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Qualitative Research in Teen Experiences Living with Food-Induced Anaphylaxis: A Meta-Aggregation

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Abstract

Aim: To describe the central experiences of teens living with Food-Induced Anaphylaxis as a first step in responding to health care needs in this population.

Background: As prevalence of allergy increases and commonly-outgrown allergies persist longer, chronic management for teens becomes increasingly important. This review seeks to understand how teens experience living with Food-Induced Anaphylaxis.

Design: Meta-aggregation for qualitative systematic review, to create synthesis for clinical improvement; guided by Joanna Briggs Institute methods and their Qualitative Assessment and Review Instrument.

Data Sources: Seven relevant databases were searched for original qualitative research July 2015; 10 studies (published 2007-2015) met inclusion criteria.

Review Methods: Both authors undertook critical appraisal, with consensus by discussion. Findings from line-by-line extraction were grouped into categories and syntheses. In studies with mixed populations, we included only teens (age 12-19) with Food-Induced Anaphylaxis.

Results: We developed three syntheses from nine categories and 64 subcategories to reflect central experiences of teens with Food-Induced Anaphylaxis, including: (1) Defining the allergic self,;(2) Finding a balance; and (3) Controlling the uncontrollable. The syntheses encompass importance of allergic identity/understanding, difficulties in coping with burdens of food allergy and reflect the complex risk interactions teens must negotiate in social contexts.

Conclusion: There is a need to respect teens as active participants in managing Food-Induced Anaphylaxis, while recognizing that social expectations and a lack of public awareness/safety can dangerously affect one's needs and decisions. This helps broaden how we conceptualize the needs of teens living with Food-Induced Anaphylaxis, informing ongoing care and management.

Keywords: meta-aggregation, teen, adolescent, anaphylaxis, food allergy, qualitative, nursing, literature review, systematic review, experience

Summary Statement

Why is this research or review needed?

- Teens with food-induced anaphylaxis have a greater likelihood of fatal anaphylaxis and have a reduced quality of life related to overlapping needs for acute and chronic management.
- International increase in prevalence and requirements for care of food-induced anaphylaxis points to a need for improved health promotion and education for long term management of allergies.

What are the key findings?

- There is only a small body of qualitative research in the area of teen experiences with food-induced anaphylaxis, where many of the studies lack a clear philosophical or epistemological basis.
- Teens with allergy experience an identity shift, must find a balance in coping with resultant burdens and learn to negotiate risk effectively in a world that is often beyond their control.

How should the findings be used to influence policy/practice/research/education?

- High-quality, philosophically consistent research should be done into teen experiences living with food-induced anaphylaxis from broader epistemological and methodological bases, particularly using methods suited to understanding meaning and experience.
- Nurses and other health care providers should acknowledge the needs of teens with food allergies and provide care that respects and engages them in a constructive manner.
- Long-term management of teens living with food-induced anaphylaxis needs to move beyond the focus on physical/medical risk to incorporate discussion of social risk and shift to prevention of anaphylaxis as a systemic health issue rather than individual responsibility.

INTRODUCTION

Studies indicate a significant increase internationally for the past decade in prevalence of Food-Induced Anaphylaxis (FIA), estimated to affect 5-8% of teens in North America and other developed countries (Sicherer and Sampson, 2014; Savage and Johns, 2015) with fewer teens resolving commonly-outgrown childhood allergies (Sicherer and Sampson, 2014). Despite attempts to create awareness of individual food allergy through policy change (Dean *et al.*, 2015), Canadian emergency department visits for anaphylaxis in the last 7 years have doubled, with the highest increase in teens (Canadian Institute for Health Information, 2015) who remain more likely to have fatal anaphylaxis than other age groups (Munoz-Furlong and Weiss, 2009; Xu *et al.*, 2014). Despite the acuity of anaphylaxis, FIA requires effective chronic management requiring improvement as prevalence and acuity increase. FIA significantly reduces quality of life during childhood (Flokstra-De Blok *et al.*, 2010), but we have only just started to systematically address improving management from the patients' perspective. At present, there are limited qualitative studies that shed light into the meanings and experiences of teens with FIA. This meta-aggregation therefore seeks to understand how teens experience living with FIA as a first step to improving care and health services for teens and their families. By synthesizing the existing evidence, we hope to provide clarity and an in-depth vantage point to guide future research.

Background

Qualitative methods allow researchers to access meaning, perception and experience as a way of understanding the lives of participants, which remains an important need in allergy research (Gallagher, Worth and Sheikh, 2009). Research into quality of life and related metrics have become more prevalent for FIA, including in the adolescent realm (Flokstra-de Blok *et al.*, 2008; van der Velde *et al.*, 2009; MacKenzie and Dean, 2010; Resnick *et al.*, 2010). Although allergy researchers have demonstrated a strong interest in quality of life (Valentine and Knibb, 2011; Van der Velde, Dubois and Flokstra-De Blok, 2013) and the detrimental psychosocial effects of FIA (Cummings *et al.*, 2010), none of these research instruments can offer us in-depth, specific reasons why quality of life is lower in young people with allergy and their families. Instead, we must turn to research methods which focus on exploring individual situations. Using scoring from quality of life assessments is an important tool for population-level analysis and holds future promise for clinical assessment. However, while understanding the significance and statistical data provides excellent justification, it is unlikely to provide all the information needed to create change in health policy and services (Zuzelo, 2012).

