

REVIEW

## Caregiver Burden of Children with Attention Deficit/Hyperactivity Disorder (ADHD): A Systematic Review

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**ABSTRACT: Background:** Raising a child with attention deficit hyperactivity disorder (ADHD) is a key challenge for the primary caregiver. This systematic review aims to identify major burdens facing the primary caregiver of a child with ADHD. **Methods:** The electronic databases CINAHL, PubMed, and Google Scholar were searched for studies published in English from 2017 to 2022 assessing the challenges facing caregivers of a child with ADHD. The Johns Hopkins Nursing Evidence-Based Practice Model was used to assess quality and risk of bias of studies identified for inclusion. Articles were synthesized by evaluating principal themes of burden to caregivers, stress of caregivers, and effectiveness of intervention programs. **Results:** Eleven articles were included in this review and included a total of 2426 participants. Findings revealed that caregivers of children with ADHD have a poor quality of life and high stress levels. Supportive parenting programs can be effective for improved coping and adaptation mechanisms with children with ADHD. However, few interventional studies were identified, increasing potential for bias. No meta-analysis was conducted. **Conclusion:** Caregivers of children with ADHD can benefit from strategies to improve their quality of life and reduce their stress levels. Targeted parenting programs can make a positive difference in the well-being of caregivers and children with ADHD. Additional research is needed to address the evidence-based effectiveness of parenting support programs.

**KEYWORDS:** Attention deficit hyperactivity disorder (ADHD); caregivers; burden of care; mothers; attention deficit disorder

### 1 Introduction

Attention deficit hyperactivity disorder (ADHD) is the most common childhood neurodevelopmental disorder and among the most prevalent chronic health conditions affecting school-age children [1]. An analysis by the National Health Interview Survey (NHIS) determined the prevalence of ADHD diagnoses increased from 1997 to 2016 in US children from 6.1% to 10.2% [2]. A similar prevalence rate was observed in the US during the years 2017 to 2022 [3]. As recognition has increased, the impact attributed to the condition has also, contributed to a global burden of increase in disability-adjusted life years (DALYs) across 204 countries from 1990 to 2019 [4].

According to the National Institute for Health and Care Excellence, the diagnosis of ADHD should only be completed by a psychosocial assessment by a pediatrician, psychiatrist, or qualified healthcare professional. It also should include a full clinical evaluation and review of the child's symptoms, including



the presence of social, educational, and psychological impairments in the different domains of the child's everyday life and settings, and not solely on rating scales. A positive diagnosis should meet the criteria in Diagnostic and Statistical Manual of Mental Disorders (DSM-5) and the International Classification of Diseases (ICD-10) [5].

The impulsivity and inattention of the child can make parenting unusually difficult, and parents may blame high stress levels on their children's behavior, unmet support needs, and stigma surrounding the condition [6,7]. Treatment approaches include pharmacological options, psychological interventions for behavior modification, and school accommodations for learning and academic support [8].

For a caregiver, responsibility for a child with ADHD means a life full of challenges. These may include difficulties in the environment, inattention, increased distractibility, and decreased self-inhibitory capacity, in addition to motor overactivity and restlessness [9]. Children with an ADHD diagnosis commonly experience academic underachievement, low self-esteem, and poor interpersonal relationships with family and friends, and may commonly be diagnosed with other behavioral, emotional, language, and learning disorders [5]. Approximately 40%–50% of children with ADHD persist with varying symptoms into adulthood, frequently leading to significant unemployment as well as increased risk of antisocial behaviors including substance abuse, difficulty sustaining social relationships, and problems with the law [10]. However, limited attention has been given to caregivers of children with ADHD and how the burden of coordinating care may impact their quality of life. Having a child with ADHD can put parents in a demanding situation [11]. Parents caring for children with ADHD face diverse challenges, including but not limited to managing their economic burden meeting the time and resources needs of their children, in addition to psychological problems, lack of support, and stigma from the community [12]. ADHD symptoms and behaviors impact the child's social and academic life affect parents and thereby influence family functioning as a whole [13]. Further, several barriers can hinder the effective parenting of children with ADHD, such as the burden of care which can cause depression symptoms among caregivers [14]. Parenting stress potentiates adverse childhood experiences as it influences the child's mental and behavioral outcomes, which in turn can be mitigated by family resilience [15]. In comparison to mothers of children with average development, mothers of children with ADHD reported significantly lower HRQoL (Health-Related Quality of Life) Mothers of Children with ADHD sought more help and used more indirect methods and coping strategies compared to mothers of children.

