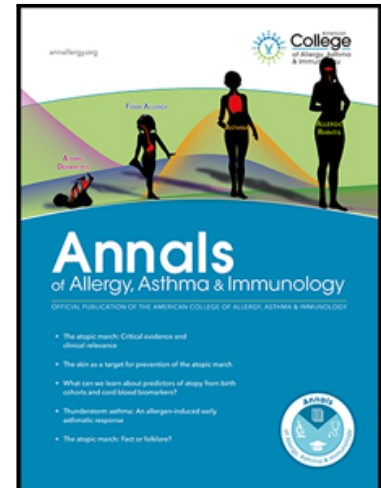


Journal Pre-proof

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PII: S1081-1206(21)00342-2
DOI: <https://doi.org/10.1016/j.anai.2021.04.034>
Reference: ANAI 3587



To appear in: *Annals of Allergy, Asthma Immunology*

Received date: 14 January 2021
Revised date: 26 April 2021
Accepted date: 28 April 2021

Please cite this article as: Michael A. Golding MA , Nina V. Gunnarsson PhD ,
Roelinde Middelveld PhD , Staffan Ahlstedt PhD , Jennifer LP Protudjer PhD , A scoping review
of the caregiver burden of pediatric food allergy, *Annals of Allergy, Asthma Immunology* (2021), doi:
<https://doi.org/10.1016/j.anai.2021.04.034>

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A scoping review of the caregiver burden of pediatric food allergy

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Conflict of Interest:

MG: none

NG: none

RM: none

SA: none

JP: sits on the steering committee for Canada's National Food Allergy Action Plan; and is Section Head, Allied Health, Canadian Society of Allergy and Clinical Immunology.

Funding source: Funding for this project was provided by the Canadian Institutes for Health Research through their Early Career Investigator in Maternal, Reproductive, Child and Youth Health operating grant, awarded to J Protudjer. Dr. Protudjer's New Investigator Grant, jointly provided by the Manitoba Medical Services Foundation and The Children's Hospital Research Institute of Manitoba, also helped to support the current study. These funding bodies had no influence on the study design, data collection, analysis and interpretation; or, on the manuscript writing.

Abbreviations:

COVID-19	coronavirus disease
EAI	epinephrine auto-injector
USD	United States dollars
PAL	Precautionary allergen labelling

Word count 3985/4000

Tables: 3

Figures: 2

Abstract

Objective: While a number of papers have described the psychosocial impact of raising a child with a food allergy, recent attempts at synthesizing this literature have been narrow in focus and/or methodologically limited. Consequently, the current study aimed to synthesize both the quantitative and qualitative literature in order to achieve a better understanding of the psychosocial and financial burdens faced by families raising children with food allergy.

Data Sources: Searches were performed on PubMed, Scopus, PsycInfo and CINAHL for articles related to the psychosocial and financial burden experienced by individuals caring for a child with food allergy.

Study Selections: English language, original research articles were included in the current review.

Results: A total of 53 articles were deemed eligible for review. Results from the quantitative literature revealed that parents of children with food allergy (i.e., food allergy and food protein-induced enterocolitis, proctocolitis, and enteropathy) consistently reported lower QoL relative to their comparison groups. Within-group analyses suggest that this burden is increased for parents managing multiple food allergies, severe food allergy, and comorbid allergic conditions. Thematic synthesis of the qualitative literature suggests that the psychosocial burden shouldered by parents of children with food allergy stems, in part, from the unpredictable threat of exposure as well as the practical and social burdens of managing a food allergy. In addition to psychosocial burdens, a small but growing body of literature suggests that families with food allergy also incur greater financial costs.

Conclusion: Findings suggest that pediatric food allergy imposes considerable burdens on parents both quantitatively and qualitatively.

Keywords: food allergy; caregiver burden; cost of illness; mixed-methods

Key messages

Parents of children with food allergy report qualitative and quantitative impairments to their quality of life.

Results from the qualitative literature suggest that this burden stems, in part, from the persistent threat of exposure as well as the practical and social demands associated with managing a pediatric food allergy.

While the burden of pediatric food allergy appears greatest after the initial diagnosis, findings suggest it never completely subsides.

Emerging evidence suggests parents of children with food allergy also experience psychological and financial consequences.

Parents who manage multiple food allergies, comorbid allergic conditions, and more severe food allergy experience particularly acute burdens.

More research is needed to better understand the financial impact of pediatric food allergy, the differences in burden between male and female caregivers, and the levels of depression among caregivers of children with food allergy.

Introduction

Food allergy refers to a group of conditions (e.g., Immunoglobulin E (IgE)-mediated food allergy, food protein-induced enterocolitis, eosinophilic esophagitis) that are characterized by adverse reactions to food.¹ While the mechanisms, symptoms, and severity of these conditions vary, food allergy is typically treated through strict avoidance of the offending food.^{2,3} Research suggests that over the last two decades, food allergy has increased in prevalence in many Western nations, which has coincided with a greater interest in the burden caused by these conditions.⁴ For younger children with food allergy, research suggests that the weight of this burden not only falls on the child, but also on parents, who often assume a large role in managing their child's allergy.^{5,6} In particular, research has shown that families with children with food allergy expend greater time and effort grocery shopping as avoidance demands that caregivers closely scan food labels for allergens.⁷ Preparing food can also result in additional work for families raising children with food allergy as caregivers are faced with the need to satisfy the competing preferences of their family members, while avoiding cross-contamination.^{8,9} Although limited relative to the body of research focused on the practical demands of food allergy, burgeoning evidence suggest that families raising a child with a food allergy also shoulder greater financial costs compared to those without children with food allergy.¹⁰

Beyond practical and financial demands, research indicates that pediatric food allergy is associated with negative psychological consequences for parents including greater stress and worry.^{11,12} While the impact of pediatric food allergy on the emotional health of parents is likely multifaceted, qualitative research suggests that the psychological burden stems, in part, from the unpredictable threat of accidental exposures.¹³ Faced with this uncertainty, some parents report maintaining heightened vigilance towards potential sources of exposure as a means to mitigate risk.¹³ However, it appears as though this strategy is not without consequences as it has been described as a source of burden for caregivers.¹⁴

Not surprisingly, the growth in research on the caregiver burden of pediatric food allergy has inspired several reviews over the past 10 years aimed at synthesizing the extant findings.¹⁵⁻²⁷ However, many of these review papers are not only narrow in focus, but also lack methodological rigor, which raises questions regarding their comprehensiveness. Moreover, none of the recently published reviews of the parental burden of pediatric food allergy have included a complete synthesis of both the quantitative and qualitative literature.²⁸ This failure to integrate the novel quantitative studies of the last decade with the growing number of qualitative studies represents a significant gap in the literature as the integration of both quantitative and qualitative research holds the potential to provide a richer and more nuanced understanding of the types and sources of burden faced by the caregivers of children with food allergy. Consequently, the current study aimed to comprehensively synthesize both the quantitative and qualitative literature in order to achieve a more complete understanding of the psychosocial and financial burdens faced by caregivers raising a child with food allergy.

Design, data sources, and study selection

The current review employed the use of a segregated, mixed research synthesis design, consistent with Heyvaert and colleagues' definition.²⁹ In this approach, the quantitative and qualitative articles are analyzed and synthesized separately. However, once synthesized, the findings from quantitative and qualitative syntheses are then integrated. In the current study, a particular focus placed on contextualizing the quantitative findings with the qualitative.