In this review we have chosen specifically to focus on research using qualitative methods to study teen experiences living with FIA for these reasons. By doing so, we can assess and evaluate the availability of studies in this area. Choosing meta-aggregation as a synthesis methodology offers several advantages. First, because its philosophical basis is pragmatic and influenced by transcendental phenomenology, it is philosophically congruent for a review that focuses on qualitative research (Lockwood, Munn and Porritt, 2015). Second, because the focus is not on reinterpretation of data as in a qualitative meta-synthesis, we are able to remain close to the data as originally presented by researchers (The Joanna Briggs Institute, 2014). Lastly, the purpose for meta-aggregation is usable data (Hannes and Lockwood, 2012), which we see value in for clinical applicability and improvement.

THE REVIEW

Aim

Turning to the experiences of teens who live with FIA every day is crucial to form a detailed understanding of how FIA affects their lives and use this knowledge appropriately to create effective policy and interventions for long-term management. This meta-aggregation aims to understand and reflect the central experiences of teens living with FIA as a first step in this process.

Design

This review has been guided by the Joanna Briggs Institute (JBI) method for meta-aggregation and evaluative processes used by the JBI's Qualitative Assessment and Review Instrument (JBI-QARI) system for quality appraisal (The Joanna Briggs Institute, 2014). We chose meta-aggregation as a mode as a way to remain close to the data rather than creating a reinterpretation. Meta-aggregation seeks to create syntheses from findings of existing studies for clinical improvement (Hannes and Lockwood, 2011).

Search Methods

Inclusion criteria

Papers from the search were included if they met the following criteria: population studied was teens aged 12-19 with FIA; research addressed the experiences and meaning of living with FIA; qualitative methods were used, including general qualitative work, grounded theory, phenomenology, ethnography and focus groups; and studies were published in English. As initial searches revealed limited studies, no date restrictions were imposed. We included studies with mixed populations as long as findings of the various groups were clearly separated and identified as relevant to our population.

Search strategy

An initial scoping search was completed using CINAHL, PubMed and Scopus to determine the most appropriate keywords for the full search. No relevant systematic reviews were found through Cochrane Library or JBI. A librarian with expertise in systematic reviews was consulted and assisted in focusing search strategies and keyword use prior to the formal search. As general search terms did not return many relevant results, we decided to use terms specific to age, the diagnosis and types of research likely to address experience. A keyword search example is as follows: (teen* OR adolesce* OR 'young people' OR youth*) AND ('food-induced anaphyla*' OR (food AND (hypersensitivit* OR anaphyla* OR allerg*))) AND (qualitative OR 'grounded theory' OR phenomenol* OR ethnograph* OR 'focus group*'). In databases using subject headings, such as PubMed and CINAHL, the headings found using the above keywords were also included alongside keywords during searches. We searched the following databases for related research: PubMed, CINAHL, Scopus, Web of Science, EMBASE, PsychINFO and Academic Search Complete in July 2015. Manual review of reference lists from studies found in the search yielded no additional publications. Duplicates, studies that failed to meet inclusion criteria and studies without a full report of findings were eliminated. We completed a confirmatory search using Google Scholar, with dates limited to 2005-2015, since 2007 was the earliest publication date. The first 100 results were scanned and confirmed as duplicates or failing to meet inclusion criteria, therefore not counted in our search algorithm.

Search Outcome

Study Selection

This meta-aggregation includes 10 original qualitative studies of teens with FIA published from 2007-2015 of 195 results from the database search (Figure 1).

Study Characteristics

Table 1 summarizes study characteristics, with more detailed information available online (Supplementary information, Table S1). Of the 10 studies, all were conducted in Europe (Ireland, Sweden and UK), except one North American study in Ontario, Canada. Several studies mixed study populations: parents and their children, different age groups and teens both with and without FIA. Most studies used qualitative descriptive methodology, with thematic analysis or coding. Other methodologies included grounded theory (DunnGalvin *et al.*, 2009) and phenomenology (MacKenzie *et al.*, 2010). Data collection and analysis for all studies focused on interview data, described as in-depth or semi-structured. However, one study relied on focus groups (DunnGalvin *et al.*, 2009) and three others used focus groups alongside individual interviews (Marklund *et al.*, 2007; Gallagher *et al.*, 2011; Sommer *et al.*, 2014). Vignettes (DunnGalvin *et al.*, 2009) and drawings (Fenton *et al.*, 2011) were also used to elicit further discussion.

Quality appraisal

Both authors reviewed the articles independently using criteria from the JBI-QARI critical appraisal tool, which assesses congruity throughout the study, researcher influence, participant/voice representation, ethics approval and appropriateness of conclusions from presented data. Although we followed the same review processes of appraisal and verification of findings as in the software, we did not use JBI-QARI software. The authors reached consensus through discussion in the case of differing assessments (see supplementary information File 1 for appraisal data). Nearly all studies neglected discussion of philosophical perspective, which was unclear at best and studies rarely discussed methodology or guiding theory in detail. Despite incongruence with stated aim and methodology, many studies displayed positivist sensibilities, such as discussing inability to generalize, or relying on data counts rather than using representative themes. Qualitative work represents a traditionally low proportion of research in allergy and clinical immunology (Gallagher *et al.*, 2009), where authors

often publish in journals with a biomedical focus. However, we have elected to include these studies due to limited available data and belief that such a perspective does not negate the utility of the findings.

Data Abstraction & Synthesis

Meta-aggregation using JBI's methods involves extraction of findings, which are then grouped into categories. The categories are combined to construct synthesis statements. Findings are conclusions reached by researchers, often presented as themes. Extraction of data using themes alone became problematic due to variation in author conception, use and communication of themes—an issue Sandelowski and Leeman (2012) have previously addressed. Due to inconsistencies in the linkage of philosophical basis to methodology to findings, the variation in authorial understandings and presentation of themes as findings became increasingly problematic. We therefore completed a line-by-line review focusing on results, discussion and conclusions for findings not explicitly listed as themes. As line-by-line extraction yielded numerous findings, we grouped the findings into subcategories then categories. We used corresponding interview excerpts to validate findings when available and to aid in categorization and synthesis. A final review helped to ensure resulting aggregated syntheses remained broadly representative of the studies. Although synthesis statements in meta-aggregation generally reflect specific clinical recommendations (Hannes and Lockwood, 2011), we instead used synthesis statements to reflect the central experiences of teens with FIA as evaluation of clinical outcomes was not the direct aim of these studies.

