



Parents Experiences Raising a Child with Food Allergy; A Qualitative Review



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ABSTRACT

Problem: Food allergies are one of the fastest growing public health concerns without a cure, affecting approximately 8% of the world's child population. Being the parent of a child with allergies may lead to concerns, and affect everyday life in the family. The aim was to synthesize and describe parents' experiences of living with food allergies in families when one of the children has a food allergy.

Eligibility criteria: A systematic search using subject terms and text words was performed in Cinahl (Ebsco), Swemed+, Medline (OVID) and Scopus in October 2017. The search was limited to parents with children and adolescents, for the years from 2006 to October 2017.

Sample: One hundred and forty articles were screened and 24 were included.

Results: A meta-summary of the results from the included studies were conducted. The parents lived in fear, after their child had their first reaction and had become allergic, a life threatening experience. They tried to live an ordinary family life and parents had to learn how to be one-step ahead and understand early signs. The family's social life was also influenced. Parents asked for support and information from health professionals and more knowledge and skills increased parents' manageability.

Conclusion: Parents need support and a seamless encounter with health professionals, with multidisciplinary collaboration and knowledge sharing to develop the parents' self-efficacy.

Implications: Health professionals must provide information and support parents on their path through the health-care system in having a child with a food allergy.

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Introduction

Food allergies affect approximately 8% of the world's child population and are one of the fastest growing public health concerns, particularly in Western countries (Gupta et al., 2011; Tang & Mullins, 2017). Children with food allergies often have multiple allergic comorbidities, such as asthma, eczema and hay fever (Gore et al., 2016).

Food allergies are hypersensitive responses by the immune system to proteins in food that can affect respiratory and cardiovascular systems, the gastrointestinal tract and the skin simultaneously and with a variety of severity (Kagan, 2003). Peanuts, tree nuts, seafood (such as fish and shellfish), sesame, soya, eggs, wheat and milk are the most common allergens. Of these, egg and milk allergies often resolve after childhood (Kagan, 2003). Allergies diagnosed in childhood predict prevailing allergies in adolescents (Kaila et al., 2009). Food allergies require long-term, often lifelong treatment to prevent reactions and promote symptom management.

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Treatment involves a complete avoidance of food allergens. The elimination of these allergens is not simple, as many products contain "hidden ingredients" or traces of food with allergens, such as nuts (Peniamina, Bremer, Conner, & Miroso, 2014). Nut and egg allergies represent the most common food-induced anaphylactic reaction, and may be life threatening, although this is rare (Akuete et al., 2017).

Parents are essential to family life, and good parenting has the potential to promote health, well-being, and emotional and physical development, in addition to preventing ill health in subsequent generations (Gage, Everett, & Bullock, 2006). Being the parent of a child with allergies may lead to concerns and affect everyday life in the family. Food allergies negatively affect the health-related quality of life (HRQL) in families as a whole, including parents and the affected children (Stensgaard, Bindselev-Jensen, Nielsen, Munch, & DunnGalvin, 2017). Mothers report greater impact on the child's HRQL and they experience more anxiety and stress than fathers (Stensgaard, Bindselev-Jensen, & Nielsen, 2017). Parents' confidence in the management of food allergies predicts a better quality of life (Knibb, Barnes, & Stalker, 2015). Families with children with food allergies report more frequent mealtime concerns than typically developing peers (Herbert, Mehta, & Sharma, 2017). Parents have also reported that food allergies had an

impact on both the family's and the child's social life, with more disruption in daily activities and restrictions in social activities (Stensgaard, Bindsløv-Jensen, & Nielsen, 2017). To develop a deeper understanding of parents' experiences living in a family with a child with food allergies, a synthesis of qualitative studies is needed (Whittemore, Chao, Jang, Minges, & Park, 2014).

Aims

The aim of this review is to synthesize and describe parents' experiences of living with food allergies in families when one of the children has a food allergy.

Methods

This review was conducted using a qualitative meta-synthesis, as described by Whittemore et al. (2014) and Sandelowski and Barroso (2007). Qualitative studies, with a focus on everyday life in families with children with a food allergy, were reviewed.

Inclusion criteria

Articles included in this review focused on everyday life in families with children with a food allergy. For the purpose of this review, parents were either biological parents or the child's main caregivers. Studies with mothers, fathers and single parents were included, as well as grandparents. The phenomena of interest were parents' perceptions of managing everyday life when having a child with food allergy. The study used a qualitative design. Studies in Scandinavian languages and English were considered for inclusion.

Search strategy

A systematic search using subject terms and text words was performed in Cinahl (Ebsco), Swemed+, Medline (OVID) and Scopus, in October 2017, with a supplementary search in spring 2018 to check whether any more studies had been published. The search was limited to parents with children and adolescents, for the years from 2006 to October 2017. The search strategy was adapted to the different databases, and the strategy from Medline (OVID) is reported in Table 1. A research librarian assisted with the literature search. To supplement the search, reference lists of all included research articles were searched for additional studies.

Search outcome

A modified flow chart (Fig. 1) shows the identification and selection process (Moher, Liberati, Tetzlaff, & Altman, 2009). The title and abstract in 140 original studies from the databases were read and screened. Of these, 107 were excluded due to the methods used (quantitative methods were excluded) or the focus of the study (the parents'

perspective was not provided). The remaining 33 full-text articles were assessed for eligibility: four were excluded because the informants were children or adolescents, and five were excluded due to the quality of the articles.