Several studies have discussed the effectiveness of positive parenting strategies to overcome the challenges facing children with ADHD's mothers. Positive parenting training has shown a significant impact on enhancing executive functions and impulsivity in children with ADHD [16]. Findings of a randomized control trial in Sweden showed improved parenting behavior and competence in addition to decreased parenting stress in a post-test behavioral management training of mothers of children with ADHD [17]. Similarly, Chesterfield et al. [18] reported less dysfunctional parenting and less disruptive child behavior after six months of follow-up post-intervention. These studies were consistent with a meta-analysis that recommended the adoption of effective parenting programs as a part of the ADHD intervention plan [19].

Despite these findings, further research is needed about the burden of the caregiver experience for children with ADHD. Exploring the nature and characteristics of this challenge can provide further insight into the development of effective management of ADHD treatment and parenting programs. Additional examination of the literature is needed to evaluate the impact of the experiences of caregivers and address this gap. This systematic review aims to identify major burdens facing primary caregivers of a child with ADHD.

## 2 Methods

The systematic review study aims to explore the most frequent challenges facing the caregiver of a child with ADHD according to the guidelines of PRISMA (see the supplementary material) [20]. The search

was designed and conducted by two PhD-prepared nurse scientists who collaborated to identify potential articles. The lead author, who has five years of nursing experience and two years of clinical experience working with children and families experiencing ADHD, personally reviewed all the articles and made a final determination regarding inclusion.

In accordance with PRISMA guidelines, a literature search was conducted utilizing the databases CINAHL, PubMed, and Google Scholar. The relevant search terms utilized included (“ADHD” AND “caregiver burden”) OR (mothers AND child with ADHD) OR (attention deficit disorder with) hyperactivity”[MeSH Terms] OR (“attention”[All Fields] AND “deficit”[All Fields] AND “disorder”[All Fields] AND “hyperactivity”[All Fields]) OR “attention deficit disorder with hyperactivity”[All Fields] OR “ADHD”[All Fields]) AND (“child”[MeSH Terms] OR “child”[All Fields] OR “children”[All Fields] OR “children’s”[All Fields] OR “children”[All Fields] OR “child’s”[All Fields]) AND (“mothers”[All Fields] OR “mothered”[All Fields] OR “mothers”[MeSH Terms] OR “caregiver”[All Fields] OR “mother”[All Fields] OR “mothering”[All Fields]).

The search was limited to English peer-reviewed research articles published in academic journals. The goal of the review was to focus on the most recent five-year period, and the search was limited to articles from 2017 onward. Inclusion criteria required the focus of the research to include children only specifically diagnosed with ADHD with their primary caregivers. Research findings focused on children with ADHD combined with other conditions such as autism or mental disorders, such as patients co-diagnosed with autism, were excluded, to avoid confounding. Additional criteria limited inclusion to articles that were primary data-driven studies, thus review and opinion articles were excluded. The articles were assessed using the Johns Hopkins Nursing Evidence-Based Practice Model to evaluate the quality and strength of evidence in healthcare research [21]. The Johns Hopkins Evidence-based Practice for Nurses and Healthcare model was developed to evaluate the quality and strength of evidence in healthcare research. It is commonly used to assess the validity and reliability of studies, assess bias, and determine the level of evidence supporting healthcare practices. This model categorizes Level I research as Experimental, Level II as Quasi-experimental, and Level III as Non-Experimental concurrently evaluates the quality and risk of bias of each study according to its type, as High, Good, or Low.