RESULTS

We developed three syntheses from nine categories and 64 subcategories. These statements are representative of the central experiences of living with FIA as a teen as reported in the included studies.

Synthesis Statement 1: Defining the Allergic Self

This experience refers to the process by which teens come to define their allergic self and identity over time. It reflects the synthesis of three categories: experiencing allergy, coming to understand allergy and redefining normal (Figure 2). As teens better understand their experiences living with FIA and begin to incorporate it into their lives they begin to redefine normal, which allows development of an ‘allergic identity.’

Experiencing allergy

This category emerged from findings expressing the individual encounter with the realities and diagnosis of FIA. MacKenzie et al. (2010) found teens with FIA saw their body as lacking or deficient. Teens experienced the vulnerability and danger of anaphylaxis as a life-or-death situation and acknowledged that they feared dying from it. Teens feared anaphylaxis and reactions increased fear, even if from long ago. Epinephrine Auto-Injectors (EAI) came to be seen as a lifeline by teens. Teens also had a strong desire for a cure as opposed to management and acknowledged that FIA changed thoughts about their futures (Stjerna, 2015). Fear resulted in a complicated, conflicting relationship with food. Food became fearful by extension (DunnGalvin *et al.*, 2009), yet also had positive connotations of healthfulness, family tradition, comforting, or helping to cope emotionally (Sommer *et al.*, 2014; Stjerna, 2015). DunnGalvin and colleagues (2009) discuss indications that gender affects coping with FIA but do not specify. The allergy experience was rooted in the embodied nature of FIA as an illness and how fear of anaphylaxis affected one's outlook on life.

Coming to understand allergy

Many teens in the studies did not feel an initial understanding of allergy, instead turning to experience and knowledge from others. Teens identified that not knowing enough about their allergies was problematic, admitting inability to recognize, treat, or prevent anaphylaxis (Akeson *et al.*, 2007; Gallagher *et al.*, 2011). How well they understood their allergy varied and teens acknowledged

needing assistance from parents and Healthcare Providers (HCP). Teens often felt as though they did not have enough experience or knowledge to deal with the realities of having FIA independently. Teens considered HCPs to be helpful resources for long-term management and assessing ongoing needs. HCPs provided information and support that offered a better understanding of anaphylaxis (Monks *et al.*, 2010) despite a difference in risk perception between teens and HCPs (Gallagher *et al.*, 2012). Education needs varied, but findings reflected teens' difficulty learning how and when to use their EAI, appreciation of practical approaches and often finding training ineffective and variable (Monks *et al.*, 2010; Gallagher *et al.*, 2011). There was also an indication that teens would prefer to learn about allergies from peers. This category reflects the range of how teens came to understand FIA from a place of not-knowing and recognized the need for multiple resources, even if not always ideal.

Redefining normal

This is a process wherein teens come to see their diagnosis with FIA and their own particular differences as a part of their life and identity overall. What is not normal for others becomes normal for them as a way to cope and enfolded into their daily life. Although this process was different for those who could not recall a time before FIA and those who developed FIA later in life (MacKenzie *et al.*, 2010), Fenton *et al.* (2011) specify 'redefining normal' as a theme for adolescents. This phrase represents how teens grappled with their need to be normal and make life normal for themselves while recognizing being different and the ways allergy changed their identity (DunnGalvin *et al.*, 2009; Fenton *et al.*, 2011; MacKenzie *et al.*, 2010; Marklund *et al.*, 2007). Aspects of their lives associated with FIA became integrated into their identity (DunnGalvin *et al.*, 2009; Marklund *et al.*, 2007). MacKenzie (2010) emphasizes the way FIA becomes a 'way of life.' Teens automatically integrate the necessary steps of living with allergy and everyday life, entering an individual state of 'normal' while understanding their experience of normal is different from other teens' without FIA.

Synthesis Statement 2: Finding a Balance

The categories involved in Finding a Balance include: the burden of allergy, ways of responding and moving towards independence (Figure 3). This synthesis reflects how teens respond to the difficulties of living with FIA in a variety of ways and must find an effective way to live with these challenges independently. The overwhelming sense from the combined studies was that teens must find a balance in coping and maintaining independence when managing the burdens of FIA.

The burden of allergy

This category refers to the difficulties teens encounter in having FIA, which was an overwhelming similarity in the studies. Teens felt as though their difficulties were not understood, or that people were ignorant of their needs to remain safe. They felt disregarded, isolated, socially excluded and were bullied or teased by peers (Akeson *et al.*, 2007; DunnGalvin *et al.*, 2009; Fenton *et al.*, 2011; MacKenzie *et al.*, 2010). Teens felt they had to deal with more ignorance from adults, who did not accept allergies as easily as friends did. They sometimes felt obligated to excuse the ignorance of people close to them despite having been treated poorly. Being allergic also resulted in unwanted attention and being treated differently, which led to feeling isolated or different. Teens concealed their allergy or avoided telling people, because it caused more problems when people knew. They experienced an inability to trust others, instead needing to ensure their own safety. Sometimes they felt increasingly burdened when coping with the worry of others, especially parents. For many teens the need for constant vigilance and strict avoidance weighed on them heavily, especially outside safe places. Significant amounts of time and effort were dedicated to dealing with these burdens. Several studies reflected the opinion that there is nothing good about allergies and burdens outweighed any positives (Akeson *et al.*, 2007; DunnGalvin *et al.*, 2009; MacKenzie *et al.*, 2010).

