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ORIGINAL PAPER

Underrepresented Caregivers in Research on Prenatal Alcohol Exposure: A Meta-Analysis and Scoping Review

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Abstract

Objectives Families of children with prenatal alcohol exposure (PAE) are diverse, raising children through birth, adoption, or fostering, including kinship care. Research has shown that caregivers of children with PAE often experience unique difficulties with parenting, which may differ across types of caregivers. Understanding the range of needs of these families is critical for program development; therefore, it is important to know which caregivers are represented in this research and how.

Methods The current meta-analysis and scoping review examined the demographic characteristics of caregivers and children included in quantitative PAE caregiver-related research. Systematic database searches using key terms led to the inclusion of 15 relevant studies involving 593 participants in total.

Results Most caregivers in the studies were adoptive parents, female, middled-aged, White, partnered, had obtained a high school education or higher, and resided in the United States. Most studies included caregivers of school-aged children diagnosed with FASD. Most studies recruited participants through pre-established lists and databases, collected data in person and for research purposes, and studied parenting stress. Attempts to study differences in representation based on research methods were unsuccessful due to a lack of differences within the literature.

Conclusions The results of this study suggest that (a) non-adoptive parents, (b) caregivers who were male, non-White, non-partnered, less educated, and living outside of the United States, and (c) caregivers of adolescents, and caregivers raising children with PAE who have not received an FASD diagnosis are currently underrepresented in the research; however, this literature is limited and requires further research.

Keywords Fetal Alcohol Spectrum Disorder · Prenatal Alcohol Exposure · Caregiver Research · Sample Characteristics · Research Methods

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Prenatal alcohol exposure (PAE) can cause various developmental challenges across a child's lifespan. According to the most recent Canadian guidelines, an individual may receive a diagnosis of Fetal Alcohol Spectrum Disorder (FASD) if there is confirmed PAE and significant challenges in at least three neurodevelopmental domains (see Cook et al., 2016 for full diagnostic criteria). Current FASD prevalence rates are estimated at 2–5% in the United States (May et al., 2018) and 4% in Canada (Flannigan et al., 2018). Along with cognitive and behavioral challenges, children with PAE often experience a range of adverse life experiences, including difficulties with school, substance problems, criminality, employment issues, and housing and living support needs (McLachlan et al., 2020; Streissguth et al., 2004). Mental health concerns are also high in this population, as 90% of children with FASD experience a co-occurring diagnosis (Clark et al., 2004), with attention-deficit/hyperactivity disorder (ADHD) being one of the most common (Cheung et al., 2021; Cook, 2022; Weyrauch et al., 2017).

Despite the various challenges and adverse life experiences that individuals with FASD experience, research has outlined many strengths. Children with PAE are described as having loving and affectionate relationships with caregivers and peers (Kautz-Turnbull et al., 2022, p. 359). A positive disposition is apparent in many children with PAE as they express pride and confidence as a result of their resilience towards life challenges (Flannigan et al., 2021).

Families also report many positive impacts while raising a child with PAE. A study by Kautz-Turnbull et al. (2022), described how the increased caregiver support needed while raising a child with PAE resulted in more family time which strengthened family unity and interpersonal relationships. These caregivers reported emotional fulfillment during family-time and personal fulfilment from learning new parenting-skills and watching their children overcome the challenges associated with PAE. The neurodevelopmental challenges and adverse life experiences associated with PAE can also cause several challenges for families of children and adolescents with FASD. Caregivers describe disruption in the family unit when navigating how to best support their child (Balcaen et al., 2021; Mukherjee et al., 2013; Sanders and Buck, 2010). Indeed, Sanders and Buck (2010) found that symptoms associated with FASD contribute to a disordered home atmosphere creating tension between family members. As a result, caregivers have reported family breakdown—including divorce—because of stress, spousal difficulties, lack of support, and social isolation (Mukherjee et al., 2013; Sanders and Buck, 2010). High levels of parenting stress are apparent in these families, with most caregivers reporting clinically elevated levels of parenting stress (Ilchena et al., 2023; Jirikowic et al., 2012) and a diminished sense of competence (Mukherjee et al., 2013).

Families of children with FASD are uniquely diverse. Many children do not remain with their birth parents, being cared for by other family members and being in and out of family/foster care. Children with FASD enter child welfare programs at a younger age and remain in care longer than children with other disabilities (Fuchs et al., 2010). In Manitoba, 89% of children with FASD are placed in care compared to 61% of children with other disabilities (Fuchs et al., 2005). Recent data from the Manitoba FASD Centre also shows a high number of foster parents (50.5%), followed by kinship family members (18.2%), and birth mothers (16.1%; Cook, 2022) participating in the diagnostic assessment process; however, the Canadian National FASD database reflects more dispersed family types, with 27.7% of children in foster care, 27.7% with other family members, 20.5% with adoptive families, and 15.9% and 8.1% with birth mothers and birth fathers, respectively (Canada FASD Research Network, 2019).

Family research in other neurodevelopmental populations, such as ADHD and autism spectrum disorder (ASD), mainly consists of partnered birth parents with high socioeconomic status (Heath et al., 2015; Jones et al., 2013). However, this family structure is infrequent in families of children with FASD. Some research suggests that foster and adoptive families have unique experiences compared to birth families, such as additional changes and diversity inherent in caring for other children, often multiple other children, which can offer both benefits and challenges. Paley et al. (2006) also found that adoptive and foster parents reported higher stress levels regarding their child's characteristics. In contrast, birth and single parents reported higher stress levels regarding their own functioning as parents and additional life and parent stressors beyond stressors relating to their child.

Birth families of children with FASD may also differ from birth families of children without FASD. An American study found that families of children with FASD experienced more vulnerabilities that may impact caregiving responsibilities than their counterparts, such as lower income, lower education, mental health concerns, and unemployment issues (Cannon et al., 2012). A Canadian study also found that birth mothers of children with FASD had lower levels of education and were more likely to receive financial support during pregnancy than birth mothers of children without FASD (Popova et al., 2020). That said, the same study did not find differences in employment status between birth mothers and fathers of children with FASD and parents of children without FASD at the time of pregnancy. It is important to consider the social determinants related to intergenerational trauma, colonization practices, racism, forced assimilation, and social marginalization that communities experiencing elevated rates of prenatal alcohol exposure have experienced. Indeed, these factors have significantly and negatively impacted the mental well-being, employment, and educational opportunities of these populations (Bombay et al., 2009; MacDonald & Steenbeek, 2015; Menzies, 2019). Therefore, the vulnerabilities reported by birth mothers may not be unique to the caregiver status but rather due to a larger social and political problem.

Understanding the experiences of all family types is important to inform supports and prevent placement breakdown. Many children with FASD experience multiple family placements, which may negatively impact them (Burnside & Fuchs, 2013). For example, both adolescents with (Burnside & Fuchs, 2013) and without (Unrau et al., 2008) FASD report diminished self-worth, difficulties maintaining relationships, and internalized self-blame for failed family placements. Representative research is needed to understand the functioning of these families to promote secure homes.