Because this systematic review was not a meta-analysis, no data conversions, subgroup analyses, effect measures, confidence interval calculations, or sensitivity analyses were conducted.

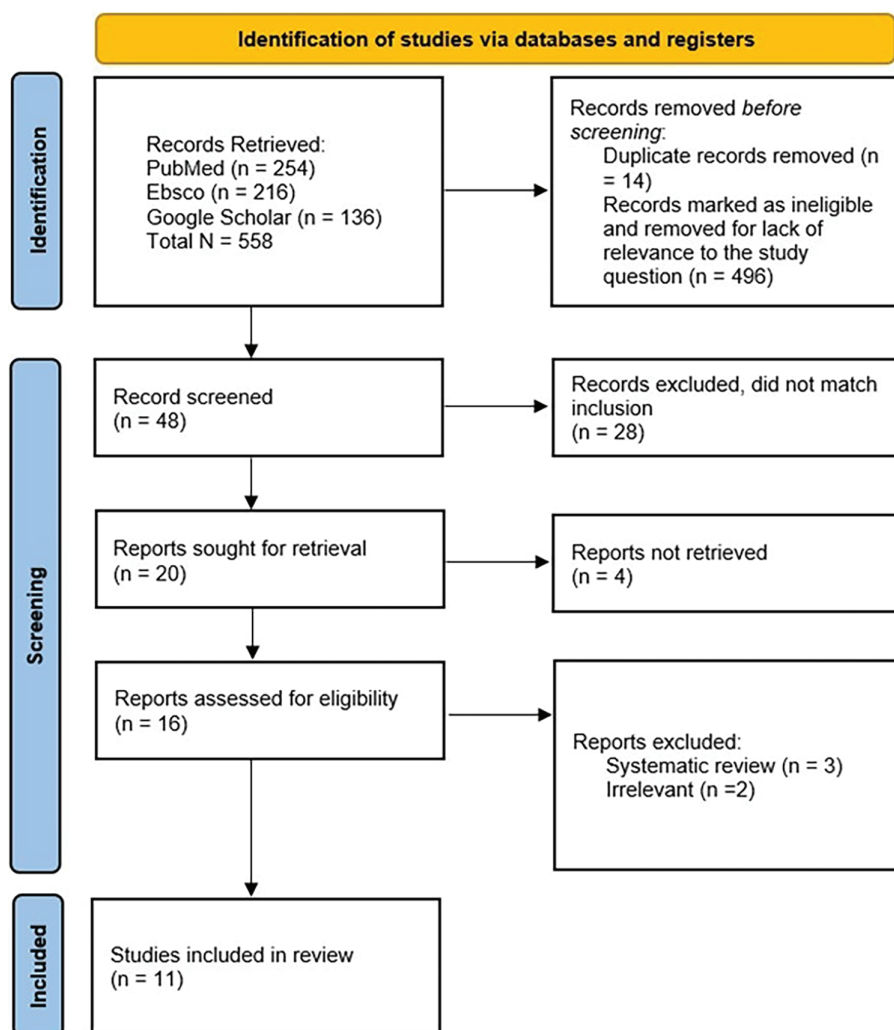
### 3 Results

#### 3.1 Study Selection

The search generated 558 articles. Duplicate articles were removed ( $n = 14$ ) and articles not relevant to the research question ( $n = 496$ ) were marked as ineligible based on a review of the abstract. Of the remaining 48 abstracts reviewed, more than half ( $n = 28$ ) were excluded as they were not specific to the condition of ADHD in children and their caregivers, for example, if the analysis incorporated a comorbid condition. Twenty articles were sought for retrieval. Four of them were not retrieved. The remaining articles ( $n = 16$ ) were assessed for eligibility. Three of these were excluded as they were conducted in a systematic review design, and two articles were excluded on the basis of relevance. Based on these exclusion criteria the final sample size was reduced to 11 articles. See PRISMA diagram (Fig. 1).