Ways of responding

This category describes the range of responses that teens have living with FIA, which affects their coping in daily life. Teens discuss a range of emotional responses: sadness, fear, frustration and worry, some having experienced these feelings very intensely. These responses center around the burdens of living with FIA as a life-threatening illness, centering on social dimensions of the issues teens face. A range of coping is noted in several studies: the more control or anxiety expressed, the higher the burden teens experienced (DunnGalvin *et al.*, 2009; Gallagher *et al.*, 2012; MacKenzie *et al.*, 2010). This can vary from to extremes, with minimization of the effect of FIA (Sommer *et al.*, 2014) to preoccupation with risks of FIA (Akeson *et al.*, 2007; DunnGalvin *et al.*, 2009). Teens made an effort to see the positive even if they felt FIA's burden strongly. This helped maintain perspective so teens saw FIA in a broader context rather than the worst possible light (Akeson *et al.*, 2007; MacKenzie *et al.*, 2010; Marklund *et al.*, 2007). Those teens who saw FIA in a positive light believed it made them stronger, encouraged healthier eating, or gave them a sense of achievement in their ability managing their allergies. Some mentioned not needing additional social support (Akeson *et al.*, 2007) or having no problems finding safe food in social situations (Sommer *et al.*, 2014), however, this perspective seems to be in the minority, or perhaps even a way to minimize impact of FIA.

Moving towards independence

This category encompasses how teens must balance self-reliance with dependence on others to best manage their FIA. As teens move into school, social and work situations apart from their parents, the struggle to feel safe and communicate needs with others became more important. Being strong and responsible were required qualities to successfully transition to caring for oneself, despite needing to rely on parents and friends. As teens shift toward increasing independence, they must take control and become more involved managing their allergy—with increasing responsibilities. However, independence was limited by knowledge of FIA and risk perception (Gallagher *et al.*, 2012; Stjerna, 2015). Teens must become competent in social interactions surrounding FIA by self-

advocating, practicing decision-making and recognizing safe/unsafe situations (DunnGalvin *et al.*, 2009; Fenton *et al.*, 2011; Gallagher *et al.*, 2012). Transitioning to increasing self-reliance with FIA was considered a gradual process that took place as children grew older and more fluent in handling their FIA (Gallagher *et al.*, 2012). However, persistent conflict between teens and their parents must be carefully negotiated over time as their relationship and abilities change (Gallagher *et al.*, 2011). Teens also identified a need to depend on others for help, especially when physically unable to help themselves during reactions. They sought assistance from parents most, but also turned to friends, virtual support through social media and those who understood and respected their needs.

Synthesis Statement 3: Controlling the Uncontrollable

This synthesis includes the categories being vigilant, negotiating risk and systemic influences (Figure 4). Controlling the uncontrollable is a phrase used by Stjerna (2015) in regards to risk management in FIA. Here it expresses teens' experiences trying to be vigilant about negotiating risk despite systemic factors beyond their control. It is impossible to control every aspect of life and there is always risk, but policy and business practices make navigating risks safely more difficult.

Being vigilant

This refers to the constant vigilance and control required by teens to begin to navigate living with their FIA (DunnGalvin *et al.*, 2009; Fenton *et al.*, 2011; Gallagher *et al.*, 2012; MacKenzie *et al.*, 2010; Marklund *et al.*, 2007). Vigilance is required due to the life and death nature of FIA, requires work to maintain and is a constant process that teens with FIA engage in (Fenton *et al.*, 2011). It is tied closely to the need for control that teens experience with regards to ensuring their own personal safety, as expressed through the actions taken to check ingredients, avoid allergens and ensure one's EAI is always available. Uncertainty occurs, especially when information regarding ingredients is either not available or trustworthy, allergens may be unexpectedly present, or teens are unsure when

or how to treat anaphylaxis. DunnGalvin *et al.* (2009) indicate that uncertainty, vigilance and a lack of personal control are central experiences when growing up with FIA. Even with reasonable precautions there is always risk of having a reaction. However, some teens had experiences where lack of vigilance—for example, not checking food ingredients—resulted in a life-threatening reaction (Monks *et al.*, 2010). The more vigilance and control teens exercised, the more it imposed limitations on their lives: eating only safe foods resulted in feeling they had no choice, which increased the burden of FIA. EAI was considered a central aspect of having FIA, however studies differed on how often and how willing teens were with regards to carrying them. One concluded that although teens often carried their EAI, they did not know when or how to use them (Gallagher *et al.*, 2011)—meaning that teens must be vigilant about more than availability of their EAI. Vigilance in this sense extends beyond concrete actions, moving into FIA knowledge development and planning skills.

Negotiating risk

This category focuses on how teens grappled with risk related to having FIA. This includes issues related to risk perception, safety recognition and decisions about risk. Risks as perceived by teens with FIA must be seen more broadly than the potential of allergen exposure and anaphylaxis. Teens with FIA must navigate multiple risks they perceive in daily life, including individual health, social identity and ability to maintain personal privacy—all of which become threatened due to the burden of their allergies (Gallagher *et al.*, 2012; MacKenzie *et al.*, 2010; Marklund *et al.*, 2007; Stjerna, 2015). Teens decide if a given risk is acceptable through negotiation—is the risk worth it, or is it simply less harmful than other options (MacKenzie *et al.*, 2010)? Teens acknowledged taking calculated risks by engaging in activities they considered risky only while having an EAI present, for example, or simply leaving an event or place if they considered it too risky. However, risks were sometimes taken to avoid embarrassing situations or to be able to participate socially when peers did not face the same limitations (Marklund *et al.*, 2007). Teens also used their social situations in protective ways, by asking friends to help them remain safe, or sharing the management of their FIA by trusting in the judgment of others, which could help prevent more embarrassing situations such as anaphylaxis in a public place (Sommer *et al.*, 2014; Stjerna, 2015).