Search strategy

Our initial search was conducted on the PubMed, Scopus, and CINAHL databases between November 26 and December 2, 2019. However, we later expanded our search to include PsycInfo to ensure no relevant articles were omitted (search conducted on December 23, 2020). We later repeated our original search on PubMed, Scopus, and CINAHL and limited the results to 2020-2021 to identify articles published over the previous year. The original search algorithm was developed for PubMed and then modified to reflect unique field codes and subject headings of the other three databases (See Table 1 for a list of the search terms). We also conducted a search of the grey literature using the CADTH Grey Matters grey literature checklist. The initial searches were conducted by one author, MG, and reviewed by a second, JP. Any disagreements regarding the inclusion of specific articles were resolved through discussion and eventual consensus.

Eligibility criteria

Articles written in English, focused on the financial or psychosocial impact of pediatric food allergy (i.e., children and adolescents 0-19 years) on caregivers were eligible for review. Eligible articles not only included those investigating the caregiver burden associated with IgE-mediated food allergies, but also non-IgE mediated allergies (i.e., food protein-induced

enterocolitis, proctocolitis, enteropathy). Studies focusing primarily on mixed IgE disorders (i.e., eosinophilic esophagitis, gastritis, gastroenteritis, and colitis) and intolerances (e.g., lactose intolerance, non-celiac gluten sensitivity) were not eligible for inclusion. While studies that explicitly included participants with non-eligible conditions were excluded, it is important to note that some of the samples were described ambiguously. Therefore, despite our best efforts, some of the reviewed articles may have included participants with non-eligible conditions. Lastly, we excluded any studies using secondary data as well as research published in conference proceedings given that it is typically not peer-reviewed and is of a preliminary nature.

Quantitative data extracted

Data extracted from the source articles included the authors' names, publication year, title, country of origin of the sample, study objectives, sample size, sample age, study design, comparator group/s, outcome measures, the allergy type, allergens studied, diagnosis type (e.g., physician-diagnosed or self-reported), burden type and key findings. Lastly, the methodological quality of the quantitative studies was assessed using the National Heart, Lung, and Blood Institute's Quality Assessment Tools.³⁰ Through these checklists, the studies were assigned a rating of good, fair, or poor based on the study's risk of bias. Given the widely varying designs, measures, and quality of the reviewed studies, the quantitative literature was synthesized through the use of a narrative synthesis rather than a meta-analysis.

Qualitative data thematic synthesis

The findings from the qualitative literature were summarized using the thematic synthesis approach, which is a qualitative methodology used to summarize and integrate the findings from multiple qualitative studies.²⁹ Consistent with this approach, the results sections from each of the

included qualitative studies were coded line-by-line with short descriptive codes. Once the findings were coded, conceptually similar codes were grouped together to form descriptive themes that captured the underlying meaning of a particular collection of codes. In the final step, the descriptive themes were grouped to form higher order analytical themes that were aimed at explaining the sources of burden faced by the caregivers of children with food allergy. Each step of the thematic synthesis was reviewed by a second author. Conflicting interpretations of the data between the two authors were resolved through discussion and eventual consensus.

Selection of eligible studies

A full overview of the search results and selection process can be found in Figure 1. Of the 3466 unique publications screened, 164 received a full text review. However, upon review, 97 of these articles were excluded from the final sample as they were not focused on the phenomena of interest. A further 10 were excluded as they failed to include primary data, 3 publications were derived from conference proceedings and 1 was excluded as the author incorrectly interpreted the scaling of their exposure measures. After excluding all the ineligible publications, 36 studies were included in the quantitative synthesis, 16 in the qualitative synthesis, and 1 mixed-methods article, had aspects included in both.

Quantitative synthesis

Impairments in quality of life

A review of the quantitative studies provided considerable evidence of the negative impact of pediatric food allergy on parental quality of life (QoL). In fact, ten of the twelve studies (83%) that employed the use of a comparison group found parents with a child with a food allergy reported reduced quality of life in at least one area of their lives (see Table 2 for a

complete summary).^{6,11,31-38} Across these studies, parents raising a child with a food allergy tended to report lower *emotional* quality of life relative to their respective comparison groups.^{6,11,32,34,35,38} Differences in emotional quality of life appeared largely consistent across studies irrespective of differences in methodology and population. While emotional impairments emerged consistently across the reviewed studies, it was not the only difference found as several studies provided evidence of social tensions and pragmatic impairments among parents raising a child with food allergy.^{5,6,11,32,36,38,39}

Results from the within-group sample of studies (i.e., restricted to families with children with food allergy) revealed several factors were predictive of reduced quality of life among parents (See Table 3 for a complete review). In particular, parents living in households with greater numbers of food allergies, either within or across children, tended to report lower quality of life relative to those with fewer allergies.^{8,9,32,33,38,40-46,47} Similarly, parents of children with comorbid allergic diseases reported a greater parental burden in comparison to parents whose children did not have allergic comorbidities.^{32,41,48} The severity of the child's food allergy also appears to play a significant role in parental burden as parents with a child with a history of severe reactions (i.e., confirmed anaphylaxis or symptoms consistent with anaphylaxis) tended to report greater burden than parents without such a history.^{9,35,40,41,43,48} Only five of the reviewed studies included an examination of the burden of food allergy across parents.^{43,45,48-50} In four of these studies (80%), however, mothers reported greater burden than fathers in at least one area of their lives.^{43,48-50}

Psychological burdens: Stress and anxiety

Consistent with the QoL findings, mothers of children with food allergy tended to report higher levels of trait anxiety and stress relative to their respective comparison groups (See Table

2 for summary of findings).^{12,33,50,52,53,54} While the same effect was not found for fathers, it should be noted that the psychological burden of male caregivers was only examined in 3 of 5 studies that examined the influence of caregiver gender.^{33,34,50} Within group analyses of the caregivers of children with food allergy provided evidence that parents of children with more severe allergy reported more psychological distress than parents of children with less severe manifestations of the condition (See Table 3 for a summary).^{12,52,55} Because only one of the reviewed studies investigated the relationship between pediatric food allergy and depression, it is unclear whether the condition is associated with a deleterious effect on parental mood.⁵⁶

Financial burdens: Increased costs of living, medications, and travel.

Relative to psychosocial burden, far fewer studies have examined the impact of pediatric food allergy on household costs. Nevertheless, a small body of research suggests that households with a child with food allergy shoulder greater costs relative to families without food allergy (See eTable 1 for a complete summary).^{7,37,57,58} In particular, Swedish findings suggest families with a child with a food allergy have higher annual out-of-pocket costs relative to healthy controls (range of additional costs across Swedish studies = \$345.98-\$2524.12 USD), with costs largely driven by greater spending on medications, medical-related travel, and the cost of living (e.g., diet and domestic help).^{7,37} Swedish research has also found that families with a child with food allergy incur significantly higher annual indirect costs (range of additional costs across Swedish studies = \$318.16 - \$1876 USD), defined as the loss of time or wages.^{7,37} In one of the Swedish studies, however, significant direct and indirect cost differences were only found among parents with children (i.e., 0-12 years) with food allergy, but not adolescents.³⁷ More recently, a Canadian study found that families with food allergy had higher direct costs (\$1707.46 USD), which were largely attributed to spending on food.⁵⁸ This finding is consistent with American

research, which found that spending on food and childcare made the largest contributions to the out-of-pocket costs attributable to food allergy.¹⁰

Qualitative synthesis

A total of 15 descriptive themes (see Figure 2) and four analytical themes were identified through our thematic synthesis. Each of the four analytical themes reflected the broad impact that pediatric food allergy has on parents (See eTable 2 for summary of the qualitative studies).