As a result of the search process, 11 articles were included in the qualitative analysis. All 11 articles were confirmed to be High or Good in quality, using reasonable research procedures to develop scientific evidence based on recommendations consistent with findings [21]. In terms of strength of evidence, a single Level I article was conducted in a randomized control trial design [22], this experimental study examined parenting

support programs. Another article of Level II was conducted in a quasi-experimental design to assess the effect of the resiliency program used on the level of care burden or stress [23].



**Figure 1:** PRISMA diagram

The rest of the studies were descriptive in nature and observational. Three of the articles [13,24,25] were conducted in a qualitative design at Level III. The remaining articles were of Level IV and framed by a quantitative design [26–31].

The sampling strategies used in these investigations were most frequently convenience sampling, such as in the cross-sectional studies. The single randomized control study blindly assigned participants to each condition [22]. Three qualitative studies relied on purposive sampling [13,24,25].

The investigations included a total of 2426 participants. Each article in the review represented research conducted in a different country or region: China, Mainland China, Taiwan, South Africa, Turkey, Iran, Japan, Philippines, Spain, Italy, Sweden, and South Korea. The settings where the identified studies were conducted included psychiatric outpatient clinics [24,25,28,29], as well as a hospital or a medical center [26]. Another two studies were conducted at a university campus [22,23]. One study was conducted using an online

questionnaire [30]. One study was performed in a primary school [13]. One other study was conducted in mixed settings of both a school and a hospital [31].

Several different methods and surveys were used in the data collection. In-depth interviews were used for qualitative study designs [13,24,25]. Several tools are used in quantitative study design to explore the caregiver challenges and difficulties, including the Goldberg General Health Questionnaire (GHQ-28) [26], the Korean ADHD rating scale-IV, Adult ADHD self-report scale State-Anxiety Inventory and Parental Stress Scale [27], the World Health Organization Quality of Life-BREF, Maslach Burnout Inventory (MBI) [28], the Multidimensional Scale of Perceived Social Support (MSPSS), Parental Attitude Research Instrument (PARI), Parent-reported version of the Strengths and Difficulties Questionnaire (SDQ), the Clinical Global Impression-Severity (CGI-S) scale of ADHD Rating Scale IV Edition (ADHD-RS-IV) [29], the Parenting Stress Index-Short-Form-Parental Distress (PSI/SF-PD) [23], and the Parenting Alliance Inventory (PAI) [31].

The samples in six studies incorporated both the mother and father of the children with ADHD [22,24,26,27,30,31]. The other five studies (45%) recruited only mothers in their samples [13,23,25,28,29]. No investigations included in the review had primary caregivers other than mothers or fathers. For a complete summary of articles, see Table 1.

**Table 1:** Summary of sample and study tools used

Origin setting	Aim	Sample size and sampling method	Tools	Findings	Johns hopkins level
Philippines/ School [13]	Explored the challenges, coping strategies, and needs of mothers with children diagnosed with ADHD.	Total of 10 mothers with children with ADHD aged 6–11 years (Purposive, non-probability sampling)	In-depth interviews	Challenges for mothers included the child's academic problems, physical aggressiveness, stubbornness, and the family's financial difficulties.	3
Spain/Clinic [26]	Analyzed the perception of emotional distress in a group of parents of children with ADHD.	Parents of 60 children with newly diagnosed ADHD and the parents of 60 healthy children were included in (Convenience sampling)	Goldberg General Health Questionnaire (GHQ-28)	Parental distress correlated positively to ADHD symptoms in children; Higher rates of separation, stress, and divorce among parents of children with ADHD.	3
South Korea/Outpatient Service of Soonchunhyang University Seoul Hospital [27]	Investigated the relationships between ADHD symptom severity of children and the mental health of their mothers and fathers.	Total of 70 children with ADHD and 140 married heterosexual parents (70 fathers and 70 mothers) (Convenience sampling)	Child Depression Inventory and State-Anxiety Inventory (for children); the Korean ADHD rating scale IV, Adult ADHD self-report scale, State-Anxiety Inventory and Patient Health Questionnaire-9 Parental Stress Scale (for parents).	Maternal anxiety correlated positively to severe ADHD symptoms and paternal parenting stress severity.	4