Systemic influences

This category addresses how teens with FIA do not live in a void and must deal with social, political and economic influences on their experience with allergies. Many of these factors are frustrating to teens as they are beyond their control: safe food being lower quality or unavailable, school environments causing allergen exposure, family dietary traditions, dependence on others to provide food and a lack of proper ingredient lists are several examples (Fenton *et al.*, 2011; Marklund *et al.*, 2007; Sommer *et al.*, 2014; Stjerna, 2015). These factors are tied to government, school and corporate policies combined with economic dependence and cultural contexts of growing up. As well, the social aspect of food plays into the difficulties experienced by a teen living with FIA, since food choices are often socially motivated (Sommer *et al.*, 2014). At school, teens felt it was important for them to be treated fairly and equitably, preferring not to be differentiated or receive special treatment compared with students who did not have allergies (MacKenzie *et al.*, 2010; Stjerna, 2015). Less regulation related to allergies in schools could mean more risk, but every measure for safety also has social impacts. Consumerism and corporate policies made life difficult by advertising foods that teens with FIA were unable to have. Teens felt limitations of overly-cautious warning labels on foods due to potential litigation were an unneeded annoyance and sometimes chose to eat foods with warning labels (Gallagher *et al.*, 2012; Monks *et al.*, 2010). Overall, teens thought of home as a safe place, while public places outside the home were dangerous and inaccessible. Although many studies indicate a need for public awareness of FIA or that it is already increasing (DunnGalvin *et al.*, 2009; Gallagher *et al.*, 2011; MacKenzie *et al.*, 2010; Marklund *et al.*, 2007; Monks *et al.*, 2010), Stjerna (2015) notes that awareness is not enough given the complicated contexts teens find themselves in and will not prevent uncertainty and risks. Even if the public is increasingly aware of FIA, this awareness does not in and of itself result in positive changes for teens living with life-threatening allergies.

DISCUSSION

This meta-aggregation developed three synthesis statements reflecting the experiences of teens living with FIA. As discussed above, these are: (1) Defining the allergic self; (2) Finding a balance; and (3) Controlling the uncontrollable. Although all included studies reflected the experiences of teens with FIA, few focused on this specific purpose and population. These syntheses give a sense of how closely tied allergy becomes to one's identity, the difficulty of coping with the burden of FIA and the challenge of dealing with multifaceted risk in social contexts.

The first synthesis overlaps with illness experiences of young peoples' experiences living with chronic illnesses more generally. A recent review of children and young peoples' feelings of being different when living with chronic illness described participation in everyday life, treatment regimens and communication as core areas of focus in how teens perceive the self differently (Lambert and Keogh, 2015). The central idea of feeling different played a part in defining teens' 'allergic identity,' and social risks centered on a lack of acceptance and similarity in this review. When young people make decisions about everyday life with chronic illness, there was a definite sense of having no choice, also echoed in some of the reviewed studies. This is reflected in how teens must try to find a balance in how they cope with FIA when that they must negotiate the associated risks, which are largely out of their hands to the extent that many choices are non-choices, or severely limited by systemic influences. A more detailed comparative study of teen experiences living with chronic illness may help delineate those peculiarities attributed to FIA itself and help shed light on the identity shift that occurs with FIA.

Although the more recent research in this review (Fenton *et al.*, 2011; Gallagher *et al.*, 2012; Stjerna, 2015) acknowledges a holistic situation-dependent perception of risk, earlier studies neglected the complex negotiations teens make as they become more independent. This may indicate a clinically paternalistic perspective in some cases. Studies of teens living with chronic illness describe teens as aware of potential poor outcomes, but weigh other factors relating to how they must

live with chronic illness differently than their parents or HCPs. This extends to everyday decision-making by teens not living with FIA (Woodgate *et al.* 2015) and points to the need for all parties to recognize the value and competence of teens who manage living with FIA daily. From the studies reviewed, teens desire guidance and support, yet those in authority tend not to listen to their needs or accept teens as experts in living with FIA. Although family, friends and HCPs show various levels of agreement with teen understandings of risk, a detailed discussion of their understanding may be helpful. Further studies elaborating on how to conceptualize the risk associated with FIA and ways to effectively communicate it may assist in addressing the health education needs of teens.

The third synthesis shows teens are enmeshed in social and political contexts that affect their experiences living with FIA. One excluded study from Ontario, Canada described the unintended effects of a school policy requiring disclosure of allergies in students: despite normalizing FIA, it also labeled students, making them subject to bullying and stigma (Dean *et al.*, 2015). The policy thus highlighted how the artificial divide between physical/medical health and social health creates conflict, reflecting the central struggle in our review that many teens faced in managing perceived risks. As media portrayals of allergy frame public conceptions of risk (Rachul and Caulfield, 2011; Harrington, Elliott and Clarke, 2012) and a multitude of institutions and corporations exert their influence (Waggoner, 2013), FIA becomes a very public social issue. Teens with FIA are often assigned a limited amount of autonomy and responsibility for their individual health, socially policed in how they manage it and detrimentally constructed as risky beings (Spencer, 2013; Glasgow and Schrecker, 2015). However, teens with FIA live in a context where they are subject to rules of others and dependent on adult and peer supports, as the reviewed studies demonstrate. Though Stjerna (2015) focused on teens' management of FIA-related risk in a wider social context, exploring systemic inequalities and the need to manage the burdens of FIA are not directly addressed in any other works.

