facilitators) "adverse effects" of these nonpharmacological interventions. Still, mostly, they are keys to improving their child's care and support in the future.

Author contributions

L.J. designed the study, collected the data, conducted the analyses, wrote the manuscript, and designed the figures. K.L. designed the study, conducted the analyses, and wrote the manuscript. B.F. participated in results interpretation and wrote the manuscript. C.C. participated in results interpretation and wrote the manuscript. S.T. participated in results interpretation and wrote the manuscript. M.-M.G. designed the study, collected the data, participated in results interpretation, and wrote the manuscript.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: Grant by the Caisse Nationale de solidarité pour l'autonomie (CNSA) as part of the call for projects launched for IReSP (Institut de Recherche en Santé Publique) in 2016 in collaboration with the Institut national de la santé et de la recherche médicale (Inserm; IReSP-17-Autisme3-16) funded the qualitative study done in parallel of an ongoing randomized controlled trial about the efficacy of a PMI. We did this meta-synthesis before launching this new qualitative study.

ORCID iDs

Lucie Jurek https://orcid.org/0000-0001-7568-568X

Kathy Leadbitter https://orcid.org/0000-0002-0744-2800

Data availability

Data are available in the supplemental material and upon request to the corresponding author.

Supplemental material

Supplemental material for this article is available online.

References

Amsbary, J., Able, H., Schertz, H. H., & Odom, S. L. (2020). Parents' voices regarding using interventions for toddlers with autism spectrum disorder. *Journal of Early Intervention*, *43*, 38–59. https://doi.org/10.1177/1053815120910744

Bearss, K., Burrell, T. L., Stewart, L., & Scahill, L. (2015). Parent training in autism spectrum disorder: What's in a name? *Clinical Child and Family Psychology Review*, *18*(2), Article 170182. https://doi.org/10.1007/s10567-015-0179-5

Blake, J. M., Rubenstein, E., Tsai, P. C., Rahman, H., Rieth, S. R., Ali, H., & Lee, L. C. (2017). Lessons learned while developing, adapting and implementing a pilot parent-mediated behavioural intervention for children with autism spectrum disorder in rural Bangladesh. *Autism: The International Journal of Research and Practice*, *21*(5), 611–621. https://doi.org/10.1177/1362361316683890

Bölte, S. (2014). The power of words : Is qualitative research as important as quantitative research in the study of autism? *Autism*, *18*(2), 67–68. https://doi.org/10.1177/1362361313517367

Booth, A. (2016). Searching for qualitative research for inclusion in systematic reviews: A structured methodological review. *Systematic Reviews*, *5*(1), Article 74. https://doi.org/10.1186/s13643-016-0249-x

Booth, A., Noyes, J., Flemming, K., Gerhardus, A., Wahlster, P., van der Wilt, G. J., Mozygemba, K., Refolo, P., Sacchini, D., Tummers, M., & Rehfuess, E. (2018). Structured methodology review identified seven (RETREAT) criteria for selecting qualitative evidence synthesis approaches.

Journal of Clinical Epidemiology, *99*, 41–52. https://doi.org/10.1016/j.jclinepi.2018.03.003

Boyd, B. A., Odom, S. L., Humphreys, B. P., & Sam, A. M. (2010). Infants and toddlers with autism spectrum disorder: Early identification and early intervention. *Journal of Early Intervention*, *32*(2), 75–98. https://doi.org/10.1177/1053815110362690

Butler, A., Hall, H., & Copnell, B. (2016). A guide to writing a qualitative systematic review protocol to enhance evidence-based practice in nursing and health care: The qualitative systematic review protocol. *Worldviews on Evidence-based Nursing*, *13*(3), 241–249. https://doi.org/10.1111/wvn.12134

Carr, T., & Lord, C. (2016). A pilot study promoting participation of families with limited resources in early autism intervention. *Research in Autism Spectrum Disorders*, *2*, 87–96. https://doi.org/10.1016/j.rasd.2016.02.003

Carroll, C., Booth, A., & Lloyd-Jones, M. (2012). Should we exclude inadequately reported studies from qualitative systematic reviews? An evaluation of sensitivity analyses in two case study reviews. *Qualitative Health Research*, *22*(10), 1425–1434. https://doi.org/10.1177/1049732312452937