Study characteristics

Table 2 summarizes the study characteristics. Most of the studies were conducted in Europe (the UK, Finland, Sweden and Denmark) (Akeson et al., 2007; Alanne et al., 2014; Alanne, Laitinen, Söderlund, & Paaivilainen, 2012; Bege et al., 2018; Gallagher et al., 2012; Gunnarsson & Hydén, 2009; Lagercrantz et al., 2017; MacKenzie et al., 2015; Pitchforth et al., 2011; Rouf et al., 2012; Stensgaard, Bindsløv-Jensen, & Nielsen, 2017; Stjerna et al., 2014; Valentine & Knibb, 2011), some from the Americas (the US, Canada and Brazil) (Abdurrahman et al., 2013; Broome et al., 2015; Franciosi et al., 2012; Gillespie et al., 2007; Gupta et al., 2008; Harrington et al., 2015; Vargas et al., 2011; Yonamine et al., 2013) and two studies were conducted in Australia and New Zealand (Crowley et al., 2012; McBride et al., 2010). Several studies had mixed study populations and included parents and children across different age groups, see Table 2. The children had different types of food allergies. Some studies had results related to the phenomenon of interest included, even though it was not the aim of the included articles. Qualitative studies were included with a diversity of qualitative methods, see Table 2. Some articles with philosophical perspectives such as phenomenology (Crowley et al., 2012; Gillespie et al., 2007) and grounded theory were described (Broome et al., 2015; Dean, Fenton, Shannon, Elliott, & Clarke, 2016). The others described a deductive or inductive qualitative approach using a content or thematic analysis. The data program, NVivo, was used in the analysis of the data in some studies (Abdurrahman et al., 2013; Akeson et al., 2007; Bege et al., 2018; Crowley et al., 2012; Dean et al., 2016; Gallagher et al., 2012; Gupta et al., 2008; Stensgaard, Bindsløv-Jensen, & Nielsen, 2017). The data were collected using individual interviews, focus group interviews and mixed methods such as interviews, diaries and photographs, see Table 2. One article had used mixed methods, qualitative and quantitative, but only the qualitative results data were used in this review (Abdurrahman et al., 2013).

Assessment of methodological quality

The Qualitative Assessment and Review Instrument (QAIR) from the Joanna Briggs Institute (JBI) (2017) was used. This is an eight-item checklist with a critical appraisal of the studies, used to extract qualitative findings from the studies in question. The quality of the studies reviewed was assessed by two independent reviewers using the standardized critical appraisal instrument, JBI-QARI (ØLM and AT).

The research studies were critically appraised by two of the researchers (ØLM and AT). Studies showed a congruity between the research methodology and research objectives' clear description of the

Table 1
Ovid Medline search.

Search history sorted by search number ascending		
#	Searches	Results Type
1	exp Food Hypersensitivity/	18,032 Advanced
2	hypersensitivity/ or hypersensitivity, delayed/ or dermatitis, allergic contact/ or hypersensitivity, immediate/ or anaphylaxis/ or conjunctivitis, allergic/ or dermatitis, atopic/ or eosinophilic esophagitis/ or respiratory hypersensitivity/ or urticaria/	136,908 Advanced
3	exp Food/	1,185,905 Advanced
4	2 and 3	8482 Advanced
5	((hypersens* or allerg*) and food*).ab.	13,407 Advanced
6	1 or 4 or 5	29,877 Advanced
7	limit 6 to ("child (6 to 12 years)" or "adolescent (13 to 18 years)")	8599 Advanced
8	limit 7 to yr = "2006–Current"	4259 Advanced
9	(qualitative or focus group or narrative* or interview*).ab.	361,711 Advanced
10	8 and 9	169 Advanced