The current literature lacks a comprehensive report on the representation of family characteristics in quantitative caregiver-research. Determining the representativeness of family-related research is important as it clarifies whose concerns are being captured and addressed. The present study focused on studies with quantitative caregiver-related outcomes because more quantitative research is needed about caregivers of children with PAE to test hypotheses and determine population-wide trends to create interventions for a wider audience. Understanding who is not being sought out, included, or represented in quantitative caregiver-related research will provide clinicians and researchers with insight into the generalizability of the current findings and directions for future researchers.

Researchers examining parenting stress in families of children with FASD often report poor generalizability, namely a lack of birth parent inclusion (Kautz et al., 2020; Mohamed et al., 2020; Petrenko et al., 2017). Considering the diversity among families of children with PAE, experiences may differ from caregiver type or within different backgrounds. For example, lower income reported in birth families can make support programs and resources inaccessible. Higher financial stress and a lack of support can cause tension between caregivers and subsequently lead to more conflict.

Additionally, birth parents experience more stigmatization and prejudices in the healthcare system (Corrigan et al., 2019) and may be exposed to various sources of stress outside of child-related stress. In comparison, adoptive parents typically have higher socioeconomic status and can seek out more respite support, counselling, educational programs, and health care resources (Miller et al., 2000). Similarly, children residing with foster parents may benefit from services being covered by the agency. However, adoptive and foster children may be more likely to have undiagnosed FASD due to unconfirmed PAE, which may prevent access to FASD-specific services (Bakhireva et al., 2018a; Chasnoff et al., 2015). Adoptive parents may need more assistance with finding and navigating available supports, obtaining an FASD diagnosis, and managing symptoms related to FASD (Bakhireva et al., 2018a; Paley et al., 2006; Petrenko et al., 2019). Although foster parents likely experience similar issues, they also have some unique experiences. For example, foster parents not being the legal guardian of the child prevents them from registering the child in programs without consent from a legal guardian. Additionally, family reunification being a goal in foster care can make planning for such interventions difficult as the length of placement may be undetermined. Foster parents may also be expected to assist in the reunification process by facilitating meetings between the child and their birth parents (Sanchirico & Jablonka, 2000). Organizing visitations can be difficult as contact between the birth parents and child may be stressful for both parties which can create tension and conflict between birth parents, foster parents and the child involved (Sanchirico & Jablonka, 2000).

Lastly, the experiences of extended family member caregivers (kinship caregivers) may also differ. Financial strain is often experienced by kinship caregivers, who do not receive financial support like foster parents and may not be provided with information and resources necessary to access available financial supports (Lee et al., 2016; Smith & Beltran, 2008). Difficulties with obtaining legal guardianship creates barriers when enrolling their child in school and accessing medical services (Lee et al., 2016; Smith & Beltran, 2008). Family strain is often reported between the kinship caregiver and the birth parents (Lee et al., 2016). Additionally, kinship caregivers are often grandparents with their own unique challenges. Grandparents report poor health conditions as they are not able to receive medical services as often while caring for a child (Smith & Beltran, 2008). Additionally, grandparents can feel lost raising a child in a new generation and may not relate to younger parents, increasing feelings of social isolation (Lee et al., 2016). Overall, the unique experiences between caregiver types need to be addressed and represented in the research to ensure that services and programs meet their needs.

Caregiver's age and gender should be considered as well. For example, Östberg and Hagekull (2000) found that older mothers reported higher levels of parenting stress than younger mothers. They considered that older mothers may find childcare more demanding after finishing a post-secondary education, starting a career, and adjusting to a life without caregiving responsibilities. Regarding gender, researchers have reported considerably more mothers than fathers in their samples of families of children with PAE (Kautz et al., 2020; Paley et al., 2005). Broadly speaking, middle-aged White partnered females with high levels of education are often more likely to be included in caregiver- or family-related research, including research regarding families of children with neurodevelopmental diagnoses, than their counterparts (e.g., Cheung & Theule, 2016; Hartley et al., 2019; Theule et al., 2013; Tseng et al., 2021). Though traditional gender roles are shifting, a disproportionate number of childcare responsibilities still fall onto female caregivers (Moyser & Burlock, 2018). Moreover, in some populations, mothers experience higher levels of parenting stress than fathers (Theule et al., 2013).

The representation of child characteristics, such as age, gender, FASD diagnosis, and co-occurring diagnoses, is essential as these factors may impact caregivers' experiences. Research on how a child's age impacts caregiver stress is mixed, with some studies showing a decrease in stress as children age (Roger, 2015) and others reporting the opposite (Kautz et al., 2020). Much of this research samples children between 1–12 years (Kautz et al., 2020; Paley et al., 2005, 2006; Petrenko et al., 2016). The age distribution of children in this research should be explored as the experiences of raising an adolescent with FASD are likely missed. Gender distribution should also be identified, as some studies report different symptoms associated with FASD depending on gender. For example, the experiences of raising male children with FASD may differ as they display more neurodevelopmental impairment than females. Co-occurring diagnoses also seem to differ between males and females with FASD (Flannigan et al., 2023). Determining the rate of caregivers of children with FASD in the samples may provide a sense of whether the research about caregivers of children with PAE narrowly focuses on caregivers of children diagnosed with FASD, as there may be differences in research participation between caregivers of children with PAE with and without FASD. Determining this rate will also provide insight into whether there is a gap in the research about caregivers of children with PAE. With respect to co-occurring diagnoses, researchers do not typically examine how other mental disorders influence caregiver stress (Ilchena et al., 2023). Determining the reported rate of co-occurring diagnoses will reveal if this topic requires further exploration.

Understanding how caregiver distribution differs across different methodological characteristics of studies (e.g., recruitment strategy, data collection methods, types of data collected, etc.) should also be examined because different research methods may be more useful for recruiting represented samples. For example, many researchers examining caregivers of children with PAE recruit participants through FASD diagnostic clinics (Mohamed et al., 2020; Petrenko et al., 2017). However, recruiting through diagnostics clinics runs the risk of missing important information from populations less likely to be involved in these clinics (Mohamed et al., 2020; Petrenko et al., 2017). Specifically, birth and adoptive parents tend to be underrepresented in diagnostic clinic in Manitoba (Cook, 2022).

The methods by which participants complete research measures can also impact participation. For example, in two online surveys distributed to caregivers of children with neurodevelopmental disorders, caregivers of children with FASD had notably low response rates (3.8%, Penner, 2021; 5%, Pizzo et al., 2022). The preference for online surveys is unknown; however, some caregivers may not have had the means or access to virtual participation. Additionally, some caregivers may not have access to transportation for in-person participation. Demographic characteristics, such as age and gender, may also influence participation rates among data collection methods. A recent meta-analysis showed that participants under 20 years-old had the highest average response rate to online surveys, while participants over the age of 40 had the lowest (Wu et al., 2022). Participants under the age of 44 also report a higher preference for app-based research and telephone interviews, whereas respondents over the age of 65 are more likely to prefer in-person surveys (Mulder & Bruijne, 2019). Slight gender preferences are shown with more women preferring mail surveys and men preferring in-person surveys (Mulder & Bruijne, 2019). Determining caregiver rates among research methods may reveal which methods yield higher response rates and representative samples.