Chandler, S., Christie, P., Newson, E., & Prevezer, W. (2002). Developing a diagnostic and intervention package for 2- to 3-year-olds with autism: Outcomes of the frameworks for communication approach. *Autism: The International Journal of Research and Practice*, *6*(1), 47–69. https://doi.org/10.1177/1362361302006001005

Chlebowski, C., Magaña, S., Wright, B., & Brookman-Frazee, L. (2018). Implementing an intervention to address challenging behaviors for autism spectrum disorder in publicly-funded mental health services: Therapist and parent perceptions of delivery with Latinx families. *Cultural Diversity and Ethnic Minority Psychology*, *24*(4), 552–563. https://doi.org/10.1037/cdp0000215

Dababnah, S., & Parish, S. L. (2016). Feasibility of an empirically based program for parents of preschoolers with autism spectrum disorder. *Autism: The International Journal of Research and Practice*, *20*(1), 85–95. https://doi.org/10.1177/1362361314568900

Dawson, G. (2008). Early behavioral intervention, brain plasticity, and the prevention of autism spectrum disorder. *Development and Psychopathology*, *20*(3), 775–803. https://doi.org/10.1017/S0954579408000370

de Korte, M. W. P., Kaijadoe, S. P. T., Buitelaar, J. K., Staal, W. G., & van Dongen-Boomsma, M. (2022). Pivotal response treatment (PRT): Parent group training for young children with autism spectrum disorder: A qualitative study on perspectives of parents. *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-021-05397-8

DePape, A.-M., & Lindsay, S. (2015). Parents' experiences of caring for a child with autism spectrum disorder. *Qualitative Health Research*, *25*(4), 569–583. https://doi.org/10.1177/1049732314552455

Divan, G., Hamdani, S. U., Vajartkar, V., Minhas, A., Taylor, C., Aldred, C., Leadbitter, K., Rahman, A., Green, J., & Patel, V. (2015). Adapting an evidence-based intervention for autism spectrum disorder for scaling up in resource-constrained settings: The development of the PASS intervention in South Asia. *Global Health Action*, *8*, Article 27278. https://doi.org/10.3402/gha.v8.27278

Donaldson, S. O., Elder, J. H., Self, E. H., & Christie, M. B. (2011). Fathers' perceptions of their roles during in-home training for children with autism. *Journal of Child and Adolescent Psychiatric Nursing: Official Publication of the Association of Child and Adolescent Psychiatric Nurses*, *24*(4), 200–207. https://doi.org/10.1111/j.1744-6171.2011.00300.x

Green, J. (2019). Editorial Perspective : Delivering autism intervention through development. *Journal of Child Psychology and Psychiatry*, *60*(12), 1353–1356. https://doi.org/10.1111/jcpp.13110

Hannes, K. (2011). Critical appraisal of qualitative research. In *Supplementary guidance for inclusion of qualitative research in Cochrane Systematic Reviews of Interventions* (Version 1). Cochrane Collaboration Qualitative Methods Group. http://cqrmg.cochrane.org/supplemental-handbook-guidance

Hannes, K., & Lockwood, C. (2011). Pragmatism as the philosophical foundation for the Joanna Briggs meta-aggregative approach to qualitative evidence synthesis: Pragmatism in the Joanna Briggs meta-aggregative approach. *Journal of Advanced Nursing*, *67*(7), 1632–1642. https://doi.org/10.1111/j.1365-2648.2011.05636.x

Koegel, R. L., Koegel, L. K., & McNerney, E. K. (2001). Pivotal areas in intervention for autism. *Journal of Clinical Child and Adolescent Psychology*, *30*(1), 19–32. https://doi.org/10.1207/S15374424JCCP3001_4

LaDonna, K. A., Taylor, T., & Lingard, L. (2018). Why open-ended survey questions are unlikely to support rigorous qualitative insights. *Academic Medicine*, *93*(3), 347–349. https://doi.org/10.1097/ACM.0000000000002088