(Continued)

Table 1 (continued)

Origin setting	Aim	Sample size and sampling method	Tools	Findings	Johns hopkins level
Taiwan/Child Psychiatric Clinic and School [28]	Investigated the impact of children's diagnosis of ADHD, children's and maternal psychopathology and significant socio-demographic variables of the children, parents, and family on HRQoL of mothers of children with ADHD with children with typical development.	Children with ADHD (n = 257) and children with typical development (n = 324) (Purposive sampling)	World Health Organization Quality of Life-BREF, the Chinese version of the Childhood Autism Spectrum Test for autistic traits, the Swanson, Nolan, and Pelham, version IV scale (for ADHD symptoms), and the Child Behavior Checklist (for behavioral and emotional problems).	Maternal depression and perceived family support correlated to worse HRQoL in all four domains for Mothers of children with ADHD compared with those of children with typical development.	4
South Africa/Psychiatric Outpatient Clinic [24]	Explored parents' experiences of living with a child with attention deficit hyperactivity disorder.	Total of 10 parents living with children with ADHD receiving outpatient treatment at a psychiatric facility (Purposive sampling)	Unstructured individual interviews	Challenges for parents living with a child with ADHD include stress and stigma from the community and burdensome emotions resulting in impaired social and occupational functioning.	3
Turkey/Outpatient Clinic of the Mental Health and Diseases [29]	Examined the perceived social support levels, burnout levels and child-raising attitudes of mothers with children diagnosed with ADHD.	Total of 159 mothers of children with ADHD (Convenience sampling)	Maslach Burnout Inventory (MBI), the Multidimensional Scale of Perceived Social Support (MSPSS) and the Parental Attitude Research Instrument (PARI)	Mothers of children diagnosed with ADHD experienced significantly low perceived social support.	4
Italy/Clinics [30]	Analyzed how the quality of life of children diagnosed with attention-deficit/hyperactivity disorder impacts the relationship between disease severity and family burden.	1478 children 6 to 18 years with ADHD analyzed to evaluate the relationships between ADHD severity, the children's quality of life and family burden (Convenience sampling)	Parent-reported version of the Strengths and Difficulties Questionnaire (SDQ), Clinical Global Impression-Severity (CGI-S) scale, and the ADHD Rating Scale IV Edition (ADHD-RS-IV)	ADHD severity and impairment associated, with worse HRQoL and higher parenting stress.	4

(Continued)

Table 1 (continued)