CONCLUSION

This review aimed to create a meta-aggregation of the experiences of teens with FIA to evaluate and synthesize the current research while providing a base for future improvement of health policy and services for this population. This area requires further investigation and would benefit from additional research that deepens and broadens the philosophical and methodological approaches in current studies, while remaining philosophically consistent. The studies we reviewed gave a sense that although teen perspectives are often marginalized, effective care hinges on a clear and respectful understanding of their needs, which must be carried into practice during clinical and health education encounters. Teens may also benefit by exploring the need to balance the risk of anaphylaxis and social risk during clinical conversations, however having feedback from peers with FIA alongside HCPs during health education would be the ideal. As teens must try to remain safe in situations outside of their control, HCPs can assist by exploring options and frustrations, as well as advocating for the needs of teens when living with FIA. Anaphylaxis prevention must move beyond the individual and become a public health issue when awareness is not enough. This synthesis can help to inform future research, interventions and policy change, allowing us to broaden how we conceptualize the needs of teens living with FIA while remaining sensitive to teen perspectives.

Author Contributions:

All authors have agreed on the final version and meet at least one of the following criteria (recommended by the ICMJE*):

- 1) substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
- 2) drafting the article or revising it critically for important intellectual content.

* <http://www.icmje.org/recommendations/>

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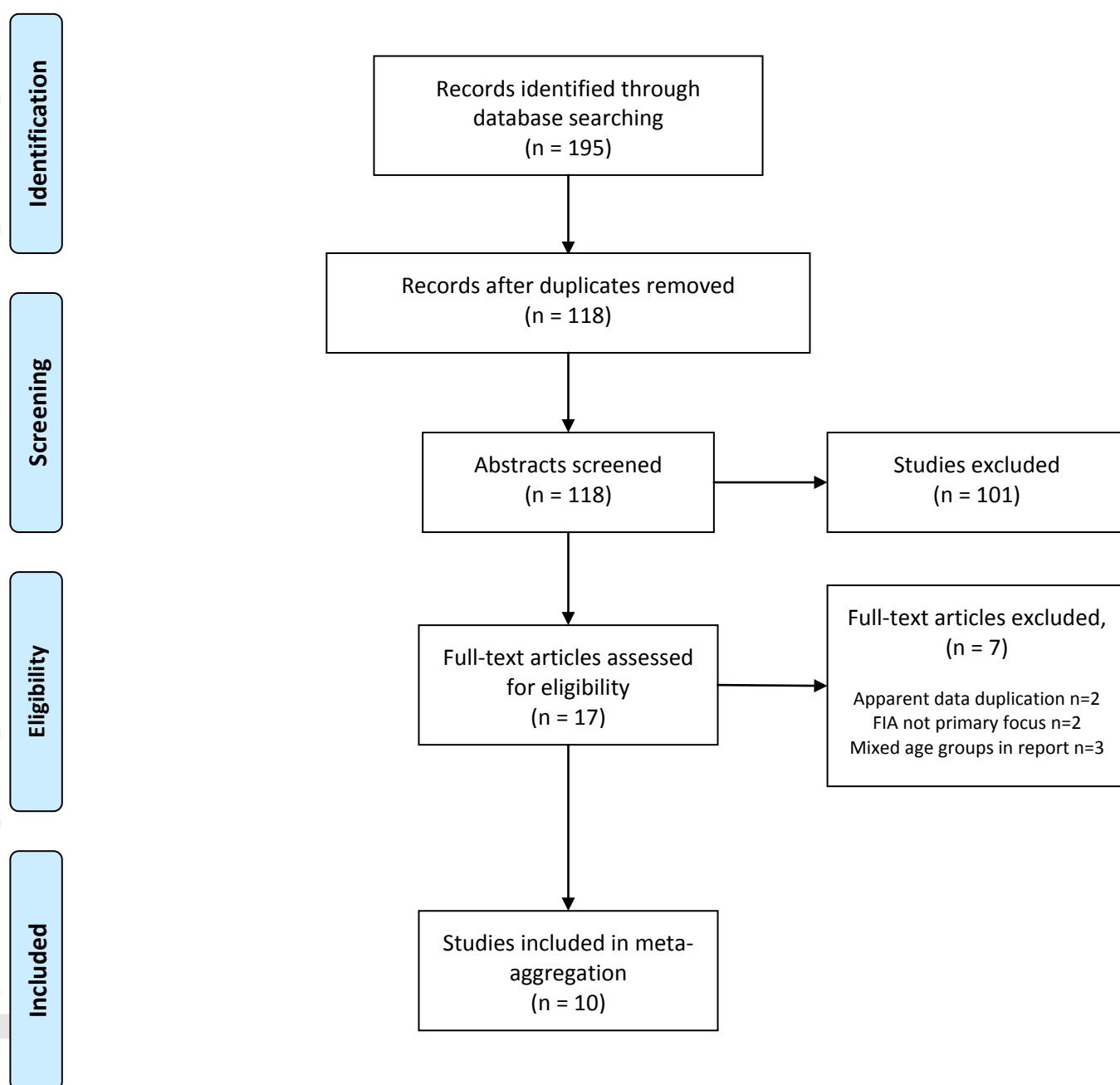
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Table 1