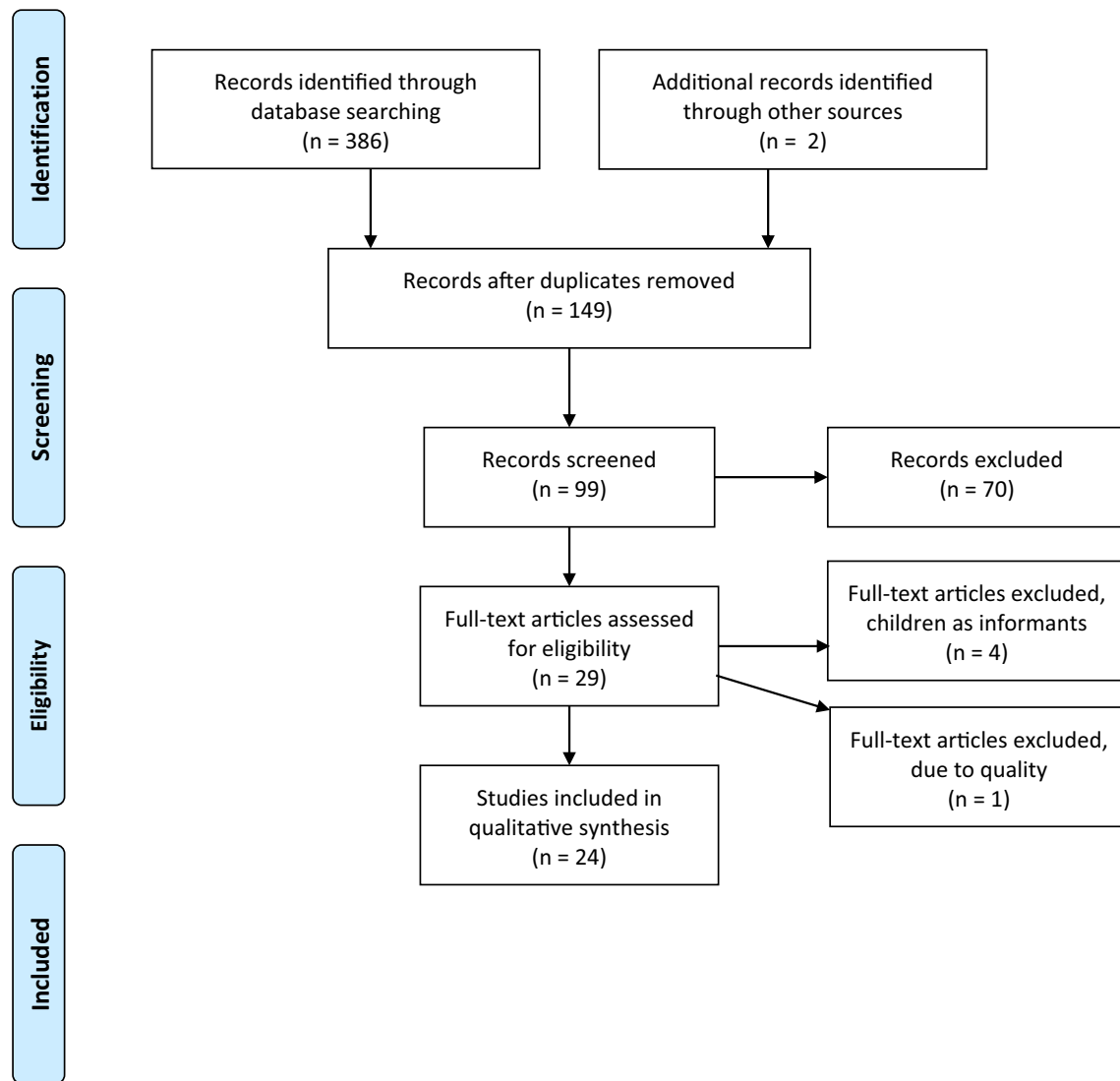


Fig. 1. Flow chart.

purpose of the study. The methods used for data collection and the reporting of results addressing methodological rigour through trustworthiness (Whittemore et al., 2014). Discussions resolved any disagreements between the reviewers. Moreover, the research articles included were of high quality, although only 26% addressed the philosophical underpinning of the research methods conducted. The researchers decided prior to the critical appraisal that this was not as essential as excluding the articles.

Data synthesis

The articles' results were analyzed using a meta-synthesis method by Sandelowski and Barroso (2007). All the articles were thoroughly read and all the findings were analyzed as a pool of meanings. Starting with the extraction of findings using a thematic analysis by the first author (ØLM) and further discussed between two of the researchers (ØLM and AT). Furthermore, the findings were presented in synthesis of themes with running text. After extracting and editing the findings that are relevant to the aim of this study, the grouping of findings started with those that appeared to cover the same topic. An abstraction of the findings was undertaken by reducing the many statements extracted and grouping them into shorter statements that preserved the contradictions and ambiguities in the findings. Two of the researchers

(ØLM and AT) discussed the narration of the findings and agreed upon it.

Findings

Synthesis 1: The families' process of being confident with a food allergy.

The parents lived in fear after their child had their first reaction and had become allergic. They tried to live an ordinary family life and the sharing of responsibility between the parents was crucial. The food allergy also influenced their social life, giving the mothers in particular many worries and making them feel isolated at times.

Family living with fear

Parents experienced anxiety after their child's first reaction (Abdurrahman et al., 2013), which was a traumatic experience (Broome et al., 2015; Rouf et al., 2012). To realize that the child's life was at risk triggered the ongoing experience of anxiety and fear (Gillespie et al., 2007) in an everyday context (Gunnarsson & Hydén, 2009). The life-threatening experience evoked strong emotions of fear, guilt and even paranoia (Gupta et al., 2008). These fears also become a limitation in family life in terms of what the families *could not do*, rather

Table 2
Characteristics of the included studies.

Study	Phenomenon of interest	Sample	Research design	Methods	Findings/Themes reported
Abdurrahman et al. (2013). Experiencing a first food allergic reaction: A survey of parent and caregiver perspectives. <i>Allergy, Asthma and Clinical Immunology</i> , 9(1).	Experiences of caregivers of children first reaction to food allergy	184 parents – most mothers	Mixed methods Quantitative and qualitative follow-up	Survey and qualitative phone interviews	First encounter with a health care professional Provision of information Family anxiety and lifestyle changes Experience of anaphylaxis
Akeson, Worth, and Sheikh (2007). The psychosocial impact of anaphylaxis on young people and their parents. <i>Clinical Experimental Allergy</i> , 37(8).	Explore the psychosocial impact of living with anaphylaxis, management and perception of health care provision.	15 adolescents 13–16 years 8 parents	Qualitative deductive	Individual in-depth interviews	Life-stage transition Management of anaphylaxis Emergency management Keeping things in perspective Anaphylaxis Campaign
Alanne, Laitinen, and Paavilainen (2014) Living Ordinary Family Life With an Allergic Child – The Mother's Perspective. <i>Journal of Pediatric Nursing</i> , 29(6).	Reveal ecological themes and activities of daily routines in the treatment of a child's food allergy and eczema.	13 mothers	Qualitative deductive	Repeated individual interviews	Friends and family Living an ordinary family life Daily activities: Observation Moisturizing Medication The elimination diet Planning the child's diet Occasional Activities: Examining and Diagnosing activities Treatment activities
Alanne et al. (2012). Mothers' perceptions of factors affecting their abilities to care for infants with allergy. <i>Journal of Clinical Nursing</i> , 21(1–2).	Mothers perceptions of the supporting or straining factors involved in motherhood child dermatitis and food allergy	32 mothers	Qualitative inductive	Semi-structured interviews individual	Mothers' perception of general supporting and straining factors Mother's personal abilities The family's internal capabilities Family's external capabilities Child's allergy belonging to family's internal capability as a straining factor for mothers The child at the age of one year The child at the age of two year
Begen et al. (2018). Parents' and caregivers' experiences and behaviours when eating out with children with a	Caregivers' experiences and behavior of eating out with their child and how they support and prepare their child	15 caregivers	Qualitative inductive	Semi-structured interviews individual	The family context. Child focused concerns

(continued on next page)

Table 2 (continued)