Origin setting	Aim	Sample size and sampling method	Tools	Findings	Johns hopkins level
Japan/Clinic [22]	Evaluated the effects of Well Parent Japan, a hybrid intervention including a group Japanese language adaptation of the New Forest Parenting Programme for ADHD (NFPP).	Mothers of children 6–12 displaying symptoms of ADHD were randomly assigned to intervention (n = 28) or a waitlist control condition (n = 24) of intervention to improve parent's psychological well-being (Random sampling)	Japanese versions of the Swanson, Nolan & Pelham rating scale, and Gilliam Autism Rating Scale 3rd Edition; semi-structured telephone interviews	Mothers post-intervention reported less parenting stress, higher parenting self-esteem, and use of more effective parenting strategies, reduction in observed negative parenting compared with controls.	1
China/School [31]	Examined the effects of the parenting role, work-family conflicts, child ADHD symptoms, parental depression, anxiety, parenting alliance, and social support on parenting stress.	Chinese families of children with ADHD (n = 314) and families with typically developing children (n = 308) (Convenience sampling)	Parenting Stress Index-Short-Form-Parental Distress (PSI/SF-PD), Parenting Alliance Inventory (PAI), Work-Family Pressure and Support Questionnaire (W-FPSQ)	Depression, Anxiety, and higher levels of parenting stress were found among parents with children with ADHD, and mothers experienced higher stress than fathers and more work-family conflict.	4
Sweden/Child Neuropsychiatry Clinic (CNC) at Queen Silvia's Children University Hospital in Gothenburg [25]	Explored experiences of the caregiver situation, and how they were affected when the young persons received Internet-Based Support and Coaching (IBSC).	Ten caregivers of 10 young persons with ADHD participated (Purposive sampling)	A questionnaire (measuring caregiver burden); chat sessions and two face-to-face meetings.	Caregiver burden decreased after the participation of the young child in IBSC.	3
Iran/Tabriz University Center [23]	Investigated the effectiveness of resiliency training on positive and negative effects and reducing the psychological distress in mothers of children with ADHD.	Mothers with children with ADHD in Tabriz, from which 30 people (n = 30) were randomly grouped into experimental and control groups (n = 15 for each group) (Convenience sampling)	Positive and Negative Emotion Scale and the Depression, Anxiety, and Stress Scale (DASS); pre-test and post-test, the resilience components training program was applied to the experimental group in 9 sessions of 90 min.	Resilience education improved the positive emotion and reduced the negative emotion and stress among mothers with children with ADHD.	2

### 3.2 Burdens of Caregivers

The majority of the observational and descriptive studies described the most common challenges of a caregiver in raising a child with ADHD. Dimensions that were influenced included social, psychological, and physical burdens in their lives as all of them concluded that the caregiver of a child with ADHD had emotional stress [25,31] and negative emotions [23]. Low social support and burnout [24,29]. Another finding

across studies was the poor quality of life for the mother in addition to poor academic achievement for the ADHD-diagnosed child [13,27,30,31].

### **3.3 Stress of Caregiver**

As a result of their research, both studies from Liang et al. [28] and Si et al. [31] concluded that stress is higher in the caregivers of a child with ADHD than among caregivers of a typically developing child. Further, several studies [26,31] correlated increased maternal stress to the severity of ADHD symptoms. Similarly, the study from [30] showed that parental stress was related to parental perception of low quality of life for their children with ADHD and not related to the severity of the symptoms.

### **3.4 Effectiveness of Intervention Programs**

Two studies [22,23] examined the positive influence of implementing intervention programs for the parents of a child with ADHD for improving parenting practices and skills in raising a child with ADHD in addition to improved self-esteem for the parent. Tabatabaei and Chalabainloo [23] found that resiliency training decreased psychological distress and increased the positive effect for the mother of a child with ADHD. On the other hand, the burden of care was not significantly improved, and another study [25], found no common trajectory in change or improvement in the burden of care post (IBSC) an Internet-Based Support and Coaching program for children. This investigation was limited to 10 caregivers and their children, however, limiting generalizability.

## **4 Discussion**

This systematic review study found strong support that caregivers of children with ADHD experience increased burdens managing the challenges of their children's condition. These burdens included feelings of stress, physical demands, and poor quality of life. The most pronounced findings were related to the deteriorating psychological status of the caregivers and the increased burden of care while having a child with ADHD [13,24,26,27,29–31]. In general, the caregiver's well-being and mental health are considered to affect the child's well-being [15]. Several papers specifically focused on the mother as the primary person and the capstone for effective family function and support. In these articles, she is perceived as the person who will mainly manage to overcome conflicts and achieve balance for the child [13,23,25,28,29]. Consequently, the mother and child's well-being are interrelated, and the severity of maternal stress has specifically been associated with a child with more complicated ADHD symptoms [27]. At the same time, Uddin et al. [15] noted the influence of parental stress on the child's behavioral outcome and adverse child experience, which could reinforce the relationship.