Table 1 - Characteristics of Included Studies							
Citation	Title	Analysis	Age	Sample	Parents	Data Separation	Themes
Akeson <i>et al.</i> 2007	The psychosocial impact of anaphylaxis on young people and their parents	Framework approach	13-19y	Teen n=7	Yes, n=8	Parent/teen themes separate and identified on excerpts.	Teen themes: 1. Mostly respect for and confidence in managing the allergy, but less knowledgeable than parents, 2. Allergy perceived as 'not a big deal', 3. Lower and narrower perception of risk in comparison with parents, 4. Inconsistency in carrying adrenaline due to practical and psychosocial obstacles, 5. Mistrust in food labelling.
Marklund <i>et al.</i> 2007	Adolescents' experiences of being food-hypersensitive: a qualitative study	Qualitative content analysis	13-19y	N=17	No	Not always clear when FIA vs. other dietary restriction.	1. Perceiving oneself as being particular, 2. Feeling constrained, 3. Experiencing others' ignorance, 4. Keeping control, 5. Feeling it's okay. Pervading theme: Striving to normalise the experience of being food-hypersensitive
DunnGalvin <i>et al.</i> 2009	Developmental pathways in food allergy: a new theoretical framework	Grounded theory	6-15y	N=62	No	Divided by age group (6-8y, 9-11y, 12-15y) and noted on excerpts.	1. Meanings of food, 2. Autonomy, control, and self-efficacy, 3. Peer relationships, 4. Risk and safety, 5. Self/identity, 6. Coping strategies.
Mackenzie <i>et al.</i> 2010	Teenagers experiences of living with food hypersensitivity: a qualitative study	Phenomenologic analysis	13-18y	N=21	No	N/A	1. Living with Food Hypersensitivity (FHS) as a way of life/coming to know FHS as a way of life, 2. Living with FHS as experiencing and coping with burden, 3. Alleviation/exacerbation of the burden of living with FHS, 4. Living with FHS involves managing acceptable risk.
Monks <i>et al.</i> 2010	How do teenagers manage their allergies?	Thematic content analysis	11-18y	N=18	No	N/A	Main themes: 1. Avoidance of allergens, 2. Being prepared for reactions, and 3. Treating reactions. Other themes: 1. Family and home, 2. School and work, 3. Friends and peers, 4. Allergy education.
Fenton <i>et al.</i> 2011	Illustrating Risk: Anaphylaxis Through the Eyes of the Food-Allergic Child	"Integrated analytic framework"	8-12y, 13-18y	Teen n=10, Child n=10	No	Excerpts not always labelled with age, themes mixed and specific.	Overall: 1. Social and environmental barriers to safety, 2. Coping strategies, 3. Emotional burden of responsibility. Teen specific: 1. Balance of responsibility – transitions, 2. Redefining normal.
Gallagher <i>et al.</i> 2011	Epinephrine auto-injector use in adolescents at risk of anaphylaxis: A qualitative study in Scotland, UK	Thematic coding	13-19y	Interviews n=26, Focus group n=8	Yes, interviews n=28, focus group n=10	Excerpts labelled, themes and findings mixed. Unclear if focus groups were mixed ages.	1. Carriage and storage of auto-injectors, 2. Desired improvements to auto-injector design, 3. The difficulty of making the decision to use an auto-injector, 4. Experiences of training, 5. Auto-injector technique.
Gallagher <i>et al.</i> 2012	Strategies for living with the risk of anaphylaxis in adolescence: qualitative study of young people and their parents	Thematic coding	13-19y	Teen n=26	Yes, n=28	Excerpts labelled, results focus more on teens.	Themes not identified
Sommer <i>et al.</i> 2014	An exploratory investigation of food choice behavior of teenagers with and without food allergies	Thematic analysis	12-18y	Focus group n=11, non-allergic n=7, allergic n=7	No	Subthemes separate, excerpts labelled.	1. Variety and enjoyment of foods as learning process, 2. Body awareness, feelings, and temptations of foods, 3. Parental control vs convenience, 4. Eating as social experience, 5. Routine, traditions, and environment, 6. Knowledge shapes understanding of foods.
Stjerna <i>et al.</i> 2015	Food, risk and place: agency and negotiations of young people with food allergy	Thematic analysis	11-17y	N=10	No	N/A	1. Management of health risks, 2. Management of social risks in different places.

Figure 1: PRISMA Flow Diagram



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement*. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit www.prisma-statement.org.