“It’s a big thing at first”

The first theme captured the initial emotional impact that follows a diagnosis of food allergy and the coping strategies motivated by the diagnosis. Through our review, it became apparent that parents often struggled with the emotional consequences of the initial reaction.^{14,59-61} For many, the initial fears that followed their child’s diagnosis appeared rooted in the rare, but potentially fatal consequences of an anaphylactic reaction^{13,14,60,62}: *“The frightening part was what could have been. And so that was a shock to the system, that I had nightmares for weeks on end after that...”*.⁶⁰ Faced with the task of keeping their child away from allergens, parents began to question their ability to keep their child safe.^{14,61} For some, these concerns were compounded not only by a lack of management information, but also by a lack of emotional support.^{14,60,61,64,65} Over time, however, most parents developed a repertoire of food allergy knowledge that appeared to moderate their worst fears^{14,61,64}: *“It’s a big thing at first, it really is a big, a huge big thing. But, you know, we’ve (...) come back on to more of an even keel”*.¹³ While caregivers reported growing more confident in their management skills over time, many expressed that the threat of accidental exposures necessitated vigilance.^{13,14,61,62,66,67} As such, even parents who learned to successfully manage their child’s food allergy appeared unable to completely avoid the practical and emotional demands of their child’s condition.

The tension between anxiety and control.

The second theme that was identified, “The tension between anxiety and control”, captured the difficult balance that parents maintained between their need for control and their desire to afford their child with a “normal” life.^{66,68,69} While parents recognized the importance of affording their child with freedom, activities where their child was in the care of others, could evoke anxiety due to their lack of control^{61,66,68}; “... *they went to a [baseball] game last Thursday in the afternoon. Well that’s a nightmare... I sent him his lunch and his drink, but where’s he sitting? Is there peanut shells all over the floor? Did the person sitting in the chair before him eat peanuts??*”.⁶⁶ Arguably, the high level of anxiety provoked by activities independent of parental supervision suggests that many parents not only struggle to trust others to keep their child safe, but also their child themselves. While the parents of older children reduced their uncertainty by passing their management skills onto their kids, they appeared unable to completely free themselves from the anxiety of food allergy given their inability to control the actions of others: “*I’m aware that he is now more with friends and he does check labels for himself . . . usually . . . but . . . what if another friend has a Snickers bar . . . or if it is a girl and he is going to . . . But that’s the next concern for me.*”⁶⁹ As their adolescents approached adulthood and began to gain more freedom, parents experienced greater worry regarding the loss of pediatric primary-care, as well as the allergy-related risks associated with drinking and late night eating.⁶⁷⁻⁶⁹ While parents were able to maintain a sense of control by instilling sound management practices in their children, it was apparent that even though their children were on the cusp of adulthood, drinking and the subsequent loss of control could still provoke worry.

A lack of understanding among others

The third theme we established, “A lack of understanding among others” described the challenges that caregivers faced as a result of others’ lack of food allergy knowledge.^{13,14,59-66,70-}

⁷² One way this lack of understanding was expressed was through poor allergen management techniques. Parents reported encountering this lack of understanding in a number of areas where food is served including restaurants, private homes, school, and childcare centres^{59,70-72}. While the public’s general lack of understanding was cause for concern, caregivers appeared more affected by instances in which the seriousness of their child’s food allergy was overtly disregarded.^{13,14,59,62,72} Arguably, these instances served to remind parents of the indifference of others to their concerns, while drawing attention to the limited number of people who can be trusted to keep their concerns in mind. In fact, some parents reported that even family members did not fully understand the seriousness of their child’s food allergy.^{14,59,62,70}: “(*Anaphylaxis is basically life or death, it’s serious and that you don’t take chances. And that people don’t understand it unless you’ve seen your child basically starting to die in front of you don’t, they don’t get it. And even now, some of our family doesn’t quite get it.*”⁶² Unfortunately, even when caregivers made efforts to inform others of the significance of their child’s food allergy it could provoke negative reactions ranging from dismissal to outright hostility.^{59,69}

The insoluble aspects of food allergy: practical burdens.

The final theme that was identified, “The insoluble aspects of food allergy: practical burdens”, captured the everyday, practical burdens that remain after the emotional burden of the initial diagnosis had subsided.^{13,14,60,62,64,65,73,74} In particular, parents described experiencing difficulties related to cooking and eating, with a number of caregivers citing label reading as a common source of strain^{14,60,66}: “*It’s frustrating to deal with the ingredients and labels and for whatever allergy it is there’s always something you’re unsure of.*”⁶⁶ Parents also described

incurring a financial burden due to the high cost of medications, allergen-friendly food, and specialized childcare^{62,64,65,72}: *“Dealing with the high cost of these foods is intense, and we are both middle-income earners. Good grief, what do low income people with allergies do?”*.⁶²

Integration of the quantitative and qualitative findings

Results from the quantitative literature revealed that parents caring for a child with a food allergy consistently report lower emotional quality of life as a result of their child’s health condition.^{6,11,32,34,35,38} Moreover, evidence from the reviewed studies suggests that parents managing a greater number of food allergies, more severe allergies, and/or allergic comorbidities were particularly burdened.^{8,9,12,32,33,38,40-45,48,52,55} While far fewer studies have examined whether parents experience mental health challenges beyond those tied to the health of their child, the extant literature does suggest that *mothers* of children with food allergy experience higher levels of trait anxiety and stress relative to healthy controls and population norms.^{12,33,50,52,53,54} Based on the qualitative literature, it appears as though some of the emotional burden of raising a child with a food allergy stems from the worries and practical concerns of food allergy management. Not surprisingly, parents described the process of constantly monitoring their child’s food and environment for potential allergens as time consuming and often stressful.^{14,60,66} Parents also cited a lack of food allergy awareness among family, friends, and the greater community as contributing to their stress and frustration.^{13,14,59-62,65,70-72}

Beyond emotional and practical burdens, families with food allergy reported additional annual direct (range across reviewed studies = \$345.98-\$2524.12 USD) and indirect costs (range across reviewed studies = \$318.16 - \$1876 USD) associated with their child’s condition.^{7,37,58} While research suggests that families with food allergy incur greater costs in a number of different areas, food and medication, emerged as consistent sources of added spending.^{7,10,37,58,75}

Interestingly, the financial impact of specialized diets and medication emerged not only in the quantitative literature, but in a number of qualitative studies as well.^{62,64,65,72}

Integration with the previous literature

Findings from the current study strengthen and extend the conclusions of Cummings and colleagues' 2010 mixed-methods review²⁸, by providing a number of novel insights into the burden of the pediatric food allergy. Most importantly, the wealth of literature published over the past decade now provides conclusive evidence that parents of children with food allergy quantitatively report lower quality of life relative to various comparison groups.^{6,11,32,34,35,38} Moreover, novel within-group studies suggest that parents of children with a history of severe reactions (i.e., confirmed anaphylaxis or symptoms consistent with anaphylaxis) experience greater burden than those without such a history.^{9,35,40,41,43,48} Lastly, the present study also adds to the work of Cummings and colleagues by demonstrating the financial burden that follows a pediatric food allergy diagnosis.^{7,10,37,57,58,62,64,65}

Implications

Arguably, the results of the current review underscore the importance of food allergy education in alleviating the burden of caregivers. Through our review of the qualitative literature, it was apparent that many parents' initial struggles stemmed, in part, from a lack of practical knowledge regarding the management of food allergy.^{14,60,61,64} While parents were able to develop their management knowledge over time, many reported being overwhelmed at the prospect of doing so on their own.^{14,61} Consequently, it would appear as though parents may benefit from greater food allergy education and training at the time of their child's initial diagnosis. Such training should strive to not only provide parents with practical food allergy

management information, but also objective information about the risks of food allergy.