Another consistent finding was the poor quality of life for a mother of a child with ADHD [28], specifically leading to burnout. Polat and Karakas [29] found that mothers of children with ADHD experienced greater burnout displaying negative child-raising attitudes. Three studies correlated this decrease in quality of life to the severity of the child's symptoms [26,30,32]. This work was consistent with Si et al. [31] who found that parents of children with ADHD reported much more parenting stress compared to parents without children with the condition. In addition to stress, the child's condition appeared to foster feelings of stigma, and social dysfunction [24]. This was similar to the study of Leitch et al. [7] who found parental stress related to child behavior and social stigma.

The caregiver of a child with ADHD needs extensive support programs to ease the burden of care and learn coping strategies. Tabatabaei and Chalabainloo [7,23] conducted an effective resiliency program found to decrease the negative mother's affect and promote positive emotions. This was in line with the demonstrated effectiveness of family resiliency on the improvement of a child's adverse experiences with

ADHD as a cause of parenting stress. Studies [15,22] found that less parenting stress, higher self-esteem, and more effective parenting strategies were the major outcomes in a randomized controlled trial of applied techniques to increase psychological well-being and gain the confidence of parents in their abilities to make changes when compared to the control group. Additionally, it was found that positive parenting training has a considerable influence on improving executive functioning and impulsivity in children with ADHD [16]. Similarly, Yusuf et al. [19] showed improvement in family functional attitude after the adoption of the triple parenting program as a part of the ADHD intervention plan.

#### **4.1 Implications**

The results of this systematic review demonstrated the necessity of identifying the burdens experienced by the caregivers of children with ADHD. This information has the potential to increase the sensitivity of healthcare providers to provide support that will enable caregivers to offer better care and understanding to their children with the condition. Further research will aid in the change and improvement in the quality of clinical care for children with ADHD and guide the inclusion of their primary caregiver or parents as an integral part of the intervention and treatment plan. This evidence calls for the incorporation of parenting programs, support groups, and education for parents of children with the condition to deliver social and functional strategies and coping mechanisms, especially for those experiencing burnout.

Despite this systematic review, there is still a knowledge gap in addressing several aspects of the burden for ADHD caregivers. For example, more research is needed specifically on the roles of other caregivers, such as grandparents. Furthermore, it is possible that the search strategy prioritized mothers as caregivers for the child with ADHD, as this was only explored in six articles of the 11 articles.

A third recommendation regards the need for randomized control trials to study to investigate the effectiveness of parenting programs on the improvement of parental attitudes and behavior in caring for a child with ADHD. Although outside the main focus of the investigation, this finding provides guidance regarding the type of intervention that should be emphasized in follow-up studies to provide support for caregivers.

This research spotlights special needs and supports the caregiver and the child with ADHD to promote an atmosphere of understanding and positive adaptation strategies and bridge a new step forward in incorporating mental health and behavioral well-being.

#### **4.2 Limitations**

One limitation of this systematic review is that it was not registered prospectively, which may be considered to reduce the potential for bias. Thus, a recommendation would be to register prospectively for a follow-up examination as further research becomes available. This important and quickly developing topic merits further examination. Besides, at this time, a limited sample of articles are available on the topic of caregivers of children specifically with ADHD. Many of the articles initially identified by the keywords did not meet inclusion criteria, as they included children with comorbid disorders rather than concentrating on children with ADHD specifically. Additionally, the quality of the articles varied considerably, including in the sampling methodology.

### **5 Conclusion**

This systematic review study adds supportive evidence that caregivers of a child with ADHD may experience a burden of care associated with their role. The findings of this study indicate more research is needed to investigate and address the burden and negative effects experienced by both caregivers of

children with ADHD. These efforts can help promote a positive quality of life for both caregivers and children with ADHD.

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**Availability of Data and Materials:** The datasets generated and/or analyzed during the current study are available from the corresponding author on reasonable request.

**Ethics Approval:** Not applicable.

**Conflicts of Interest:** The authors declare no conflicts of interest to report regarding the present study.

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