Study	Phenomenon of interest	Sample	Research design	Methods	Findings/Themes reported
food hypersensitivity. <i>BMC Public Health</i> , 18(1).	in negotiating safe eating out experiences.				Age-related factors Guiding child's choices Venue focused issues
Broome, Lutz, and Cook (2015). Becoming the parent of a child with life-threatening food allergies. <i>Journal of Pediatric Nursing: Nursing Care of Children and Families</i> , 30(4).	To understand parents perspectives about the impact of having a child with severe food allergies and adjustment required to effectively manage the condition.	20 parents	Qualitative Grounded Theory	Interviews individual	Phase I: Questioning competency Phase II: Expanding competency Phase III: Regaining competency
Crowley, Williams, and Brown (2012). How do mothers juggle the special dietary needs of one child while feeding the family? A qualitative exploration. <i>Nutrition & Dietetics</i> , 69(4).	Lived experience of implementing a specialized diet and how this impacted on their decision of whether or not to continue	21 mothers and 1 grandmother	Qualitative phenomenological	Semi-structured individual interviews	Maternal desire to please the family with food. Sharing responsibility for the diet with the child and family Development of existing skills in food provision Influences on dietary changes post-study Disclosure
Dean et al. (2016). Disclosing food allergy status in schools: Health-related stigma among school children in Ontario. <i>Health and Social Care in the Community</i> , 24(5).	Health related stigma and differentiated from peers.	10 children (8–12) 10 children (13–17) parents 17	Qualitative – Grounded Theory	In-depth interviews individual	Stigmatization Normalization Tension and disclosure Food and eating domain.
Franciosi, J. P., et al. (2012). Quality of life in pediatric eosinophilic oesophagitis: what is important to patients? <i>Child: care, health and development</i> , 38(4).	Identify quality of life concerns	24 parents 18 children	Instrument development with qualitative	Focus groups	Symptoms domain. Activities and school domain. Treatment domain. Feelings domain. Communication domain.
Gallagher, Worth, Cunningham-Burley, and Sheikh (2012). Strategies for living with the risk of anaphylaxis in adolescence: Qualitative study of young people and their parents. <i>Primary Care Respiratory Journal</i> , 21(4)	How adolescents and their parents live with and manage risk of anaphylaxis, risk and risk management	26 adolescents 28 parents	Qualitative	Semi-structured interview individual or family	Experiences of anaphylaxis. Managing allergies and preventing further reactions. Eating away from home. Risk and 'may contain' labels. Support from health professionals. Transition from parental to self-management. Living with risk.
Gillespie, Woodgate, Chalmers, and Watson (2007). "Living with risk": mothering a child with food-induced anaphylaxis. <i>Journal of Pediatric Nursing</i> ,	Mothers lived experience of parenting and how they adjusted to caring a child with food-induced anaphylaxis.	6 mothers	Qualitative phenomenological	Semi-structured individual	Living with fear.

Table 2 (continued)

Study	Phenomenon of interest	Sample	Research design	Methods	Findings/Themes reported
22(1).					Worrying about well-being. Looking for control. Relying on resources. It is hard but it is not. Pre-problems: allergy awareness and preventive actions. Emerging problems.
Gunnarsson and Hydén (2009). Organizing allergy and being a 'good' parent: parents' narratives about their children's emerging problems. <i>Health: An Interdisciplinary Journal for the Social Study of Health, Illness & Medicine</i> , 13 (2).	The early and problem-solving phases of the child's illness trajectory and on how child allergies are constructed and organized by the parents in a moral everyday context.	18 mothers 1 father	Qualitative	Narrative oriented individual	Maintaining parental identity. Perceptions of quality of life; Emotional response Impact on relationship Effect on daily social life
Gupta et al. (2008). Food allergy knowledge, attitudes and beliefs: focus groups of parents, physicians and the general public. <i>BMC pediatrics</i> , 8(1).	To better understand current knowledge, attitude and beliefs surrounding food allergy	parents 13 mothers 5 fathers physicians 14 general public 14	Qualitative	Focus groups	Effect on marriage Awareness Risk-taking Safety Belonging Limitations Control Injustice
Harrington, Dean, Wilson, and Qamar (2015). "We don't have such a thing, that you may be allergic": Newcomers' understandings of food allergies in Canada. <i>Chronic Illness</i> , 11(2).	To understand newcomers' perceptions and knowledge of food allergies and related policies developed to protect allergic children	46 parents 28 affected 18 indirectly affected	Qualitative	Focus groups	Fear and anxiety Helps me to protect my child and keep them healthy. Teaches me to become an expert. Provides me with hints and tips to help maintaining normality. Helps to promote my child's independence.
Lagercrantz, Persson, and Kull (2017). "Healthcare seems to vary a lot": A focus groups study among parents of children with severe allergy. <i>Journal of Astma</i> , 54(7).	Family life with children with severe allergic disease.	18 parents, equal groups of mothers and fathers	Qualitative	Focus groups	Advocates, helping me fight my child's corner. Provides me with emotional support. The experience of isolation. The burden of accessing resources.
MacKenzie, Grundy, Glasbey, Dean, and Venter (2015). Information and support from dietary consultation for mothers of children with food allergies. <i>Annals of Allergy, Asthma & Immunology</i> , 114(1).	Explore what information and support parents require	17 mothers	Qualitative	Focus groups	The cost. First reaction to
McBride, McBride-Henry, and Van Wissen (2010). Parenting a child with medically diagnosed severe food allergies in New Zealand: The experience of being unsupported in keeping their child healthy and safe. <i>Contemporary Nurse</i> , 35(1).	Lived experience being a parent	4 mothers	Qualitative	Individual interviews	
Pitchforth et al. (2011). A qualitative	Life experiences, nut allergy	26 families	Qualitative	Individual	

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Table 2 (continued)