Although the incidence of fatal anaphylaxis for individuals with food allergy has been found to be lower than that of accidental deaths in the general population, many of the fears discussed by parents in the current study appeared to be animated by the potential for fatal outcomes.^{13,14,60,62,76} Moreover, a number of parents expressed worries regarding unlikely sources of serious reactions including casual contact and sexual activity.^{62,66} Taken as whole, these findings highlight the importance of communicating the risk of food allergy in way that is objective, but sympathetic to the concerns of families. While educators and clinicians should be careful not to trivialize the seriousness of anaphylaxis, findings from both the current review suggest that some parents may be relieved to learn that the actual risk of fatal outcomes is exceedingly low.⁷⁶

Gaps in the literature

While the number of studies devoted to understanding the psychosocial burden of food allergy has increased dramatically over the past decade, the current review did reveal several gaps in the literature including a lack of research focused on the relationship between childhood food allergy and parental depression. Given the established links between chronic stress and depressed mood, future research should aim to determine whether the emotional burden of childhood food allergy has an impact on parental mood.⁷⁷ Further research is also needed to understand the differences in burden among male and female caregivers as the vast majority of studies to date have failed to examine differences between caregivers. Lastly, it should be noted that although researchers have begun to trace the impact of childhood food allergy on household finances, much more research is needed to determine with greater certainty the types of costs incurred as well as their magnitude.

Limitations

Several limitations of the current review should be noted including the methodological quality of the included studies. While few of the studies received a “poor” quality rating, many made use of population norms or historical cohorts that may not have been comparable to their food-allergic samples. Moreover, a number of the reviewed studies may have exaggerated the burden of food allergy by failing to control for allergic comorbidities.⁷⁸⁻⁸⁰ Lastly, because of the wide variations in the quality, design, and measures of the reviewed studies, we did not undertake a formal meta-analysis of the quantitative literature.

Conclusion

Findings from the current review suggest that the caregivers of children with food allergy experience a greater emotional burden relative to those without children with food allergy. Results from the qualitative literature suggest that this burden stems, in part, from the persistent threat of exposure as well as the practical and social demands associated with managing a pediatric food allergy. While the emotional impact of pediatric food allergy is greatest after the initial diagnosis, findings suggest the burden never completely subsides. Results from the review also provide evidence that childhood food allergy can have a financial impact on some families due to the increased costs of food, medication, and time. Lastly, findings underscore the need for more research in several areas including the financial impact of pediatric food allergy, comparison of the burden faced by male and female caregivers, and levels of depressive symptomology among the parents of children with food allergy.

Acknowledgements

We would like to thank Ayel Batac for his help with the literature review and for his substantial contributions to the creation of the paper’s many tables and figures.

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Figure 1. Flowchart of the study selection process.

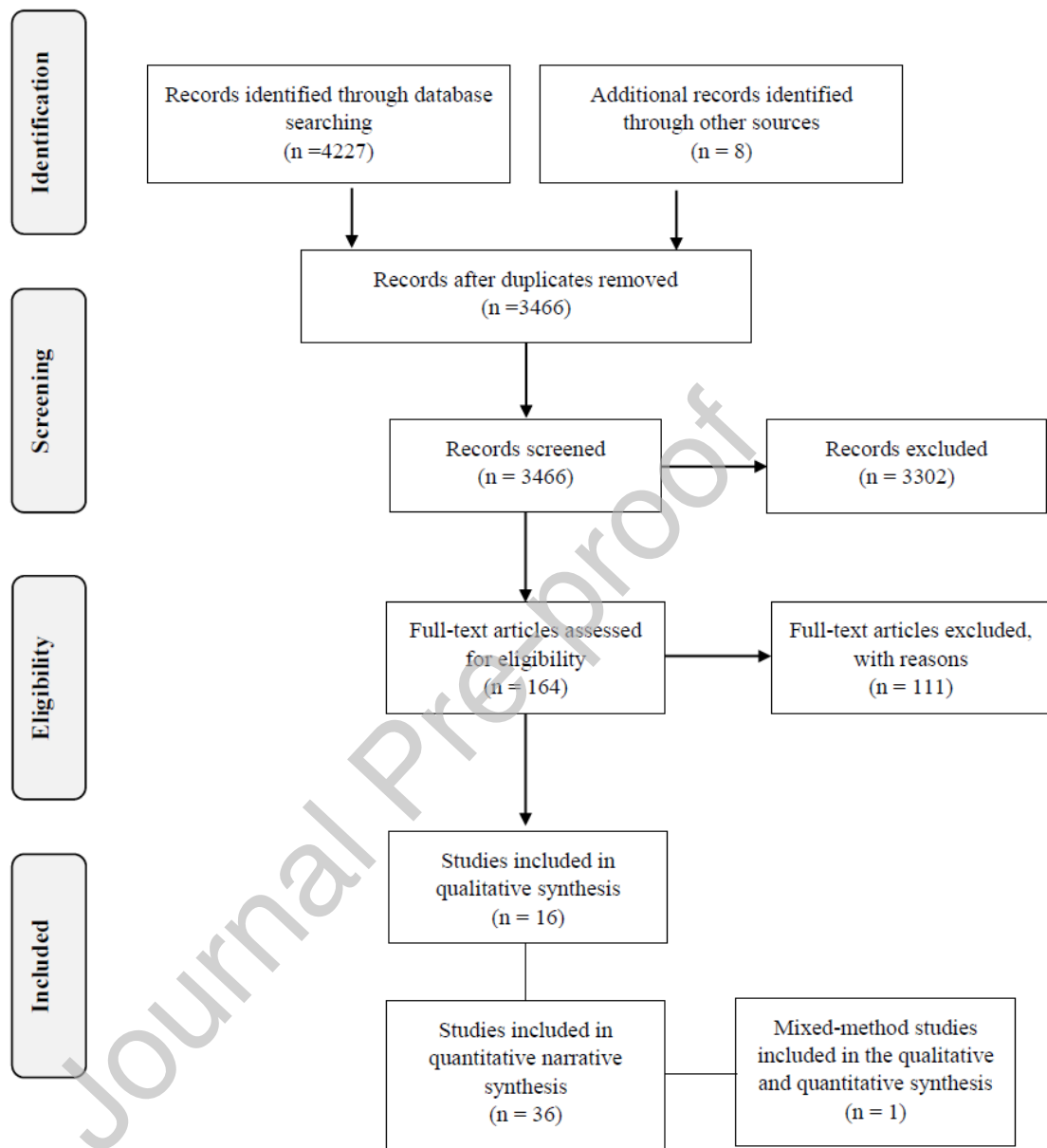


Figure 2. Analytical themes and their constituent descriptive themes.