The first goal of this study was to describe who is being represented in research about caregivers of children with PAE and who is not. The second goal of this study was to identify the methodology used in research involving caregivers of children with PAE and whether the methods moderate the distribution of the caregiver types (e.g., birth, adoptive, foster parents, and other family members). A meta-analysis and scoping review were conducted to examine several research questions. The following caregiver-related research questions refer to the sample of caregivers of children with PAE included in quantitative caregiver-related research: (1) What is the mean age of the sample of caregivers? (2) What is the gender distribution of caregivers? (3) What is the rate of (a) birth parents, (b) adoptive parents, (c) foster parents, and (d) extended family members as caregivers? The following child-related research questions refer to the sample of children of caregivers who are included in quantitative caregiver-related research: (4) What is the mean age of the child sample? (5) What is the gender distribution of the child sample? (6) What is the rate of children diagnosed with (a) FASD, (b) ADHD, (c) a specific learning disorder (SLD) or learning disability (LD), or (d) an intellectual disability (ID)? The following methodological research questions refer to the recruitment methods, the primary purpose of data collection, methods of data collection, the type of construct studied, and the country where the study was conducted: (7) Do methodological characteristics moderate the rate of birth parents of children who are included in quantitative parenting-related studies? (8) Do methodological characteristics moderate the rate of adoptive parents of children with PAE who are included in quantitative parenting-related studies? (9) Do methodological characteristics moderate the rate of foster parents of children with PAE who are included in quantitative parenting-related studies? (10) Do methodological characteristics moderate the rate of extended family members as caregivers of children with PAE who are included in quantitative parenting-related studies?

Methods

Search Strategy and Identification of Studies

A meta-analysis and scoping review were conducted to summarize and analyze sample characteristics in the literature on caregiver outcomes in families of children with PAE. The Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) guidelines were used for identification, screening, and eligibility for the reports comprised in the study (Page et al., 2021).

Literature Search Strategy

The following five databases were searched for both published and unpublished reports created up to October 2022: (a) PsycINFO, (b) PsycARTICLES, (c) ProQuest Dissertations & Theses A&I, (d) Scopus, and (e) Google Scholar. Both published and unpublished reports were included to account for publication bias. Google Scholar produces an extensive list of search results; therefore, we reviewed the search results for eligibility for up to 200 consecutively irrelevant studies. The following keywords were used in all databases to obtain relevant studies: (*fetal alcohol OR FAS OR FASD OR Foetal alcohol OR partial FAS OR alcohol-related neurodevelopmental disorder OR prenatal alcohol exposure OR PAE OR alcohol exposure OR ethanol exposure OR exposure to alcohol OR* in utero *exposure to alcohol OR* in utero *alcohol exposure OR alcohol exposed) AND (parent OR parental OR parenting OR caregiver OR carer OR guardian OR mother OR father OR maternal OR and paternal).* Search strategies were customized depending on the features available for each database, including the use of operators, field codes, truncation of keywords, and options to limit or expand search results based on the type of document, population, and methodology.

Criteria for Inclusion and Exclusion of Studies

Studies were deemed eligible for inclusion if they were published (e.g., journal article) or unpublished studies (e.g., masters theses and doctoral dissertations) initially reported in English; published (or prepared), or published online before October 2022; involved any caregiver (i.e., not limited to birth parents) of children or adolescents who (a) were 18 years of age or younger and (b) had a history of confirmed PAE; and included a direct, current, quantitative parent- or caregiver-related outcome/construct, including but not limited to parenting behaviors, parental self-efficacy/parenting sense of competence, parenting stress, parenting styles, and parental attributions of child behavior.

Parenting/caregiving and parent/caregiver/carer are all interchangeable terms for this study. Confirmed PAE, rather than confirmed FASD, was selected for the study criteria because this study aims to determine if all caregivers raising children with PAE are represented in the research to ensure that everyone's experiences are being captured and appropriately supported. Many children with PAE who do not meet the FASD diagnostic criteria also experience difficulties. Additionally, caregivers of children with PAE may be at various stages of the diagnostic assessment process or may not be seeking an FASD diagnosis. A coding manual with more details about eligibility criteria and data extraction is available on Open Science Framework (OSF; https://osf.io/zfnd2?view_only=f8a594969869499ea6c0202112928fa6).

Screening Procedure

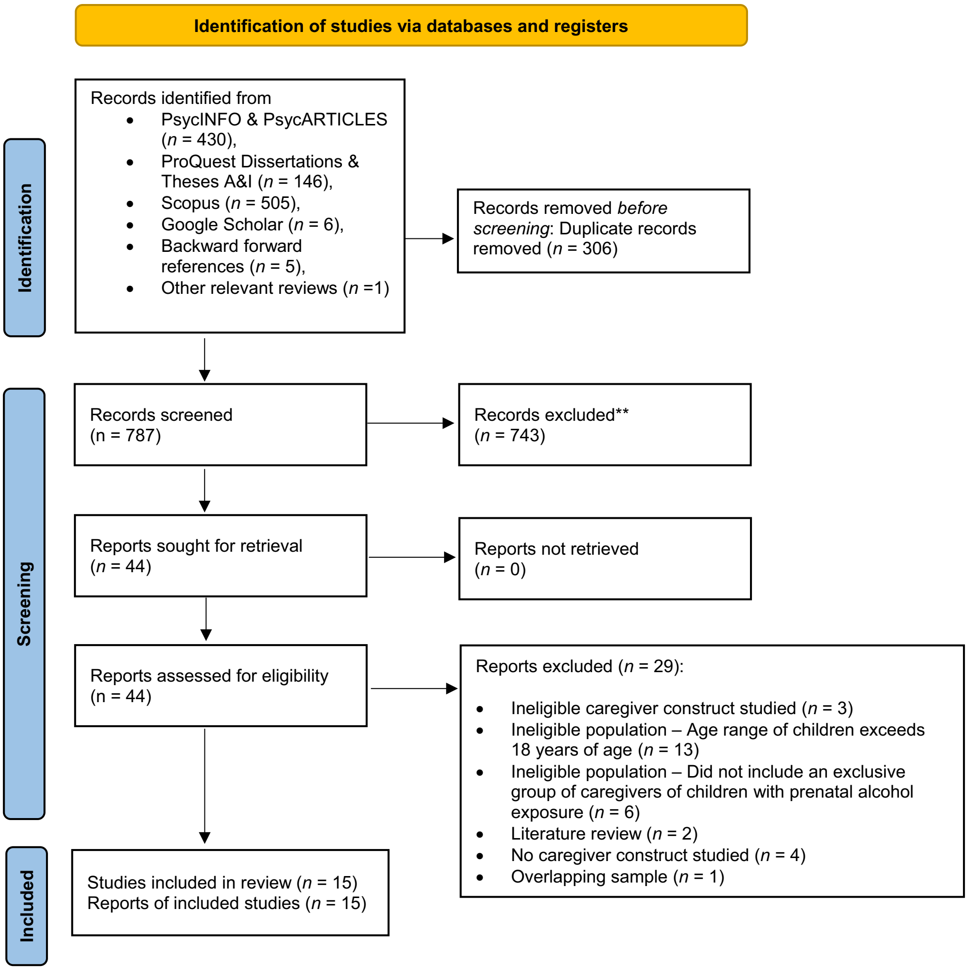
Once the database searches were complete, the studies underwent a multistep eligibility screening process. The PRISMA flow diagram presents the number of studies included at each step (see Fig. 1). The list of studies was first screened based on the title and abstract using the above eligibility criteria. Studies with eligible titles and abstracts were given a unique study number, recorded in a tracking file, and underwent a full review using the predetermined eligibility criteria above. When data from the same participants were reported across multiple studies (i.e., an overlapping sample), the study with the most complete dataset was included.