Leadbitter, K., Aldred, C., McConachie, H., Le Couteur, A., Kapadia, D., Charman, T., Macdonald, W., Salomone, E., Emsley, R., & Green, J. (2018). The Autism Family Experience Questionnaire (AFEQ): An ecologically-valid, parent-nominated measure of family experience, quality of life and prioritised outcomes for early intervention. *Journal of Autism and Developmental Disorders*, *48*(4), 1052–1062. https://doi.org/10.1007/s10803-017-3350-7

Leadbitter, K., Macdonald, W., Taylor, C., Buckle, K. L., & the PACT Consortium. (2020). Parent perceptions of participation in a parent-mediated communication-focussed intervention with their young child with autism spectrum disorder. *Autism*, *24*(8), 2129–2141. https://doi.org/10.1177/1362361320936394

Levinson, W., Kao, A., Kuby, A., & Thisted, R. A. (2005). Not all patients want to participate in decision making: A national study of public preferences. *Journal of General Internal Medicine*, *20*(6), 531–535. https://doi.org/10.1111/j.1525-1497.2005.04101.x

Lewin, S., Bohren, M., Rashidian, A., Munthe-Kaas, H., Glenton, C., Colvin, C. J., Garside, R., Noyes, J., Booth, A., Tunçalp, Ö., Wainwright, M., Flottorp, S., Tucker, J. D., & Carlsen, B. (2018). Applying GRADE-CERQual to qualitative evidence synthesis findings—paper 2: How to make an overall CERQual assessment of confidence and create a Summary of Qualitative Findings table. *Implementation Science*, *13*(S1), Article 10. https://doi.org/10.1186/s13012-017-0689-2

Lewin, S., Booth, A., Glenton, C., Munthe-Kaas, H., Rashidian, A., Wainwright, M., Bohren, M. A., Tunçalp, Ö., Colvin, C. J., Garside, R., Carlsen, B., Langlois, E. V., & Noyes, J. (2018). Applying GRADE-CERQual to qualitative evidence

synthesis findings: Introduction to the series. *Implementation Science*, *13*(S1), Article 2s13012. https://doi.org/10.1186/s13012-017-0688-3

Lockwood, C., Munn, Z., & Porritt, K. (2015). Qualitative research synthesis: Methodological guidance for systematic reviewers utilizing meta-aggregation. *International Journal of Evidence-based Healthcare*, *13*(3), 179–187. https://doi.org/10.1097/XEB.0000000000000062

Manohar, H., Kandasamy, P., Chandrasekaran, V., & Rajkumar, R. P. (2020). Can RCTs capture it all?—Need for qualitative studies on parent-mediated interventions for children with Autism Spectrum Disorder. *Asian Journal of Psychiatry*, *48*, Article 101915. https://doi.org/10.1016/j.ajp.2019.101915

McConnell, D., Parakkal, M., Savage, A., & Rempel, G. (2015). Parent-mediated intervention: Adherence and adverse effects. *Disability and Rehabilitation*, *37*(10), 864–872. https://doi.org/10.3109/09638288.2014.946157

Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *Journal of Clinical Epidemiology*, *62*(10), 1006–1012. https://doi.org/10.1016/j.jclinepi.2009.06.005

Nilses, Å., Jingrot, M., Linnsand, P., Gillberg, C., & Nygren, G. (2019). Experiences of immigrant parents in Sweden participating in a community assessment and intervention program for preschool children with autism. *Neuropsychiatric Disease and Treatment*, *15*, 3397–3410. https://doi.org/10.2147/NDT.S221908

Ong, S. Y., Roslan, S., Ahmad, N. A., Ayub, A. F. M., Chen, L. P., & Taresh, S. M. (2021). Parents' experience in children's friendship training programme for their children with autism spectrum disorder: A qualitative inquiry. *Children*, *8*(9), Article 763. https://doi.org/10.3390/children8090763

Oono, I. P., Honey, E. J., & McConachie, H. (2013). Parent-mediated early intervention for young children with autism spectrum disorders (ASD). *Cochrane Database of Systematic Reviews*, *2013*, Article CD009774. https://doi.org/10.1002/14651858.CD009774.pub2

Palmer, M., San José Cáceres, A., Tarver, J., Howlin, P., Slonims, V., Pellicano, E., & Charman, T. (2020). Feasibility study of the National Autistic Society EarlyBird parent support programme. *Autism: The International Journal of Research and Practice*, *24*(1), 147159. https://doi.org/10.1177/1362361319851422