It's a big thing at first	The tension between anxiety and control	A lack of understanding among others	The insoluble aspects of food hypersensitivity: Practical burdens
• Emotional difficulties follow the initial reaction • Early burden compounded by a lack of information • Information and professional support • Burden improves over time • The importance of vigilance	• Concerns with management outside of the home • Concerns with the transition to self-management	• Allergen management • Dismissal of risk • Raising awareness: necessary, but difficult	• Cooking/eating • Increased burden of finding suitable childcare • Travelling is difficult • Financial burden: Food • Financial burden: Medication

Table 1. Search strings

Bibliographic databases	Search String
PubMed	(psychological health[tw] OR "cost of illness"[MeSH Terms] OR "quality of life"[MeSH Terms] OR "socioeconomic factors"[MeSH Terms] OR "stress, psychological"[MeSH Terms] OR "mental disorders"[MeSH Terms] OR "social adjustment"[MeSH Terms] OR burden[tw] OR community[tw] OR economic[tw] OR HRQL[tw] OR mental[tw] OR psychologic[tw] OR social[tw]) AND (allergen avoidance[tw] OR ige sensitization[tw] OR ige sensitization[tw] OR food hypersensitivity[tw] OR "food hypersensitivity"[MeSH Terms] OR food protein induced enterocolitis[tw] OR "lactose intolerance"[MeSH Terms] OR "food intolerance"[MeSH Terms] OR food allergy[tw] OR peanut allergy[tw] OR dairy allergy[tw] OR immunoglobulin e-mediated[tw]) AND "humans"[MeSH Terms] AND English[lang] NOT ("systematic review"[Publication Type] OR "systematic reviews as topic"[MeSH Terms] OR "systematic review"[All Fields]) NOT ("review"[Publication Type] OR "review literature as topic"[MeSH Terms] OR "review"[All Fields]) NOT ("meta-analysis"[Publication Type] OR "meta-analysis as topic"[MeSH Terms]).
Scopus	TITLE-ABS-KEY (("stigma" OR "psychological health" OR "cost of illness" OR "quality of life" OR "socioeconomic factors" OR stress OR "mental disorders" OR "mental disease" OR "social adjustment" OR burden OR community OR economic OR hrql OR mental OR psychologic OR social OR "psychological wellbeing" OR anxiety OR depression) AND ("allergen avoidance" OR "ige sensitization" OR "ige sensitisation" OR "food hypersensitivity" OR "food protein induced enterocolitis" OR "lactose intolerance" OR "food intolerance" OR "food allergy" OR "peanut allergy" OR "dairy allergy" OR "milk allergy" OR "immunoglobulin e-mediated")) AND (LIMIT-TO (DOCTYPE , "ar")) AND (LIMIT-TO (LANGUAGE , "English")) AND (EXCLUDE (SRCTYPE , "k") OR EXCLUDE (SRCTYPE , "d") OR

	EXCLUDE (SRCTYPE , "b"))
CINAHL	MH stigma OR MH psychological wellbeing OR MH quality of life OR MH stress, psychological OR food allergy/economics OR food hypersensitivity/economics OR MH socioeconomic factors OR MH caregiver burden OR "psychological health" OR burden OR community OR economic OR HRQL OR mental OR psychologic OR social) AND (MH food hypersensitivity OR MH food intolerance OR MH milk hypersensitivity OR "allergen avoidance" OR "ige sensitization" OR "ige sensitisation" OR "food protein induced enterocolitis" OR "lactose intolerance" OR "food allergy" OR "peanut allergy" OR "peanut hypersensitivity" OR "dairy allergy" OR "dairy hypersensitivity" OR "immunoglobulin e-mediated")*
PsycInfo	((("stigma" or "psychological health" or "cost of illness" or "quality of life" or "socioeconomic factors" or stress or "mental disorders" or "mental disease" or "social adjustment" or burden or community or economic or hrql or mental or psychologic* or social or "psychological wellbeing" or anxiety or depression) and ("allergen avoidance" or "ige sensitization" or "ige sensitisation" or "food hypersensitivity" or "food protein induced enterocolitis" or "lactose intolerance" or "food intolerance" or "food allergy" or "peanut allergy" or "dairy allergy" or "milk allergy" or "immunoglobulin e-mediated"))).mp*

Note. Initial searches on PubMed, Scopus, and CINAHL conducted on November 26, 27, and December 2, 2019, respectively. PsycInfo search conducted on December 23, 2020. PubMed, Scopus and CINAHL were searched a second time on February 5, 2021 to identify articles published in the previous year. Although intolerance was included a search term, articles pertaining to intolerances were ultimately excluded *Search limited to peer-reviewed and English language articles.

Table 2 Summary of the quantitative studies that included a comparison group

Study	Country	Allergy Type	Comparison Group	Between Group Outcomes	Direction of Association	Within-group analyses		Quality
						Aggravating Factors	Mitigating Factors	
Acaster et al., 2020 (31)	United Kingdom	IgE-mediated allergy	Population norms	HRQL (↑=✓)				Poor
				Total	NS	Pessimistic food allergy expectations	-	
				VAS	Negative	Pessimistic food allergy expectations +2 reactions in the previous year	Caregiver confidence	
				Anxiety (↓=✓)	Positive	Pessimistic food allergy expectations	Caregiver confidence	
				Depression (↓=✓)	Positive	Pessimistic food allergy expectations +2 reactions in the previous year	Caregiver confidence	
				Parental Burden (↓=✓)	N/A	Pessimistic food allergy expectations +2 reactions in the previous year	Caregiver confidence	
Borres, et al., 2016 (11)	Sweden	IgE-mediated allergy	Caregivers of children with grass allergy	HRQL (↑=✓)				Fair
				Parental impact - emotional	Negative	-	-	
				Parental impact - time	Negative	-	-	

Table 2 continued

Study	Country	Allergy Type	Comparison Group	Between Group Outcomes	Direction of Association	Within-group analyses		Quality
						Aggravating Factors	Mitigating Factors	
Borres, et al., 2016 cont'd	Sweden	IgE-mediated allergy	Caregivers of children with grass allergy	HRQL (↑=✓)				Fair
				Family activities	Negative	-	-	
				Family cohesion	NS	-	-	
Burke and Hopper, 2017 (51)	Australia	IgE-mediated allergy & intolerances*	Caregivers of children with food allergy	Distress (↓=✓)				Fair
				General distress	NS	-	-	
				Performance difficulties	NS	-	-	
				Somatic distress	NS	-	-	
				Positive Adjustment (↑=✓)	NS	-	-	
Cummings et al., 2010 (52)	United Kingdom	IgE-mediated allergy	Population norms	QoL (↑=✓)				Poor
				Total	N/A	EAI prescription Outgrown previous allergy	-	
				Physical health	Positive	-	-	
				Psychological health	NS	-	-	
				Social relationships	NS	-	-	

Table 2 continued

Within-group analyses

Study	Country	Allergy Type	Comparison Group	Between Group Outcomes	Direction of Association	Aggravating Factors	Mitigating Factors	Quality
Cummings et al., 2010 cont'd	United Kingdom	IgE-mediated allergy	Population norms	Parental Burden (↓=✓)	N/A	Avoidance of PAL products	-	Poor
				Trait Anxiety (↓=✓)	Positive	Outgrown previous allergy	EAI prescription	
				State Anxiety (↓=✓)	NS	-	-	
				Stress (↓=✓)	NS	Outgrown previous allergy	-	
DunnGalvin et al., 2020 (53)	Russia	IgE-mediated allergy	Population norms	Anxiety (↓=✓)	Positive	-	-	Poor
Goodwin et al., 2017 (56)	U.S.A.	IgE-mediated allergy	Caregivers of children without food allergy	Depression (↓=✓)	NS	-	-	Fair
				Anxiety (↓=✓)	NS	-	-	
Herbert et al., 2017 (39)	U.S.A.	Not explicitly stated	Population norms	Mealtime concerns (↓=✓)		Risk of allergen exposure	-	Poor
						Parenting stress	-	
						Parenting burden	-	
						-	-	
						-	-	
King et al., 2009 (50)	United Kingdom	IgE-mediated allergy	Population norms	QoL (↑=✓)		Gender (Mothers < Fathers) [†]		Poor
				Total		-	-	