Backward and forward reference searches were conducted to locate any studies that may have been missed in the initial database searches (Card, 2012). Backward reference searching involved checking each eligible study's reference list to locate other potentially eligible studies, while forward reference searching involved reviewing studies that had cited eligible studies. Studies found during this process went through the same screening procedure described above. We also reviewed the reference list of a relevant review of the literature for additional potential studies (Ilchena et al., 2023).

Information on the Studies

A coding manual was created based on the research questions, and contained instructions for extracting bibliographic information, demographic details, research methods, and outcomes. Past meta-analyses were used

Fig. 1 PRISMA 2020 Flow Diagram of the systematic searches of studies for analysis



as a guide to create the coding manual. A coding form was used to record and extract the data from the studies. Bibliographic information was collected, including: (a) publication type, and (b) year of publication. The following characteristics were recorded for both child and caregiver samples: (a) mean age, (b) gender composition, (c) co-occurring diagnoses, and (d) ethnic/racial background. Additional caregiver and family characteristics collected included: (a) family composition of the sample (birth, foster, adopted, extended family members/kin or kinship, other), (b) level of education of the caregiver sample, (c) relationship status of the caregiver sample (e.g., married/living with a partner/cohabiting), (d) number of children, dependents and caregivers in the household, and (e) the length of time the caregiver has cared for the child. The following methodological characteristics were gathered: (a) participant recruitment methods, (b) data collection source (i.e., routine diagnostic process or research project), (c) data collection methods, (d) measured caregiver-related outcome, (e) study location, (f) study design (i.e., longitudinal, intervention), and (g) sample size.

Data from unweighted samples were used when studies provided data from both unweighted and weighted samples (i.e., Hennessey, 2015). Due to a high number of recruitment methods, the recruitment methods were grouped into one of three categories to increase the power for moderator analyses: (a) researcher-initiated (i.e., the researchers contacted participants from pre-existing lists), (b) participant-initiated (i.e., participants contacted the researchers to participate), and (c) both researcher- and participant-initiated. Data was entered into the Comprehensive Meta-Analysis (CMA) software version 4.0 (Borenstein et al., 2022).

We emailed 12 authors of studies that were missing data required (a) to calculate an effect size or (b) for descriptive purposes (e.g., age range). Half of the authors replied, five of whom provided the required information and were included in this meta-analysis. A Bachelor's-level student who was thoroughly trained in the coding manual and input of data coded all the studies, and a Master's-level student who received the same training second-coded 25% of the eligible studies to ensure interrater reliability. There were no disagreements between the coders.

Statistical Analysis

A random effects model was utilized throughout the analyses because it was expected that there would be a wide range of variation (i.e., heterogeneity) between the studies (Borenstein et al., 2021). Individual meta-analyses were performed to address research questions 1 to 6. The ability to conduct each meta-analysis depended on the number of studies that included the required information, where at least three unique studies were required to conduct a meta-analysis. The effect size index depended on the type of data collected, where the effect size index for research questions 1 and 4 was the mean, and for the remaining research questions was the event rate. Subgroup analyses were also conducted. Moderator analyses, using an analog ANOVA, were planned but not conducted (see the Results section for more details).

Results

Participant Sample and Study Characteristics

Figure 1 shows the process and results of the study screening process. Two of the five additional studies identified through backward and forward reference searching were included in the meta-analysis (Davis, 2013; McCall, 2007). Fifteen studies published from 2000 to 2022 met all the inclusion criteria for review. Table 1 shows the study characteristics of the eligible studies, including the publication type, place of study, type of study, and total sample size. Notably, most eligible studies were conducted in the United States ($k = 11$).

Table 2 summarizes the methodological characteristics of the studies (Supplementary Table 1 provides the methodological characteristics of each study). A variety of recruitment methods were used, with some studies reporting more than one recruitment method (Hanlon-Dearman et al., 2017; Paley et al., 2006; Petrenko et al., 2016). One-third of the studies recruited participants through FASD diagnostic clinics, while two studies recruited using targeted advertisements. About half ($k = 8$) of the studies recruited participants through other medical or health facilities. Twenty percent ($k = 3$) of the studies recruited participants through existing support groups such as a provincial Family Services FASD Outreach program (Hanlon-Dearman et al., 2017) and other local parent support groups (Petrenko et al., 2016; Roger, 2015). Finally, Getty (2000) recruited participants through a state-run social service agency. Categorizing the recruitment methods based on researcher-initiated contact, participant-initiated contact, and both researcher- and participant-initiated contact revealed that for most studies, researchers contacted participants ($k = 11$), with one of the studies using both methods (Petrenko et al., 2016). Every study collected data for research purposes, except for Mohamed et al. (2020), which used data collected during a routine diagnostic process. Most studies ($k = 13$) collected data in-person, except Phillips et al. (2022), which used an online survey. Kautz et al. (2020) used two different methods: Participants completed questionnaires at research visits (i.e., in-person) and at home, depending on the intervention trial they were assigned to.

Parenting stress was the most common construct studied (86.67%, $k = 13$) and was often measured using a version of the Parenting Stress Index (PSI; 92.31%, 12 of the 13

Table 1 Study-Related Characteristics of Quantitative Caregiver-Related Research

Study	Publication Type	Place of study	Type of Study	*N*
Bakhireva et al. (2018b)	Journal article	U.S	Longitudinal	39
Davis (2013)	B.A. senior thesis	U.S	Intervention	31
Getty (2000)	Dissertation	U.S	Cross-sectional	4
Hanlon-Dearman et al. (2017)	Journal article	Canada	Intervention	12
Hennessey (2015)	Dissertation	U.S	Cross-sectional	13
Jirikowic et al. (2012)	Journal article	U.S	Cross-sectional	52
Kautz et al. (2020)	Journal article	U.S	Cross-sectional	46
Mattson et al. (2022)	Journal article	U.S	Cross-sectional	17
McCall (2007)	Dissertation	U.S	Longitudinal	130
Mohamed et al. (2020)	Journal article	Britain	Cross-sectional	70
Paley et al. (2006)	Journal article	U.S	Cross-sectional	100
Petrenko et al. (2016)	Journal article	U.S	Cross-sectional	31
Phillips et al. (2022)	Journal article	Australia	Cross-sectional	35
Roger (2015)	Dissertation	Canada	Intervention	3
Zarnegar et al. (2016)	Journal article	U.S	Intervention	10