Study	Phenomenon of interest	Sample	Research design	Methods	Findings/Themes reported
study of families of a child with a nut allergy. <i>Chronic illness</i> , 7(4).		11 children 25 mothers 12 fathers		semi-structured interviews	nuts and getting a diagnosis. Nut allergy as stigma. The protector role and it's stigma. Creating 'safe places'. Trying to control risks outside the home. Pubs, restaurants and cafés. Supermarkets and shops.
Rouf, White, and Evans (2012). A qualitative investigation into the maternal experience of having a young child with severe food allergy. <i>Clinical Child Psychology and Psychiatry</i> , 17(1).	Parental experiences of severe food allergy – recently diagnosed younger child	8 mothers	Qualitative	Individual semi-structured interviews	Parental adjustment – re-establishing an 'even keel'. It's a big responsibility: Living with risk.
Stensgaard, Bindselev-Jensen, & Nielsen (2017). Peanut allergy as a family project: social relations and transitions in adolescents. <i>Journal of Clinical Nursing</i> , 26(21–22).	The impact peanut allergy can have on family everyday life	5 families 5 adolescents 5 siblings 5 mothers 5 fathers	Qualitative phenomenological-hermeneutical	Individual semi-structured interviews	Identity and social aspects of allergy. The nuclear family – safety and understanding. When the nuclear family is challenged. The importance of having a social life.
Stjerna, Vetander, Wickman, and Olin Lauritzen (2014). The management of situated risk: a parental perspective on child food allergy. <i>Health: An Interdisciplinary Journal for the Social Study of Health, Illness & Medicine</i> , 18 (2).	Management of allergy risk seems to permeate most aspects of everyday life as well as how the parents draw on a dominant norm of risk avoidance as well as a counter-discourse of calculated risk taking	31 parents 25 mothers 6 fathers	Qualitative Grounded Theory	Focus groups	Risk avoidance: a dominant discourse of constant vigilance. To constantly be one step ahead. To make unsafe zones safe. A counter-discourse of risk taking. Taking calculated risks.
Valentine and Knibb (2011). Exploring quality of life in families of children living with and without a severe food allergy. <i>Appetite</i> , 57(2).	To explore the impact of food allergy on quality of life in children with food allergy and their primary caregivers	34 children 30 primary caregivers	Mixed methods-Quantitative and Qualitative	Questionnaire, Photographs and diary	Sometimes you have no choice. Activities of daily living Education and employment Food and drink Health
Vargas et al. (2011). Developing a food allergy curriculum for parents. <i>Pediatric Allergy and Immunology</i> , 22(6).	Topics identified by parents as key for successful management included as expected: (i) early signs/symptoms, (ii) 'cross-contamination', (iii) label-reading, (iv) self-injectable	36 parents 32 mothers	Qualitative	Focus groups	Leisure Understanding early signs/symptoms. Understanding

Table 2 (continued)

Study	Phenomenon of interest	Sample	Research design	Methods	Findings/Themes reported
	epinephrine; and (v) becoming a teacher and advocate.				issues of allergen 'cross-contact'. Understanding label reading. Understanding use of self-injectable epinephrine. Treatment and education of the patient and their caregivers. Resolution of the disease. Quality of life.
Yonamine, Contim, Castro, Jacob, and Pastorino (2013). Perceptions of caregivers of patients with cow's milk allergy regarding the treatment. <i>Journal of Human Growth and Development</i> , 23 (1).	Treatment and education of the patient and their caregivers, resolution of the disease (hope, gradual improvement), quality of life (social inclusion, family daily activities, costs of dietary treatment). Caregivers experienced difficulties	9 female caregivers	Qualitative	Individual	

than what they *could do*, and they felt safest at home (Lagercrantz et al., 2017; Stensgaard, Bindslev-Jensen, & Nielsen, 2017). They needed to carefully plan and prepare in everyday life to avoid such fear and anxiety. One father used the metaphorical expression “to be caught in a bubble”, thereby capturing the experience of how food restrictions may affect and limit family life (Stjerna et al., 2014). The parents also described that their child experienced anxiety and fear, and that this limited the family's everyday life (Lagercrantz et al., 2017). When receiving the diagnosis, the parents felt shock and anxiety (Pitchforth et al., 2011).

Parental role – sharing responsibility

Parents were also focused on living an ordinary life in relation to caring for an allergic child (Alanne et al., 2014; Yonamine et al., 2013), but they always had to plan and prepare for this (Lagercrantz et al., 2017; Stjerna et al., 2014). The home became a safe place (Pitchforth et al., 2011). Mothers seem to be in charge and the gatekeeper in the family, having routines and being responsible for the food and housekeeping (Alanne et al., 2012; Crowley et al., 2012; Lagercrantz et al., 2017). A well-functioning relationship between the parents helped the mother to cope, and reduced her tiredness (Alanne et al., 2012). Mothers and fathers had differing opinions regarding protection of the child. Mothers tended to shelter the child, whereas the fathers expressed a desire to expand their child's life. One father said: “My wife is much more into prevention all the time and I am more into trying to maximize what my son can do” (Gupta et al., 2008, p. 5). These different opinions may have an effect on the marriage (Gupta et al., 2008) and they are exacerbated when the parents were separated and living apart (Gillespie et al., 2007). The parents felt a strong need to have control of their child's everyday life (Lagercrantz et al., 2017; Stensgaard, Bindslev-Jensen, & Nielsen, 2017). Nevertheless, other family members, such as the child with an allergy and the siblings, were also involved by the mother in sharing the responsibility for cooking (Crowley et al., 2012; Gillespie et al., 2007). Parents wanted to support their child in negotiating the balance between safety and food variety (Begen et al., 2018).