Table 2 continued

Within-group analyses

Study	Country	Allergy Type	Comparison Group	Between Group Outcomes	Direction of Association	Aggravating Factors	Mitigating Factors	Quality
King et al., 2009 cont'd	United Kingdom	IgE-mediated allergy	Population norms	QoL ($\uparrow=\checkmark$)		Gender (Mothers < Fathers) [†]		Poor
				Maternal physical health	Positive	-	-	
				Paternal physical health	Positive	-	-	
				Maternal psychological health	NS	-	-	
				Paternal psychological health	Positive	-	-	
				Maternal social health	Positive	-	-	
				Paternal social health	Positive	-	-	
				Maternal environment quality	Positive	-	-	
				Paternal environment quality	Positive	-	-	
				Trait Anxiety ($\downarrow=\checkmark$)		Gender (Mothers > fathers) [†]		
				Maternal Trait Anxiety	Positive	-	-	
				Paternal Trait Anxiety	NS	-	-	

Table 2 continued

Study	Country	Allergy	Comparison	Between Group	Direction of	Within-group analyses		Quality
						Aggravating	Mitigating Factors	

		Type	Group	Outcomes	Association	Factors	
King et al., 2009 cont'd	United Kingdom	IgE-mediated allergy	Population norms	State anxiety (↓=✓)		Gender (Mothers > fathers) [†]	Poor
				Maternal state anxiety	NS	-	-
				Paternal state anxiety	Negative	-	-
				Perceived stress (↓=✓)		Gender (Mothers > fathers) [†]	
				Maternal perceived stress	Positive	-	-
				Paternal perceived stress	NS	-	-
Lau et al., 2014 (12)	United Kingdom	IgE-mediated allergy	Mothers of children without food allergy	Perceived Stress (↓=✓)	Positive	Previous anaphylaxis	-
						Asthma diagnosis	-
						Uncontrolled asthma	-
						Moderate/sever rhinitis	-
				Anxiety (↓=✓)			
				Trait Anxiety	NS	Previous anaphylaxis	-
						Asthma diagnosis	-
						Uncontrolled asthma	-

Table 2 continued

Study	Country	Allergy Type	Comparison	Between Group	Direction of	Within-group analyses		Quality
						Aggravating	Mitigating Factors	

			Group	Outcomes	Association	Factors	
Lau et al., 2014 cont'd	United Kingdom	IgE-mediated allergy	Mothers of non- food-allergic children	Anxiety (↓=✓)			Fair
				Trait Anxiety	NS	Moderate/severe rhinitis	-
				State Anxiety	Positive	Previous anaphylaxis	-
						Eczema diagnosis	-
						Asthma diagnosis	-
						Uncontrolled asthma	-
						Moderate/severe rhinitis	-
Maciag et al., 2020 (46)	U.S.A.	Non-IgE mediated allergy (FPIES)	Parents of children with IgE- mediated food allergy	Parental Burden (↓=✓)	Positive	Income <\$100,000	-
						Lower food allergy self- efficacy	-
						Greater number of foods avoided [‡]	-
						Avoidance of cow's milk	-
						School/daycare avoidance due to FPIES [§]	-

Table 2 continued

Study	Country	Allergy Type	Comparison Group	Between Group Outcomes	Direction of Association	Within-group analyses		Quality
						Aggravating Factors	Mitigating Factors	

Maciag et al., 2020 cont'd	U.S.A.	Non-IgE mediated allergy (FPIES)	Parents of children with IgE- mediated food allergy	Anxiety (↓=✓)	N/A	Greater number of foods avoided [‡]	-	Fair
						School/dayca re avoidance due to FPIES [§]	-	
				Stress (↓=✓)	N/A	Avoidance of cow's milk	-	
						School/dayca re avoidance due to FPIES [§]	-	
Meyer et al., 2017 (32)	United Kingdom	Non-IgE mediated allergies	Historical cohort of caregivers of children with sickle cell disease	Worry (↓=✓)	N/A	School/dayca re avoidance due to FPIES [§]	-	Poor
				HRQL – Family Impact (↑=✓)				
				Total score	Negative	Younger child age	-	
						Number of foods avoided	-	
						Symptom severity	-	
						Chronic nasal congestion	-	
				Physical functioning	Negative	-	-	
				Emotional functioning	Negative	-	-	

Table 2 continued

Study	Country	Allergy Type	Comparison Group	Between Group Outcomes	Direction of Association	Within-group analyses		Quality
						Aggravating Factors	Mitigating Factors	

Meyer et al., 2017 cont'd	United Kingdom	Non-IgE mediated sensitivities	Historical cohort of caregivers of children with sickle cell disease	HRQL – Family Impact (↑=✓)				Poor
				Social functioning	Negative	-	-	
				Cognitive functioning	Negative	-	-	
				Communication	Negative	-	-	
				Worry	Negative	-	-	
				Daily activities	Negative	-	-	
				Family relationships	Negative	-	-	
			Historical cohort of caregivers of children with intestinal failure	Total score	NS	-	-	
				Physical functioning	Negative	-	-	
				Emotional functioning	Negative	-	-	
				Social functioning	NS	-	-	

Table 2 continued

Study	Country	Allergy Type	Comparison	Between Group	Direction of	Within-group analyses		Quality
						Aggravating	Mitigating Factors	

			Group	Outcomes	Association	Factors	
Meyer et al., 2017 cont'd	United Kingdom	Non-IgE mediated sensitivities	Historical cohort of caregivers of children with intestinal failure	HRQL – Family Impact (↑=✓)			Poor
				Cognitive functioning	NS	-	-
				Communication	NS	-	-
				Worry	Negative	-	-
				Daily activities	NS		
				Nutritional concerns	Positive	Caregivers of older children	-
						Avoidance of two of more foods	-
						FA child at least second in birth order	-
				Family Relationships	NS		
Mikkelsen et al., 2013 (33)	Sweden	Not explicitly stated	Caregivers of children without food allergies	Stress – total score (↓=✓)	Positive	Caregivers of older children	-
						FA child at least second in birth order	-
				Family Impact (↓=✓)			
				Total score	N/A	Caregivers of older children	-

Table 2 continued

Within-group analyses

Study	Country	Allergy Type	Comparison Group	Between Group Outcomes	Direction of Association	Aggravating Factors	Mitigating Factors	Quality
Mikkelsen et al., 2013 cont'd	Sweden	Not explicitly stated	Caregivers of children without food allergies	Family Impact (↓=✓)				Poor
				Total score	N/A	Avoidance of two or more foods	-	
						FA child at least second in the birth order	-	
				Nutritional concerns	Positive	Caregivers of older children	-	
						Avoidance of two of more foods	-	
						FA child at least second in birth order	-	
				Everyday life	N/A	Caregivers of older children	-	
						Avoidance of two of more foods	-	
						FA child at least second in birth order	-	
Mikkelsen et al., 2015 (34)	Sweden	Not explicitly stated	Caregivers of children with resolved food allergies	Stress - total score (↓=✓)	NS	-	-	Fair