B.A. = Bachelor of Arts; Cross-sectional = Data was collected at a single time-point; Longitudinal = Data was collected at more than one time-point, but the study was not an intervention; U.S. = United States

Table 2 Methodological Characteristics of Quantitative Caregiver-Related Research

		k	% of total studies
Recruitment method[a]	Researcher-initiated contact	11	73.33
	Participant-initiated contact	0	0
	Both	1	6.67
	Unclear	3	20.00
Purpose of data collection	Clinical	1	6.67
	Research	14	93.33
Methods of data collection	At home/in-person	1	6.67
	In-person	13	86.67
	Online survey	1	6.67
	Phone survey	0	0
	Virtual interview	0	0
Type of construct studied (Scales used)	Parental attributions (PPI)	1	6.67
	Parenting behaviors (AAPI-2; MBRS/CBRS; PS; SCA)	4	26.67
	Parenting sense of competence (PSOC)	3	20.00
	Parenting stress (CFS; IOF; PSI; PSI-SF; PSI-3; PSI-4)	13	86.67
	Parenting styles (Unknown)	1	6.67

[a] The recruitment method was categorized as researcher-initiated or participant-initiated contact. AAPI-2 = Adult-Adolescent Parenting Inventory, 2nd Edition; CFS = Coaching Family Stress scale; IOF = Revised Impact on Family scale; MBRS/CBRS = Maternal Behavioral Ratings Scale and Child Behavioral Ratings Scale; PPI = Parenting Practices Interview; PS = Parenting Scale; PSI = Parenting Stress Index; PSI-SF = Parenting Stress Index—Short Form; PSI-3 = Parenting Stress Index, Third Edition; PSI-4 = Parenting Stress Index, Fourth Edition; PSOC = Parenting Sense of Competence Scale; SCA = Self-Care Assessment

studies). The second most frequently studied construct was parenting behavior (26.67%, $k = 4$), with each study measuring a different type of parenting behavior. Parenting sense of competence was measured in 3 studies. Hennessey (2015) measured parenting style using a self-report questionnaire measured on a 6-point Likert scale. Lastly, Petrenko et al. (2016) measured parental attributions for child behavior using the Parenting Practices Interview, quantitively coded afterward.

Caregiver and Family Characteristics

The following caregiver characteristics can be found in Table 3. The mean age of the

caregiver sample was 40.76 years of age, 95% confidence interval (CI) [32.57, 48.95]. The overall age range in the sample of caregivers was 15 to 75 years of age ($k = 11$). The caregiver samples were primarily female (89.01%), White/Non-Hispanic or Caucasian or Caucasian/White (82.39%), partnered (64.95%), and obtained a high school education or higher (69.87%). Adoptive parents were the most common caregiver type at 35.58%, followed by birth parents (23.16%) and extended family members (14.47%). Foster parents were the lowest reporting caregiver type (10.95%). Of note, the caregiver type categories were not always mutually exclusive. For example, Zarnegar et al. (2016) noted that half of the adoptive parents were related to the child, and the other half were not. Considering that other studies did not report this degree of detail, for the purpose of simplicity, adoptive parents included the adoptive parents who were related to the child as described in the Zarnegar et al. study, with the rationale that adoptive and foster parents may differ in terms of (a) access to different resources and (b) processes required to adopt the child. We also conducted an analysis where adoptive parents who were related to the child in the Zarnegar et al. study were included in the extended family member category (Supplementary Table 2). Post-hoc analyses were conducted to examine if the rate of caregiver types differed when kinship adoptive parents from the Zarnegar et al. study were categorized as extended family members. These analyses revealed minimal rate differences. Paley et al. (2006) also noted that all the foster parents included in their study were undergoing the adoption process. Decisions were made on how to categorize such cases, but it became evident that other studies could have similar situations without reporting it. Studies also varied in how they categorized caregiver types, with one study grouping foster and adoptive parents into one category (Davis, 2013) and two studies reporting "other legal guardians" as a category (Jirikowic et al., 2012; Mattson et al., 2022). Caregivers from these categories were not included in our analysis. The extended family member category included stepparents that were reported in two studies (Jirikowic et al., 2012; Phillips et al., 2022). Additionally, one study did not report any caregiver type categories (Mohamed et al., 2020).

Table 3 Sample Characteristics of Families Included in Quantitative Caregiver-Related Research

		Summary effects (95% CI)	*k*
Caregiver Characteristics			
Demographics	Age[a]	40.76 (32.57, 48.95)	8
	Female gender	89.01% (80.65, 94.03)	11
	White/Non-Hispanic, Caucasian, Caucasian/White	82.39% (72.26, 89.37)	5
	Black, African American	9.67% (4.03, 21.42)	5
	Native Ancestry, Native American, American Indian	12.12% (7.47, 19.07)	5
	Partnered (Married, Married/living with partner, Married/cohabiting)	64.95% (54.42, 74.21)	9
	High School Education or Higher	69.87% (56.21, 80.73)	4
	Years of Education[a]	14.92 (12.79, 17.06)	4
Relationship with the child	Birth parent	23.16% (9.47, 46.48)	14
	Adoptive parent	35.58% (19.64, 55.51)	14
	Extended family member	14.47% (7.93, 24.94)	14
	Foster parent	10.95% (4.08, 26.24)	14
Child Characteristics			
Demographics	Age[a]	7.38 (6.39, 8.37)	10
	Female gender	43.68% (37.36, 50.22)	15
	White/Non-Hispanic, Caucasian, Caucasian/White	53.41% (44.26, 62.34)	6
	Black, African American	15.90% (8.37, 28.13)	6
	Hispanic/White, Hispanic/Latino	10.69% (5.67, 19.23)	6
	Aboriginal Australians, Native Ancestry, Native American, American Indian	9.89% (2.45, 32.45)	6
	Other or mixed ethnicity, mixed ethnicity	9.12% (3.10, 23.93)	6
Diagnoses	Fetal Alcohol Spectrum Disorder	95.54% (77.78, 99.24)	10

[a] Effect size index for the mean age and years of education of the sample is the mean. All other effect size indexes are the event rate

Child Characteristics

Table 3 also provides the characteristics of the children of caregivers represented in these studies. The mean age of the child sample was 7.38 years of age (95% CI [6.39, 8.37]). The age range of the child sample was ten months to 17.80 years ($k = 12$). The gender distribution of the sample of children was roughly even, with 56.32% and 43.68% male and female participants, respectively. About 53.41% of the child sample was White/Non-Hispanic, Caucasian, or Caucasian/White; followed by 15.90% Black or African American; 10.69% Hispanic/White or Hispanic/Latino; 9.89% Aboriginal Australians, Native American, American Indian, or having Native Ancestry; and 9.12% classified as "other or mixed ethnicity." Other ethnicities, including Asian, were not reported across enough studies to meta-analyze the data. The rate of FASD diagnoses includes those reported as having FASD, Fetal Alcohol Syndrome (FAS)/partial FAS (pFAS), Alcohol-Related Neurodevelopmental Disorder (ARND), and Static Encephalopathy/Alcohol Exposed. We found that 95.54% of the child sample had an FASD diagnosis. Kautz et al. (2020) and Roger (2015) reported that 80.4% and 33.3% of their child sample had a diagnosis of ADHD, respectively. Mattson et al. (2022) also reported that 29.41% of children in their sample took medication for symptoms related to ADHD; however, the number of children diagnosed with ADHD was not included. No studies reported the number of children with a specific learning disability or intellectual disability.