Being social or experience of isolation

Parents, particularly mothers, felt anxious about family gatherings because others might then feed their food-allergic child, with the parents experiencing a loss of control (Abdurrahman et al., 2013). One mother said: “Just to relieve my own anxiety, I've turned into a control freak, and I've had to have all the family gatherings at my house so at least I know that everything is safe.” (Abdurrahman et al., 2013, p. 4). The parents' responsibility in avoiding allergens was tested when a young child showed curiosity and was tempted by other people's food

(Begen et al., 2018). Birthday parties with peers or staying with peers were perceived as a threat to the mothers. The child was sometimes excluded from these parties, either because the parents did not want them to go or the child was no longer invited (Abdurrahman et al., 2013; Begen et al., 2018). The child described a feeling of isolation and stigma (Broome et al., 2015; McBride et al., 2010; Pitchforth et al., 2011). Eating out in restaurants or away from home challenged the assurance of safe eating for their child. This affected both the frequency of eating out and venue selection, often in a favour of a “safer” venue (Begen et al., 2018; Gallagher et al., 2012; Stensgaard, Bindslev-Jensen, & Nielsen, 2017; Valentine & Knibb, 2011). Eating at the school or nursery also often raised concerns in parents because of a lack of understanding from personnel, as well as a lack of routines (Begen et al., 2018; Lagercrantz et al., 2017; Stjerna et al., 2014; Valentine & Knibb, 2011). This entailed more work for mothers since they had to prepare safe food (Gillespie et al., 2007). Being allergic may have an impact on relationships because the child feels different from their peers insofar as having a sense of fatigue, difficulty with school and school work. Moreover, many social activities were centred on food or the feeling of being sick in front of others, which concerned the mothers (Franciosi et al., 2012; Harrington et al., 2015; Stensgaard, Bindslev-Jensen, & Nielsen, 2017). Mothers wanted their child to be treated as normal, but described a delicate balance in being safe and reducing stigma (Dean et al., 2016; Rouf et al., 2012; Yonamine et al., 2013). Family and friends were perceived as supportive (Akeson et al., 2007) and were able to provide assistance in various ways (Alanne et al., 2012). Adolescents described feeling secure when they were with friends who knew them well (Stensgaard, Bindslev-Jensen, & Nielsen, 2017).

Transition to adulthood

The adolescents appeared to be less concerned than their parents were, with lower and narrower perception of risk (Akeson et al., 2007). Mothers were closely involved with managing the transition from parent-management to the self-management of their child to a greater extent than the fathers (Gallagher et al., 2012). Parents perceived an increased risk of adolescents having more freedom as teenagers and becoming independent, which possibly involved risk taking (Gallagher et al., 2012). One mother of a 13-year-old boy said: “I would say this time from now up until early adulthood is the most vulnerable time... This will be the time where he's got more choices and it's a time where you want him to be confident in everything that he does and you don't want him to be frightened” (Gallagher et al., 2012, p. 395). Parents mostly believed that their child and adolescent were aware of the seriousness of this issue (Gillespie et al., 2007). Parents had to learn how to let go, but extending safety zones was associated with much concern

and anxiety (Lagercrantz et al., 2017), for example, their child's alcohol debut (Stensgaard, Bindslev-Jensen, & Nielsen, 2017). Some adolescents with a peanut allergy found it irritating that their parents worried and wanted to control their lives (Stensgaard, Bindslev-Jensen, & Nielsen, 2017).

Synthesis 2: Gaining knowledge about living with food allergy, a pathway in self-education.

This synthesis describes how the parents experienced the first allergic reactions in their child as life threatening. They had to learn how to be one step ahead and understand early signs. They wanted support and information from health professionals, which they experienced that many of the health professionals did not give them. They felt that they managed their life situation better after gaining more knowledge and skills.

The experience of symptoms, anaphylaxis and emergency

Parents vividly recalled reactions they experienced as life threatening in contrast to their children who remembered minor allergic responses (Akeson et al., 2007). The symptoms were experienced by the parents, as extreme and traumatic (Gunnarsson & Hydén, 2009). The parents needed to be one step ahead and keep on the alert in order to avoid allergic reactions and understand early signs and symptoms (Stjerna et al., 2014). Experiencing anaphylaxis left them with a heightened sense of danger (Gallagher et al., 2012). The self-administration of adrenaline in EpiPen was the main emergency management strategy (Akeson et al., 2007; Gallagher et al., 2012). Only a few had used an EpiPen, but they felt secure in having it and carrying it with them when going out (Akeson et al., 2007). Mothers weighed the severity of the symptoms against the advantage of adding new food (Alanne et al., 2012) and the need for variety in eating experiences (Begen et al., 2018). The children's symptoms were described as chest or abdominal pain, nausea, vomiting, feeling unwell with eating, trouble swallowing and difficulties in eating or maintaining weight (Franciosi et al., 2012). Children and adolescents with an allergy needed continuous observation of the skin with moisturizing treatment and medication (Alanne et al., 2014).

Encounter with health professionals – support or lack thereof

Parents stated that their physician lacked knowledge about the recognition, diagnosis and management of allergy and anaphylaxis (Abdurrahman et al., 2013; Akeson et al., 2007). The primary healthcare professionals demonstrated limited involvement and knowledge (Gallagher et al., 2012; Lagercrantz et al., 2017; Valentine & Knibb, 2011). Physicians and families did not “speak the same language”, with the physicians expressing themselves unclearly. There was a lack of dialogue between parents and the physicians which led to a lack of trust in health professionals on the part of the parents (Lagercrantz et al., 2017). Parents perceived that health professionals had a lack of empathy in that they focused on the medical aspect of the diagnosis and ignored the emotional side (Broome et al., 2015). Parents thus believed that they did not receive enough information from health professionals (Gillespie et al., 2007). Some parents described how they had to convince their physician to refer their child to an allergist (Abdurrahman et al., 2013). Other parents experienced a delay in referrals and diagnosis (Pitchforth et al., 2011). Their children had finally seen a specialist once they were diagnosed (Akeson et al., 2007; Gallagher et al., 2012), whereas others had not seen a specialist at all (Gallagher et al., 2012). Parents described that healthcare could be a burden, entailing many visits to different health-care professionals, which frequently resulted in inappropriate, unhelpful or contradictory advice (McBride et al., 2010). MacKenzie et al. (2015) focused on how dieticians supported the mothers, and how the mothers described becoming experts during these consultations.