Table 2 continued

Within-group analyses

Study	Country	Allergy Type	Comparison Group	Between Group Outcomes	Direction of Association	Aggravating Factors	Mitigating Factors	Quality
Mikkelsen et al., 2015 cont'd	Sweden	Not explicitly stated	Caregivers of children with resolved food allergies	Family Impact (↓=✓)				Fair
				Total score	Negative	-	-	
				Nutritional concerns	Negative	-	-	
				Health & Emotions	Negative	-	-	
				Everyday life	Negative	-	-	
Ostblom et al., 2008 (35)	Sweden	Non-IgE/IgE-mediated allergies	Caregivers of children free of allergic disease	HRQL (↑=✓)		Lower airway symptoms	-	Good
						More than 2 symptoms	-	
						More frequent symptoms	-	
				Parental impact - emotional	Negative	-	-	
				Parental impact - time	NS	-	-	
				Family activities	NS	-	-	
				Family cohesion	NS	-	-	
Primeau et al., 2000 (36)	Canada	IgE-mediated allergy	Caregivers of children with rheumatological disease	Family Impact (↓=✓)				Fair
				Family disruption	Positive	-	-	
				Personal strain	NS	-	-	
				Financial impact	Negative	-	-	

Table 2 continued

Within-group Analyses

Study	Country	Allergy Type	Comparison Group	Between Group Outcomes	Direction of Association	Aggravating Factors	Mitigating Factors	Quality
Primeau et al., 2000 cont'd	Canada	IgE-mediated allergy	Caregivers of children with rheumatological disease	Coping mastery (↑=✓)	Positive	-	-	Fair
Protudjer et al., 2020 (54)	Canada	Not explicitly stated	Caregivers of children without food allergy	Anxiety (↓=✓)	Positive	-	-	Fair
Protudjer et al., 2015 (37)	Sweden	Not explicitly stated	Caregivers of children without food allergy	Perinatal Anxiety (↓=✓) Well-Being (↑=✓)	NS	-	-	Fair
Sicherer et al., 2001 (38)	U.S.A.	Not explicitly stated	Population norms	Overall well-being HRQL (↑=✓)	Negative	-	-	Poor
Valentine & Knibb, 2011 (6)	United Kingdom	IgE-mediated allergy	Caregivers of children without food allergy	Parental impact - emotional	Negative	More than 2 food allergies	-	Poor
				Parental impact - time	Negative	More than 2 food allergies	-	
				Family activities	Negative	More than 2 food allergies	-	
				Family cohesion	Positive	-	-	
				QoL (↑=✓)				
				Total score	Negative	-	-	
				Physical health	NS	-	-	
				Psychological health	NS	-	-	
Table 2 continued								
Study	Country	Allergy Type	Comparison Group	Between Group Outcomes	Direction of Association	Within-group Analyses		Quality
						Aggravating Factors	Mitigating Factors	

Valentine & Knibb, 2011 cont'd	United Kingdom	IgE-mediated allergy	Caregivers of children without food allergy	QoL (↑=✓)				Poor
				Social relationships	Negative	-	-	
				Environment	NS	-	-	

Note. – = no significant aggravating/mitigating factors were analysed and/or identified. * Analyses of parents of children with non-immune intolerances were excluded from the current review. [†] Mothers reported higher state anxiety, trait anxiety, perceived stress, and lower physical and psychological HRQL. [‡] Finding specific to parents of pre-school and elementary aged children. [§] Finding specific to parents of pre-school aged children

Table 3. Summary of findings from within-group studies of parental burden

Study	Country	Allergy Type	Outcomes	Significant Inferential Findings		Quality
				Aggravating Factors	Mitigating Factors	

Abrams et al., 2020 (72)	Canada	Not explicitly stated	Parental Burden	Milk allergy	-	Fair
Allen et al., 2015 (40)	Australia	IgE-mediated allergy	Parental burden	Previous administration of EAI	-	Fair
Bollinger et al., 2006 (8)	U.S.A.	Not explicitly stated	Parental Burden	>2 sensitivities	-	Poor
Hoehn et al., 2017 (49)	U.S.A.	IgE-mediated allergy	Parental impact	Caregiver gender (mothers reported greater impact relative to fathers)	-	Poor
Howe et al., 2014 (41)	U.S.A.	IgE-mediated allergy	Parental burden	Egg allergy	Accurate reaction perception	Fair
				>1 food allergy	Most severe reaction occurred at an older age	
				History of anaphylaxis	Higher income	
				Comorbid eczema		
Knibb et al., 2016 (42)	United Kingdom	Not explicitly stated	Parental Burden	-	Greater management self-efficacy	Fair
				-	Greater parental mental health	
				-	Lower perceived likelihood of a reaction	
				-	Older child age	
				-	Fewer number of allergies	
Komulainen, 2010 (9)	Finland	Not explicitly stated	Parental Burden	Greater number of avoided foods	-	Fair
				Keeping a diary of symptoms	-	
				Child tearfulness	-	
				Child diarrhea	-	
				Child sleep troubles	-	
				Receipt of childcare allowance	-	
				History of anaphylaxis	-	

Table 3 continued

Study	Country	Allergy Type	Outcomes	Significant Inferential Findings		Quality
				Aggravating Factors	Mitigating Factors	

Leung, et al., 2009 (45)	China	Not explicitly stated	Parental Burden	Number of foods avoided	-	Fair
Middelveld et al., 2020 (47)	Sweden	Not explicitly stated	Life status	Family member (Mothers > other family members)	-	Fair
Springston et al., 2010 (43)	U.S.A.	Not explicitly stated	Parental burden	Comorbid milk and nut allergies*	-	Fair
				Greater food allergy knowledge	-	
				Greater EAI administration knowledge	-	
				Multiple food allergies	-	
				Emergency room visits in the previous year	-	
				Wheat allergy	-	
				Milk allergy	-	
Warren et al., 2015 (48)	U.S.A.	IgE-mediated allergy	Parental burden Maternal burden	Parent gender (mothers > fathers)	-	Fair
				Greater food allergy severity	Greater social support	
				Allergic comorbidities	Greater perceived resources	
				-	Caucasian ethnicity of child	
				-	Younger child age	
			Paternal burden	Greater food allergy severity	Greater social support	
				Male food allergic child	Greater perceived resources	
				Hispanic ethnicity	Caucasian ethnicity of child	
Williams et al., 2009 (55)	U.S.A.	Not explicitly stated	Parental distress	Younger food allergic child	Greater perceived emotional resources	Fair
				Greater severity of previous reactions	-	
				Child with emotional problems	-	

Table 3 continued

Study	Country	Allergy Type	Outcomes	Significant inferential findings		Quality
				Aggravating Factors	Mitigating Factors	
Ward and Greenhawt, 2016 (44)	U.S.A.	IgE-mediated allergy	Parental burden	Recruitment source: Allergy advocacy groups	-	Fair
				History of anaphylaxis	-	
				Past EAI use	-	
				Milk/egg allergy	-	
				Multiple food allergies	-	
				Lower food allergy self-efficacy	-	

Note. – indicates that no significant aggravating/mitigating factors were analysed and/or identified. * finding specific to mothers

eTable 1 Summary of the reviewed studies examining the financial burden of pediatric food allergy