Family Characteristics

Most studies reported the percentage of caregivers who were married, living with a partner, or cohabiting; although, none of the studies reported the total number of caregivers in the participants' households, which may also include other family members. Additionally, the length of time that the caregiver had cared for the child was only reported in one study, which was based on the length of time that the child had been adopted, ranging from less than one year to nine years (Roger, 2015). The number of other children or dependents residing in the home was reported in three studies, two of which were based on the number of children in the home (one to four children; Jirikowic et al., 2012; Roger, 2015). The other study reported that three participants had other children but did not specify how many (Zarnegar et al., 2016). The number of other dependents was not reported.

Relationship to the Child in Relation to Methodological Characteristics

Moderator analyses could not be conducted because there were not enough (a) studies to meta-analyze (e.g., country of study) or (b) variability across studies, as almost all the studies recruited participants through researcher-initiated methods and collected data in-person and for research purposes. We conducted subgroup analyses to examine potential trends in the rate of caregiver types across the methodological characteristics (see Table 4). Most of the trends observed could be explained by the inclusion and exclusion of specific studies in the analyses. For example, the three studies that included only birth parents collected data in-person (Bakhireva et al., 2018b; Hennessey, 2015; McCall, 2007), which explains the higher rate of birth parents when analyzing the in-person data collection subgroup.

Discussion

Overall, the results of the current meta-analysis and scoping review offer some understanding of the generalizability and sample representativeness of the quantitative research literature about caregiver outcomes among caregivers of children with PAE. However, this literature is limited and underexplored, with only 15 eligible studies resulting in a relatively small review compared to other meta-analyses on parenting outcomes of caregivers of children with other neurodevelopmental disorders (e.g., Theule et al., 2013). Notably, the earliest studies were completed in 2000. The infancy of this research is predictable, as researchers only started investigating symptoms related to PAE in the 1970s (Jones & Smith, 1973). At this time, the literature is too limited to make strong conclusions about who is being included in the literature and who is not, especially regarding caregiver type; however, some general trends were noted.

Caregiver Characteristics

We found a larger composition of female caregivers and adoptive parents included in this literature, followed by birth parents, extended family members, and foster parents. The caregiver samples also tended to be middled-aged, White/Non-Hispanic or Caucasian or Caucasian/White, partnered, and had obtained a high school education or higher.

The overall mean age of the caregivers included in research about caregivers of children with PAE of 40.76 years was similar to the average age of caregivers of children with neurodevelopmental diagnoses included in research, such as ASD (37.5 years of age: Hartley et al., 2019) and ADHD (42.8 years of age: Tseng et al., 2021). However, the overall age range of 15–75 years of age gives us more detail on just how different caregivers of children with PAE can be, ranging from adolescents, who may be at-risk for prenatal alcohol use (Genna et al., 2007), and older caregivers, who may be grandparents. Older caregivers were reported in samples consisting primarily of adoptive, foster,

Table 4 Pooled and Subgroup Prevalence of Caregiver Types Based on Research Methods Used in Quantitative Caregiver-Related Research

Research Method	Subgroup	*k*	Birth	Adoptive	Foster	Extended
			Prevalence % [95% CI]			
Recruitment method[a]						
	Researcher-initiated	10	14.42 [4.65, 36.80]	35.00 [15.32, 61.57]	16.27 [5.03, 41.58]	15.64 [7.81, 28.84]
	Participant/Researcher-initiated	1	–	–	–	–
Methods of data collection						
	In-person[b]	13	31.28 [12.34, 59.53]	36.51 [18.94, 58.60]	8.08 [3.08, 19.57]	14.10 [6.55, 27.76]
	Online	1	–	–	–	–
Type of construct studied						
	Parenting behaviors	4	5.81 [2.25, 14.17]	55.14 [24.03, 82.68]	19.32 [1.83, 75.42]	25.61 [9.15, 54.07]
	Parenting sense of competence	3	3.03 [0.75, 11.43]	68.74 [57.82, 77.92]	10.98 [5.69, 20.12]	20.59 [12.97, 31.08]
	Parenting stress	13	19.32 [7.15, 42.71]	35.11 [18.18, 56.85]	11.70 [4.23, 28.48]	15.37 [8.39, 26.48]
	Parenting styles	1	–	–	–	–
Country of study						
	Australia	1	–	–	–	–
	Britain	1	–	–	–	–
	Canada	2	–	–	–	–
	United States	11	30.50 [10.93, 61.07]	45.03 [26.89, 64.60]	7.19 [4.00, 12.59]	13.16 [6.09, 26.16]
Total prevalence		15	23.16 [9.47, 46.48]	35.58 [19.64, 55.51]	10.95 [4.08, 26.24]	14.47 [7.93, 24.94]

Insufficient data was available to conduct a meta-analysis for other variables not listed in the table. [a]Recruitment method was categorized as researcher-initiated, participant-initiated contact or both. [b]One group of participants completed the questionnaires in the laboratory, and another group completed the questionnaires at home, depending on the trial group and extended family member caregivers, which may explain some of the older ages reported. Simmons and Dye (2003) found that 4.5 million children in the U.S. lived with their grandparents, and Smith et al. (2006) found that of 15,947 adopted children, roughly half the children were adopted by a relative. Given this, it is possible that adoptive parents included in this research were also relatives of the children. Some studies failed to include caregiver age, which should be a priority in future studies, given that caregiving experiences may differ across the lifespan (Ha et al., 2008; Östberg & Hagekull, 2000). Other caregiver sample characteristics (i.e., predominately female, White/Non-Hispanic or Caucasian or Caucasian/White, partnered, and having a high school education or higher), also mirror the typical research participant in caregiver- and family-related research, including families of children with neurodevelopmental disorders (Cheung & Theule, 2016; Theule et al., 2013; Tseng et al., 2021). Of note, three studies specifically recruited birth mothers (Bakhireva et al., 2018b; Hennessey, 2015; McCall, 2007), which could have inflated the gender composition of caregivers across these studies. Mothers also tend to be more likely to complete parent-related studies due to the lingering traditional gender roles that predominantly place child-related responsibilities on the mother (Moyser & Burlock, 2018). From a research standpoint, this finding is not surprising and reflects a continued lack of diversity among research participant samples. Clinically, families of children with PAE are diverse, and this lack of heterogeneity is problematic and not representative of the families typically seen in diagnostic settings.