Patterson, S. Y., & Smith, V. (2011). The experience of parents of toddlers diagnosed with autism spectrum disorder in the more than words parent education program. *Infants and Young Children*, *24*(4), 329–343. https://doi.org/10.1097/IYC.0b013e31822c10e4

Pickard, K. E, Rowless, S., & Ingersoll, B. (2019). Understanding the impact of adaptations to a parent-mediated intervention on parents' ratings of perceived barriers, program attributes, and intent to use. *Autism*, *23*(2), 338–349. https://doi.org/10.1177/1362361317744078

Pickard, K. E., Wainer, A. L., Bailey, K. M., & Ingersoll, B. R. (2016). A mixed-method evaluation of the feasibility and acceptability of a telehealth-based parent-mediated intervention for children with autism spectrum disorder. *Autism*, *20*(7), 845–855. https://doi.org/10.1177/1362361315614496

Pickles, A., Le Couteur, A., Leadbitter, K., Salomone, E., Cole-Fletcher, R., Tobin, H., Gammer, I., Lowry, J., Vamvakas, G., Byford, S., Aldred, C., Slonims, V., McConachie, H., Howlin, P., Parr, J. R., Charman, T., & Green, J. (2016). Parent-mediated social communication therapy for young children with autism (PACT): Long-term follow-up of a randomised controlled trial. *Lancet (London, England)*, *388*(10059), 2501–2509. https://doi.org/10.1016/S0140-6736(16)31229-6

Rogerson, J., Falkmer, M., Cuomo, B., Falkmer, T., Whitehouse, A. J. O., Granich, J., & Vaz, S. (2019). Parental experiences using the Therapy Outcomes by You (TOBY) application to deliver early intervention to their child with autism. *Developmental Neurorehabilitation*, *22*(4), 219–227. https://doi.org/10.1080/17518423.2018.1440259

Sandelowski, M. (2004). Using qualitative research. *Qualitative Health Research*, *14*(10), 1366–1386. https://doi.org/10.1177/1049732304269672

Schertz, H. H., Baker, C., Hurwitz, S., & Benner, L. (2011). Principles of early intervention reflected in toddler research in autism spectrum disorders. *Topics in Early Childhood Special Education*, *31*(1), 4–21. https://doi.org/10.1177/0271121410382460

Schertz, H. H., Lester, J. N., Erden, E., Safran, S., & Githens, P. (2020). Challenges and contributors to self-efficacy for caregivers of toddlers with autism. *Autism: The International Journal of Research and Practice*, *24*, 1260–1272. https://doi.org/10.1177/1362361319899761

Stahmer, A. C., Brookman-Frazee, L., Rieth, S. R., Stoner, J. T., Feder, J. D., Searcy, K., & Wang, T. (2017). Parent perceptions of an adapted evidence-based practice for toddlers with autism in a community setting. *Autism: The International Journal of Research and Practice*, *21*(2), 217–230. https://doi.org/10.1177/1362361316637580

Tong, A., Flemming, K., McInnes, E., Oliver, S., & Craig, J. (2012). Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Medical Research Methodology*, *12*(1), Article 181. https://doi.org/10.1186/1471-2288-12-181

Wainer, A. L., Hepburn, S., & McMahon Griffith, E. (2017). Remembering parents in parent-mediated early intervention: An approach to examining impact on parents and families. *Autism*, *21*(1), 5–17. https://doi.org/10.1177/1362361315622411

Zand, D. H., Bultas, M. W., McMillin, S. E., Halloran, D., White, T., McNamara, D., & Pierce, K. J. (2018). A pilot of a brief positive parenting program on children newly diagnosed with autism spectrum disorder. *Family Process*, *57*(4), 901–914. https://doi.org/10.1111/famp.12334

Zhao, M., Fu, W., & Ai, J. (2021). The mediating role of social support in the relationship between parenting stress and resilience among Chinese parents of children with disability. *Journal of Autism and Developmental Disorders*, *51*, 3412–3422. https://doi.org/10.1007/s10803-020-04806-8