Study	Country	Allergy Type	Comparison Group	Outcome	Between Group Outcomes	Cost Differential	Within group analyses			Quality
							Predicted Costs	Cost Increasing Factors	Cost Decreasing Factors	
Alanne et al., 2012 (75)	Finland	Not explicitly stated	None	Total out of pocket costs (first 2 years)	N/A	N/A	\$640.26	-	-	Fair
Dilley et al., 2019 (57)	U.S.A.	IgE / Non-IgE mediated allergies	Healthy controls	Food security (↑=✓)	NS (full sample) Negative (children with both milk and egg allergy)	N/A	N/A	-	-	Fair
Golding et al., 2021 (58)	Canada	IgE-mediated allergy	Healthy controls	Total household costs	NS	NS	N/A	-	-	Fair
				Total direct costs	Positive	\$1707.46	N/A	-	-	
Gupta et al., 2013 (10)	U.S.A.	Not explicitly stated	None	Household out of pocket costs	N/A	N/A	\$931 per child annually	-	-	Fair
				Opportunity costs	N/A	N/A	\$2399 per child annually	-	-	
Protudjer et al., 2015 (37)	Sweden	Not explicitly stated	Healthy controls	Costs for children with food allergy						Fair
				Total household costs	Positive	\$4795.22	N/A	-	-	

eTable 1 continued

Study	Country	Allergy Type	Comparison Group	Outcome	Between Group Outcomes	Cost Differential	Predicted Costs	Within-group analyses		Quality
								Cost Increasing Factors	Cost Decreasing Factors	
Protudjer et al., 2015 cont'd	Sweden	Not explicitly stated	Healthy controls	Costs for children with food allergy						Fair
				Total direct costs	Positive	\$2524.12	N/A	History of anaphylaxis	-	
				Total indirect costs	Positive	\$2270.94	N/A	-	-	
				Costs for adolescents with food allergy						
				Total household costs	Positive	\$5800.70	N/A	-	-	
				Total direct costs	NS	NS	N/A	-	-	
				Total indirect costs	NS	NS	N/A	Food allergy severity	-	
								Concomitant allergic disorders	-	
								Number of offending foods	-	

eTable 1 continued

Study	Country	Allergy Type	Comparison Group	Outcome	Between Group Outcomes	Cost Differential	Predicted Costs	Within-group analyses		Quality
								Cost Increasing Factors	Cost Decreasing Factors	
Wai et al., 2019 (7)	Sweden	Not explicitly stated	Healthy controls	Total household costs	NS	NS	N/A	-	-	Fair
				Total direct household costs	Positive	\$345.98	N/A	-	-	
				Total indirect household costs	NS	NS	N/A	-	-	

Note. Findings from the European studies were converted from Euros to US dollars on December 8, 2020. – indicates that no significant cost increasing/decreasing factors were identified and/or analysed. *total costs only reported across ethnic and socio-economic subgroup

eTable 2 Summary of the reviewed qualitative studies

Study	Country	Aim	Allergy Type	Participants*	Data collection method	Analysis
Abdurrahman et al., 2013 (60)	Canada	To understand the experiences of caregivers of children with first-time	IgE-mediated allergy	17 caregivers of a child with a newly diagnosed food allergy .	Semi-structured interviews and opened ended	Constant comparative method

		allergic reactions to food (within 12 months of the study) and to identify any existing deficiencies in the information they received at diagnosis			questionnaire questions	
Abrams et al., 2020 (72)	Canada	To examine the perception of burden among families with children with multiple food allergies	Not explicitly stated	The parents of 64 children with multiple food allergies	Open-ended survey questions	Content analysis
Alanne et al., 2011 (74)	Finland	To identify mothers' perceptions of the supporting or straining factors involved in motherhood generally and in relation to child's atopic dermatitis and food allergy at the age of one and two years	Not explicitly stated	13 mothers of children with food allergy and/or atopic dermatitis	Semi-structured interviews	Deductive content analysis
Akeson et al., 2007 (69)	United Kingdom	To explore the psychosocial impact of living with anaphylaxis on adolescents and their parents; their management of the condition; and perceptions of health care provision.	IgE-mediated allergy	9 parents with children with a history of anaphylaxis	Unstructured interviews	Framework analysis

eTable 2 continued

Study	Country	Aim	Allergy Type	Participants*	Data collection method	Analysis
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Broome et al., 2015 (14)	U.S.A.	This study seeks to understand parents' perspectives about the impact of having a child with severe food allergies and adjustments required to effectively manage the condition	IgE-mediated allergy	20 parents of children with life-threatening food allergies	Asynchronous interviews	Dimensional analysis
Bute et al., 2021 (70)	U.S.A.	To explore how parents navigate the nuances of food allergy maintenance while negotiating and preserving valued relationships and identities through everyday talk	Not explicitly stated	26 parents of children with food allergies	Semi-structured interviews	Phonetic-iterative analysis
Chooniedass et al., 2018 (65)	Canada	To describe parents' perceptions and experiences with epinephrine use during a child's anaphylactic reaction	IgE-mediated allergy	10 caregivers of children with a history of anaphylaxis	Semi-structured interviews	Not specified
DunnGalvin et al., 2020 (73)	United Kingdom France Germany Ireland Spain Italy Denmark Netherlands	To gain qualitative insight on the strategies used to cope with and manage PA and the impact of these strategies on the quality of life of children, teenagers and caregivers	IgE-mediated allergy	44 caregivers of children/teens with moderate to severe food allergy	Semi-structured interviews	Thematic analysis

eTable 2 continued

Study	Country	Aim	Allergy Type	Participants*	Data collection method	Analysis
Gillespie et al., 2007 (66)	Canada	To develop a narrative description detailing the central underlying meaning of the mothers' lived experience of parenting a child with food-induced anaphylaxis	IgE-mediated allergy	6 mothers of a child at risk for food-induced anaphylaxis	Semi-structured interviews	Not explicitly stated, but appears rooted in phenomenology.
Lagercrantz et al., 2017 (67)	Sweden	To gain deeper knowledge of what life is like for families of children with severe allergic disease, in order to improve care and thereby reduce the consequences of living with a chronic disease.	Not explicitly stated	18 parents of children with severe allergic disease†	Focus groups	Systematic Text Condensation
Mandell et al., 2005 (61)	Canada	To construct a picture of how parents and children cope with the day-to-concerns of anaphylaxis, how they adapt to them, and what they need as supports to positive adaptation.	IgE-mediated allergy	12 mothers of children diagnosed with anaphylaxis	Semi-structured interviews	Grounded theory-based analyses
Minaker et al., 2015 (63)	Canada	To explore experiences and coping strategies of low-income families affected by food allergies	IgE-mediated allergy	13 low-income families with food allergy	Semi-structured interviews	Thematic analysis
Pitchforth et al., 2011 (59)	United Kingdom	To explore, using qualitative methods, the experiences of children and their parents living with nut allergy	IgE-mediated allergy	26 families with a child with nut allergy	Semi-structured interviews	Constant comparative method

eTable 2 continued

Study	Country	Aim	Allergy Type	Participants*	Data collection method	Analysis
Rouf et al., 2011 (13)	United Kingdom	To explore parental experience of severe food allergy, in relation to recently diagnosed younger children (five years and under)	IgE-mediated allergy	8 mothers of children with a severe food allergy	Semi-structured interviews	Interpretative phenomenological analysis
Sanagavarapu, 2018 (71)	Australia	To understand selected Australian families' concerns and experiences in relation to transitioning their children with food allergy to school.	IgE-mediated allergy	10 mothers of school-age children with food allergy	Photo Elicitation Interview	Not explicitly stated, but appears to be thematic analysis.
Stensgaard et al., 2016 (68)	Denmark	To explore and better understand the impact that allergy can have on everyday life in families with an adolescent/young adult with peanut allergy	Not explicitly stated	5 families with a child with peanut allergy	Semi-structured interviews	Approach based on Ricoeur's theory of interpretation
Yonamine et al., 2013 (64)	Brazil	To understand the perceptions of caregivers of children and adolescents with cow's milk allergy regarding the disease and its treatment	IgE-mediated allergy	9 caregivers of children with cow's milk allergy	Semi-structured interviews	Content analysis

Note. * The table only lists the number of caregivers included in each of the studies. In some instances, however, data was also collected from children/teens with food allergy. † Only findings pertaining to food allergy were assessed and synthesized.

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