It is difficult to determine the true rate of different caregiver types, as the caregiver categories sometimes overlap (i.e., Zarnegar et al., 2016), and most studies did not indicate whether adoptive or foster parents were related to the child. There were also inconsistencies in how the studies categorized caregivers, with one study combining adoptive and foster parents in one category (Davis, 2013) and other studies categorizing caregivers into “kinship care” and “non-kinship care foster” (Hanlon-Dearman et al., 2017) and “other legal guardians” (Jirikowic et al., 2012; Mattson et al., 2022). Aside from Paley et al. (2006), who noted that all the foster parents in their study were in the process of adopting the child, it is also unknown how many caregivers switched between caregiver types during the child’s life. Therefore, the caregiver type outlined in each study only reflects the caregiver status at one point in time. The fluctuation in caregiver status and child placement history is outlined in Getty’s (2000) study, where one child was removed from their birth parent and placed in foster care multiple times.

There were notable differences between the rate of caregiver types who were included in research and seen at diagnostic clinics; however, given the possibility that all caregiver types, except birth parents, can overlap, the following discussion is based on the categories assigned by the researchers and may not reflect the true relationships. Birth parents were the second highest caregiver type in our study (23.16%) but the lowest reported caregiver type seen at diagnostic clinics in Canada (15.9% birth mothers and 8.1% birth fathers: Canada FASD Research Network, 2019). These differences could be attributed to the fact that three of the 15 studies only recruited birth mothers, which would inflate the overall rate. Adoptive parents had the highest rate in our study (35.58%) but are only the third most common caregiver type seen in Canadian clinics (20.5%: Canada FASD Research Network, 2019). Foster parents are the most common caregiver type seen at FASD diagnostic clinics in Canada (27.7%: Canada FASD Research Network, 2019); however, foster parents were the lowest reporting caregiver type represented in research (10.95%). It is possible that this trend could reflect various ethical requirements to participate in research studies, such as consent from a legal guardian. Similarly, extended family members are the second highest caregiver type seen in Canadian clinics (27.7%: Canada FASD Research Network, 2019) but were second lowest in our study (14.47%). As noted above, some of the adoptive and foster parents could also be extended family members and this result may be an underestimation. These differences may also be related to the fact that most studies in our meta-analysis were conducted in the United States, where the type of caregivers raising children with PAE may differ from Canada. There may also be other variables unique to each caregiver type that affect their inclusion in research, including resources and time.

Child Characteristics

The average age of the child sample, 7.38 years of age, is surprisingly young considering that the study eligibility criteria included children up to 18 years of age; however, 13 studies that would otherwise be eligible consisted of caregivers of individuals with PAE over 18 years of age, with two of the excluded studies including caregivers of adults with PAE who were 37 years of age (Coons et al., 2018; Pepper et al., 2019). This suggests that adults with PAE may stay with or rely on their caregivers well into adulthood. Additionally, only two studies included adolescents with PAE (Phillips et al., 2022; Roger, 2015); however, neither provided the mean age of the child sample and, therefore, could not be included in the age analysis. Also, 12 studies in the current meta-analysis measured parenting stress using a version of the PSI normed for caregivers of children aged 0–12 (Abidin, 1983, 1990, 1995, 2012). This may have contributed to a younger child sample. The average age of the child sample may also reflect a combination of the ages of children in care and diagnostic capacity focusing on school-aged children and less so adolescents and preschoolers, as children may be referred once they enter school.

The gender distribution in the child sample, being roughly even with slightly more males than females, is similar to the gender distribution seen in other studies using clinical databases in Canada (58.3% males; Flannigan et al., 2023) and the United States (61.8% males; Jirikowic et al., 2012). The trend that caregivers of male children with PAE are represented in the research slightly more than their counterparts likely reflects who is being seen in diagnostic clinics, with slightly more males than females (Flannigan et al., 2023). Flannigan et al. (2023) also found that males seen at FASD diagnostic clinics in Canada had higher rates of ADHD and disruptive behavior disorders, and more reported difficulties with school than females, challenges which may lead to a higher likelihood of referral compared to females.

Although there was more diversity across the child sample regarding ethnicity and race than the caregiver sample, over 50% of the child sample were White/Non-Hispanic or Caucasian or Caucasian/White. This finding follows the general trend in research and further highlights the lack of generalizability of the literature to clinical settings. Interestingly, there were differences between the distribution of caregiver and child ethnic and racial backgrounds, which likely reflect some of the families of children who are adopted or in foster placements.

Almost 96% of the child sample had FASD diagnoses. This high rate is likely due to the fact that most studies required an FASD diagnosis to be eligible to participate in the research. The variation in the terms used across the studies made it challenging to determine the rate of FASD diagnoses without expertise in FASD. This is due to the changes in FASD terminology over the years and across countries. Terms like FAS, pFAS, ARND and encephalopathy/alcohol exposed, and neurodevelopmental disorder associated with PAE (American Psychiatric Association, 2013) are currently being used in the United States. Based on the most recent Canadian guidelines for diagnosing FASD (Cook et al., 2016), FAS is equivalent to FASD with sentinel facial features, while pFAS and ARND are equivalent to FASD without sentinel facial features; however, FASD is used as an umbrella term under which FAS, pFAS, ARND, and static encephalopathy/alcohol exposed all fall. Given that the publication process can be lengthy, and that the new FASD diagnostic guidelines were only implemented in 2016, we may expect that future studies will start using the new terms to classify FASD diagnoses, at least in Canada and other countries that use the Canadian guidelines.

Unfortunately, rates of co-occurring diagnoses could not be investigated in the present review, as few studies included this information and it was presented inconsistently across studies when it was provided. We anticipated high rates of co-occurring diagnoses, given that previous reports have found high rates of ADHD among children with PAE seen in diagnostic clinics with FASD (Cook, 2022, 69.3%) and without FASD (Cheung et al., 2022; 53.10%). A meta-analysis also found that the pooled rate of ADHD among individuals with FASD was 51.2% (Popova et al., 2016).

Strengths

Our study had several strengths. Foremost, we considered extensive demographic and methodological variables when developing our study. Analyzing a range of demographic characteristics allowed us to gauge who is currently included in the research about caregivers of children with PAE. Similarly, we explored (a) trends in the research designs of these studies by examining several methodological variables and (b) what is being missed within the research (e.g., parenting-related constructs aside from parenting stress).