Information, knowledge in developing skills

Being the parent of a child with life-threatening food allergies required expanding parental competence in developing new skills – an ongoing process (Broome et al., 2015). One parent said: “I threw myself into research... just tried to learn everything possible about how to protect him” (Broome et al., 2015, p. 536). Parents searched for food information online and expressed a need for better information (Abdurrahman et al., 2013). Parents did not believe that they had received enough information from their physician (Broome et al., 2015; Gillespie et al., 2007) or they had experienced conflicting guidelines (Gupta et al., 2008). They believed it was important to learn about the allergy and its management (Gillespie et al., 2007; Stensgaard, Bindslev-Jensen, & Nielsen, 2017; Yonamine et al., 2013). The food allergy curriculum and information should be specific in time regarding complexity and length (Vargas et al., 2011). Parents were vigilant about consumption (Abdurrahman et al., 2013). They were self-educated and trained their child to avoid trigger factors (Abdurrahman et al., 2013; Broome et al., 2015; Rouf et al., 2012). Some mothers described themselves as being ‘their own doctor’ (Gunnarsson & Hydén, 2009). The mothers own knowledge and experience and hope for improvement were a supporting factor (Alanne et al., 2012).

Studying food labelling was a way of managing risk avoidance (Abdurrahman et al., 2013). The provision of tools and support groups helped the mothers to extend their skills in food shopping and reading labels (Crowley et al., 2012). One mother of a 6-year-old said: “...get in contact with others with children with the same... to have something in common with another person and be able to help each other out in that regard” (Crowley et al., 2012, p. 276). Parents questioned the lack of reviews or information (Akeson et al., 2007; McBride et al., 2010). They had to educate and inform family, friends, school and kindergarten (Alanne et al., 2014; McBride et al., 2010; Pitchforth et al., 2011). Those with regular specialist contact appeared to be better informed about managing allergies (Gallagher et al., 2012).

Discussion

Parents described the life of their child as being threatened, with family life first characterized as living with fear. Stensgaard, Bindslev-Jensen, and Nielsen (2017) describe that food allergies had an impact on the quality of life. With more food restrictions, the number of foods avoided had a negative impact on the quality of life. A review of children with asthma found mothers exhibited greater anxiety and depressive symptoms compared with mothers of healthy children (Easter, Sharpe, & Hunt, 2015). The cause of the anxiety was unclear but it was postulated that the living with a child with a potentially life-threatening illness might lead to higher levels of anxiety symptoms in caregivers. Given that food allergies may be comparable with asthma in terms of being potentially a life-threatening experience, this description may be applicable to mothers of children with a food allergy. The need for support from health professionals is essential, as these mothers may need referrals and support for their own sake.

The mothers in the included studies were those with responsibility for the planning and preparation of food, and may represent the one parent in charge. When the responsibility was shared, this may have eased the burden and provided opportunities for the family to live a good life with a child with a food allergy. Knibb et al. (2015) concluded that greater confidence in the management of a food allergy by parents predicted a better quality of life, with self-efficacy as the biggest predictor. How to develop the parents' self-efficacy, meaning the parents' perception of feelings of competence, in addition to their perceptions of being able to influence their child, may be a crucial task for health professionals (Glatz & Buchanan, 2015).

Other studies have also shown that mothers are in charge in the family when it comes to attending to the follow-up of a child with special needs (Moen, Hall-Lord, & Hedelin, 2011; Moen, Hall-Lord, & Hedelin,

2014). One intervention to facilitate knowledge and perceptions of responsibility in the family is the family-centred care conversation between health professionals and the family (Wright & Leahey, 2009). The purpose of these discussions is to increase coping in everyday family life through creating a context of change to help facilitate new beliefs, meanings and possibilities in relation to the family's current concerns (Benzein, Hagberg, & Saveman, 2012; Benzein, Olin, & Persson, 2015). This may ease the burden for the mothers, and give them support from the fathers or other caregivers in the family. The family-centred care conversation may also give the child with a food allergy, along with their siblings, the ability to describe their perception of the situation of being a part of a family. A review of studies of chronic childhood illness shows that this illness influences the siblings' bond, the parent-child relationship and the family as a whole (Knecht, Hellmers, & Metzger, 2015). In further research, studies with the entire family should be included.

Social life was experienced as challenging and the food allergy limited the family and the child's possibilities since social life is often associated with sharing a meal. According to Stensgaard, Bindsvlev-Jensen, and Nielsen (2017), food allergies had an impact on the family's social life, with the lower quality of life related to greater restrictions on social life. Smith, Cheater, and Bekker (2015) describe some of the same influences on the social life of families with children with chronic illnesses. On the other hand, the families lacked a social life because of hospitalization, and that may be something different than dealing with food allergy in a social setting. A social relationship may be experienced as life threatening to the parents of children with a food allergy, so giving information and skills to the child, their peers and the family's social relationships may be crucial. Supporting parents and making them more secure in their parental role is also crucial in helping the child in social settings, important for the child's development, and for giving the child a sense of responsibility and a playground in life. This is one of the responsibilities of health professionals, and nurses may play a key role giving information in schools and nurseries both other parents, peers and staff.

The parents in the reviewed studies thought the child's transition to adulthood was challenging, whereas the adolescents were more explorative than the parents wanted, regarding testing food and drinking alcohol. In a review from the adolescent's perspective, Johnson and Woodgate (2017) describe that adolescents must be competent in managing their life with a food allergy, and the transition to an increase in self-reliance is a gradual process. Based on the results in the current review, the sharing of responsibility from the parents' perspective highlights the well-functioning relationship between parents and the sharing of cooking as a strength. Many support groups with other parents and families with experience in living with a food allergy help parents as "newcomers" in this life situation. The importance of support from others is also described in other family situations such as living with a child with Attention Deficit Hyperactivity Disorder (ADHD) (Moen et al., 2011). Nurses who meet these parents may introduce parents to such support groups or voluntary groups.