Limitations and Future Research

This study demonstrated several limitations, some of which reflect limitations in the literature, while others reflect limitations in the current study design. First, the diversity of caregivers of children with PAE was greater than expected—for example, foster and adoptive parents who were and were not related to the child. However, not every study included this level of detail, which leaves our study with an incomplete picture of caregiver types in research on caregivers of children with PAE. This is a notable limitation given that there may be differences in parenting experiences between related and unrelated caregivers with and without legal guardianship of the child. Second, categorizing the research methods for this meta-analysis was difficult because researchers often used recruitment strategies that did not fall into the categories we had originally expected. Even with the creation of new recruitment method categories, there was not enough variation between the studies to run the moderator analyses. Third, a lack of variation across the data collection methods and constructs studied also precluded our ability to run related moderator analyses. This area of research may be too novel to run these analyses. Fourth, our inclusion criteria limited eligibility to those studies of caregivers with a child sample aged 18 years or younger, which resulted in the exclusion of numerous studies. Including these studies may have provided valuable information or allowed for more analyses but may have also resulted in unmanageable heterogeneity. Fifth, other caregiver- and family-related characteristics that could pose barriers to participate in research, such as socioeconomic status (SES) and caregiver resources, were not explored in the current study. Both factors can be challenging to meta-analyze as the data are not consistently presented in the primary studies or tend to vary (e.g., the mean or median household income, percentage of families falling into specific income quartiles, percentage of families living in conditions of poverty, advantage vs. disadvantaged, etc.). Data related to SES is also challenging to interpret across studies from varying countries and points in time (e.g., it would be difficult to take inflation and differences in cost of living across time into account). Lastly, our inclusion criteria did not account for the inclusion and exclusion criteria in the reviewed studies. Studies including specific individuals (e.g. Bakhireva et al., 2018b; Hennessey, 2015; McCall, 2007) could have inflated the rates of some caregivers (e.g. birth parents and females), which makes underrepresentation in other caregivers partially due to exclusion based on study interests, rather than the research methods used or caregivers' interest in participating. For example, Zarnegar et al. (2016) only included adoptive parents of children who cared for the child for at least 6 months and Hennessey (2015) narrowed their eligibility criteria to mothers of children with PAE during the last three months of pregnancy.

The results of our study suggest that caregivers of children with PAE who identify as males, are foster parents or extended family members, are younger, are non-White, are not partnered, have less than a high school education, and live outside of the United States are underrepresented in the research. Caregivers of children with PAE who are non-White, without a diagnosis of FASD, and adolescents with PAE were also underrepresented in the research. Considering that caregivers of children with PAE often report increased levels of parenting stress (Ilchena et al., 2023; Jirikowic et al., 2012) and come from diverse family structures (Canada FASD Research Network, 2019), the representation of all caregiver types is needed to understand different families' unique strengths and concerns. Despite the limitations of this study, this research may act as a call to action for future studies in this domain and encourage researchers to make more significant attempts to recruit caregivers who are currently underrepresented in the research. One way to try to promote the inclusion of caregivers who are not currently captured in the literature could be through patient engagement, where caregivers with living or lived experience partner or collaborate with researchers for all or various aspects of a study (e.g., research questions and hypotheses, methods, recruitment strategies, identifying and providing solutions to barriers to research participation, etc.). Before designing a quantitative study on caregiver-related outcomes, researchers and family partners could also conduct a brief preliminary study to understand barriers to research participation among families of children and adolescents with PAE. FASD conferences that caregivers and researchers attend may be an ideal venue for connecting by offering presentations about or creating networking opportunities specifically for research collaboration. It is also important to consider that caregivers who completed quantitative measures may differ from those included in qualitative research, and future studies could explore these potential differences.

Considering that some caregivers of children with PAE can be classified under multiple caregiver type categories, future studies should collect this information by providing a more comprehensive list of caregiver categories (e.g., adoptive parents related to the child, adoptive parents not related to the child) and encouraging caregivers to mark all the categories that apply to them. Additionally, researchers should ask caregivers to indicate if their relationship with the child has changed over time (i.e., foster to adoptive parents). This information could offer context to the caregiver-child dynamic, which may help better gauge who is represented in the research. For example, the results suggest that foster parents are underrepresented in the research; however, if some adoptive parents were previously foster parents, then perhaps there is no unique factor in foster parents that is lowering their participation rate. Researchers could also capture this information by conducting longitudinal studies. Few studies examined caregivers of children with PAE over time, apart from research involving intervention follow-up. Longitudinal studies are needed because they can reveal how (a) the child came into the caregiver's care, (b) this relationship developed and changed over time, and (c) parenting experiences vary over time and based on other factors (e.g., before and after the diagnostic process, number of placements, length of time the child has lived in the home, number of caregivers, children, and dependents in the home). This may also provide (a) more accurate information on the rate of caregiver types represented in the research and (b) some information on the length of time the child had been in the caregiver's care, which is not often reported in the literature. Length of time would be especially interesting to examine. For example, there may be differences between the experience of caregivers who have known the child for 6 months (an inclusion criteria in some studies) and caregivers who have known the child since birth.

Our study also revealed inconsistencies and gaps in reporting participant- (i.e., caregiver mental disorders, and child co-occurring diagnoses) and family- (i.e., number of children, dependents, or caregivers in the home) related characteristics. Child-, caregiver-, and family-related characteristics would be helpful to include in future research studies, as each could impact the caregiver-related constructs being studied. For example, researchers should gather information on co-occurring diagnoses commonly among children with PAE, as symptoms related to other neurodevelopmental disorders may affect parenting outcomes (Gallagher et al., 2008; Theule et al., 2013). Moreover, aside from their exclusionary criteria, none of the studies included the rate of diagnosed mental disorders in caregivers of children with PAE. Future investigation on this topic should be prioritized because symptoms of mental disorders can affect parenting behaviors (Cheung & Theule, 2019b) and parenting abilities (Leinonen et al., 2003). Studies have also shown a relationship between parental mental disorders and child externalizing behaviors (Cheung & Theule, 2019a) and ADHD symptoms (Cheung & Theule, 2016), both of which are common in children with PAE (Cheung et al., 2022) and FASD (Popova et al., 2016). Family-related characteristics, such as the number of children in the home, could also provide some helpful context, as a higher number of children in the home has been found to be associated with higher levels of parenting stress (e.g., Viana & Welsh, 2010).

Finally, other caregiver-related constructs should be examined aside from parenting stress. For example, the lack of research on parental attributions for child behavior is surprising, given that FASD resources frequently highlight the importance of shifting attributions from the child's behavior as being willful and intentional to skill difficulties based on brain differences (e.g., Fetal Alcohol Spectrum Consultation, Education and Training Services; Brain-Based Approach to Working with Individuals with an FASD Diagnosis presented by The FASD Collaborative Project). The lack of variability in the research methods may also influence researchers to examine whether different study methods result in higher inclusion of underrepresented caregivers. Overall, future research in this area will help researchers and clinicians better understand the functioning of these families and offer better support in more areas. Providing a comprehensive picture of this novel area of research is important as it can ensure that more caregivers of children with PAE are heard and supported.

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Author Contributions SR: designed and executed the study, assisted with the data analysis, and wrote the paper. CB: assisted with the execution of the study and collaborated with the writing of the study. JT: designed the study and collaborated with the writing of the study. AH-D: collaborated in the writing and editing of the final manuscript. MW: collaborated in the writing and editing of the final manuscript. KC: designed and executed the study, assisted with the data analysis, and collaborated with the writing of the study. All authors approved the final version of the manuscript for submission.

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Data Availability The coding manual and coding form are available on Open Science Framework (OSF; https://osf.io/zfnd2?view_only=f8a594969869499ea6c0202112928fa6).

Declarations

Ethics Approval Ethics approval was not required for conducting a meta-analysis.

Conflict of Interest The authors declare no conflict of interest.

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