The transition to adulthood was described in the studies as frustrating and Heath, Farre, and Shaw (2017) described the transition as a forward and backward process on the continuum of the transition to adulthood. While the parents had to relinquish responsibility and the child gained more responsibility, in other situations the parents had to take more responsibility. Both the child's management of responsibility and overall maturity played a central role in terms of the parents' ability to let go (Heath et al., 2017). The children and adolescents described the transition to adulthood as a minor issue more than the parents did, in articles included in this review. The transition to adulthood also includes the transition from pediatric to adult services. Since parents are the key facilitators of healthcare for their child, they want to know what their new role is when their child turns 18 and becomes legally health independent. They also wish to be informed about legislation that changes their responsibility and rights and shifts in the allocation

of treatment responsibility (Heath et al., 2017). This transition was not highlighted in the included studies, but is still an important issue reported in other studies with parents of children with a chronic illness and ADHD, have described this transition as frustrating (Heath et al., 2017; Moen et al., 2014). Having their child achieve healthcare independence requires a gradual transition of responsibility from the parents, which also requires a dialogue with health professionals (Moen et al., 2014). Transitions that begin early with support from health professionals might make the process easier. As Heath et al. (2017) describe, health professionals may support parents by helping them to identify particular anxiety-provoking situations and teaching parents adaptive coping skills.

The first allergic reaction was experienced as threatening, and those who had experienced anaphylaxis realized the life-threatening situation their children were living in. Moving anaphylaxis prevention from an individual focus to a societal responsibility results in increased focus (Johnson & Woodgate, 2017). The legislation then places greater responsibility on schools that have children with allergies, such as in Canada.

As regards individual focus, the parents, especially the mothers in the reviewed articles, introduced a strict diet to avoid any allergic reactions. Other research has shown that restricted diets can lead to malnutrition in children with a food allergy (Meyer et al., 2014). The malnutrition may lead to both underweight and overweight, hence contributing to the avoidance of food and the compensation of energy-dense food. A dietary consultation was described as giving the parents the knowledge and skills to manage the food restrictions imposed on their child (MacKenzie et al., 2015). It is important that the health professionals who first meet these parents and their children focus on a healthy dietary plan for the child to ensure health development and growth.

The parents in this review described their own knowledge-seeking as guiding them into managing their child's life with a food allergy. Hill, Knaf, and Santacroce (2018) state that the key issue in information sharing is the health professional's use of "normal people language" making it easier for the parents to understand. Parents may misunderstand the severity of their child's illness when health professionals use terminology parents are not familiar with. Majdalani, Doumit, and Rahi (2014) say that parents would be hesitant to communicate or ask questions when the health professionals use unknown terms. Although the encounter with health professionals was described as being supportive, it also gave a feeling of a lack of support. This is also reported in other studies such as Smith, Cheater, & Bekker (2015) who describe in a systematic review focusing on the parents of children with chronic illnesses that the parents are not given sufficient information, and that their knowledge regarding their child's condition is undervalued. Furthermore, Smith, Swallow, and Coyne (2015) have incorporated attributes regarding family-centred care and partnership-in-care with the following domains: Valuing parents' knowledge and experiences, Supporting parents in their role as caregivers, and Incorporating parents' experiences into clinical and psychosocial care. The settings in Smith, Swallow, and Coyne (2015) were both hospital and organizations but are transferable to families with a child having food allergy. From this current review, these children and their parents are both in the hospital setting and in the community health setting making it transferable to families with children having food allergy. Smith, Swallow, and Coyne (2015) also revealed obstacles in embedding family-centred care and partnership-in-care such as: health professionals' attitudes, unclear roles between parents and health professionals and established hierarchies, organization culture and practice hinder involving parents. Moreover, poor information sharing and lack of understanding of family context, not valuing parents' knowledge and contributions all hinder support to parents in their role as caregivers. There seems to be a need for studies on implementing interventions such as Family-centred care conversations, characterized as mutual dialogues between family members and health professionals.

This may be one solution to meeting the parents' and the family's needs for information and knowledge sharing.

Strengths and limitations

The search strategy on which the review is based could have been more sensitive in searching for text words in all fields. We chose a pragmatic approach, weighing sensitivity and overall time use, and considered the use of subject headings and additional methods to supplement the search as suitable techniques for strengthening a comprehensive literature review. We have included both subject-specific databases and one interdisciplinary database, which is also a strength.

Two researchers (ØLM & AT) have worked closely together to ensure rigour in all stages, inclusion of relevant studies, quality assessment and data extraction, which strengthen the trustworthiness of the study (Sandelowski & Barroso, 2007).

A strength of this review is that by consolidating qualitative findings from studies of families with children with a food allergy, we were able to identify a range of common parental experiences and needs.

Relevance to clinical practice

It is important to examine the parents' experiences of living with a child with a food allergy. Access to this knowledge can help health professionals in their meeting with families in this situation, which may improve our efforts to give higher quality care and provide the families with a way to manage a food allergy in their children.

Conclusion

Parents face many challenges in having a child with a food allergy. They may experience episodes of allergic reactions as life threatening for their child, thereby creating a family life characterized by living with fear. The parents' experience of managing a life with a food allergy is crucial in the child's development and growth in order to achieve independence. Parents need support and a seamless encounter with health professionals. Both multidisciplinary collaboration and knowledge sharing help develop the parents' self-efficacy, thus making family life with food allergy predictable and safe. There is need of change in the health service to enable the parents' role as caregivers to be valued more highly.

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Declarations of interest

None

Contributions

Study design: ØLM, EO and AT; search strategy: EO, AT and ØLM; synthesis: ØLM and AT, manuscript preparation: ØLM, EO, and AT. All the authors have seen this last version and agreed upon it.

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