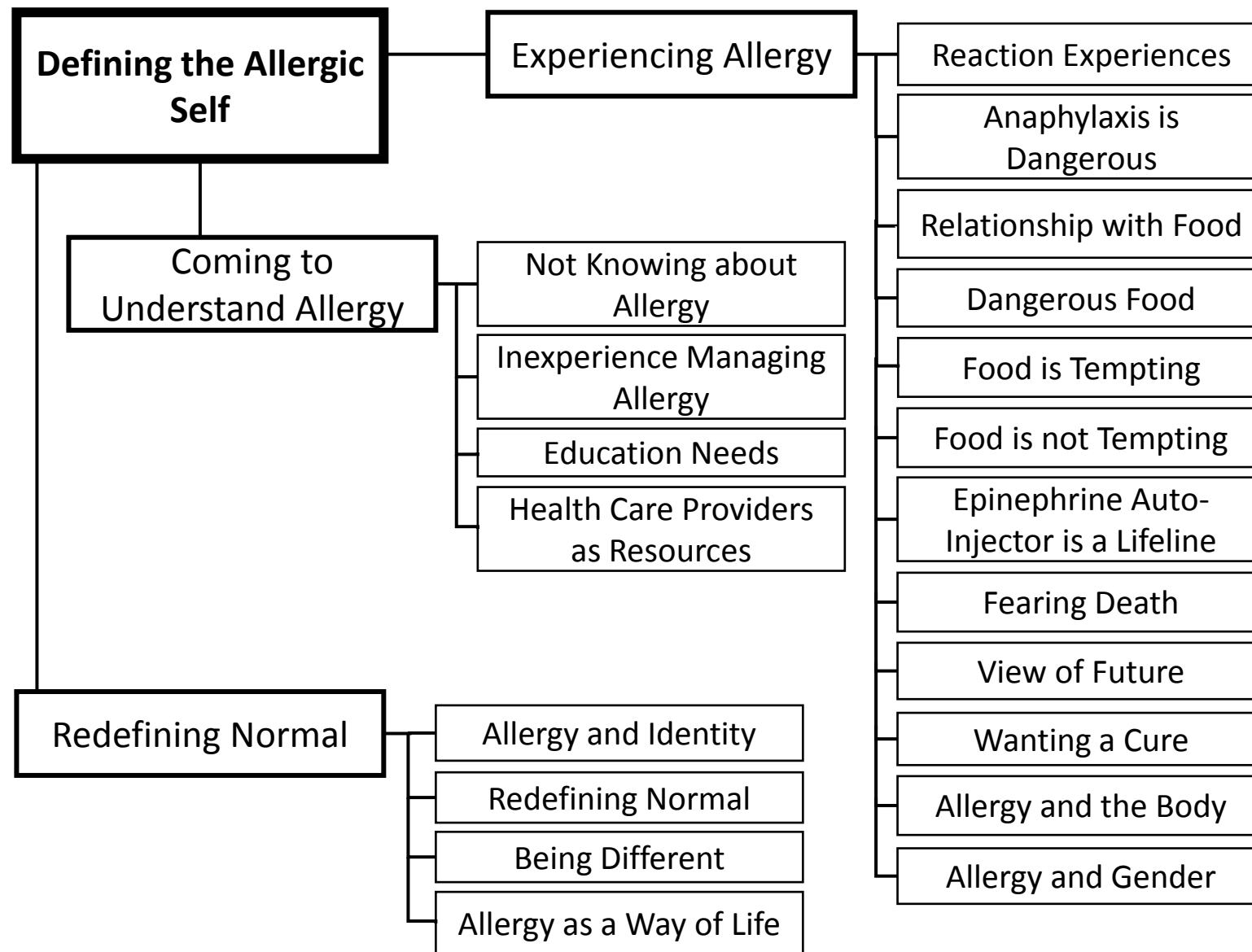


Figure 2: Synthesis Statement 1, Defining the Allergic Self

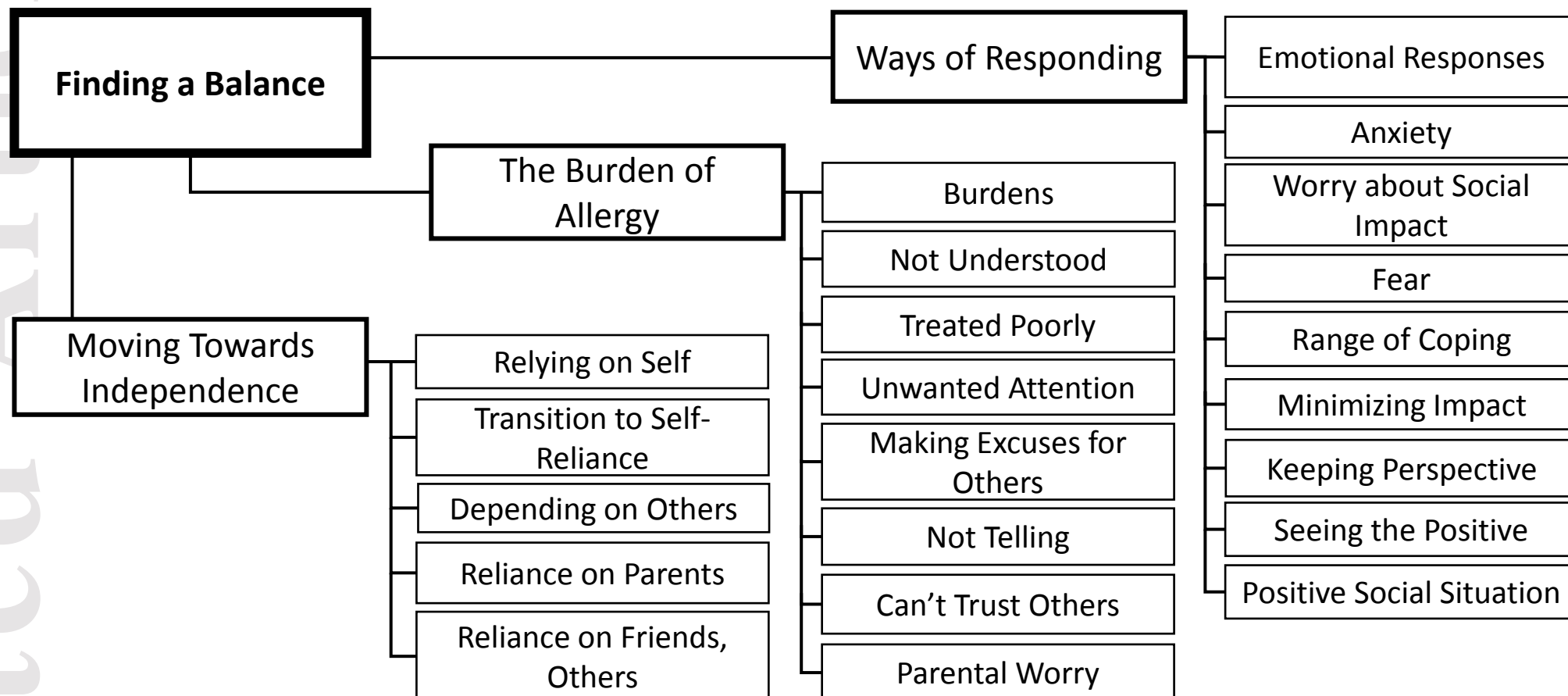


Figure 3: Synthesis Statement 2, Finding a Balance

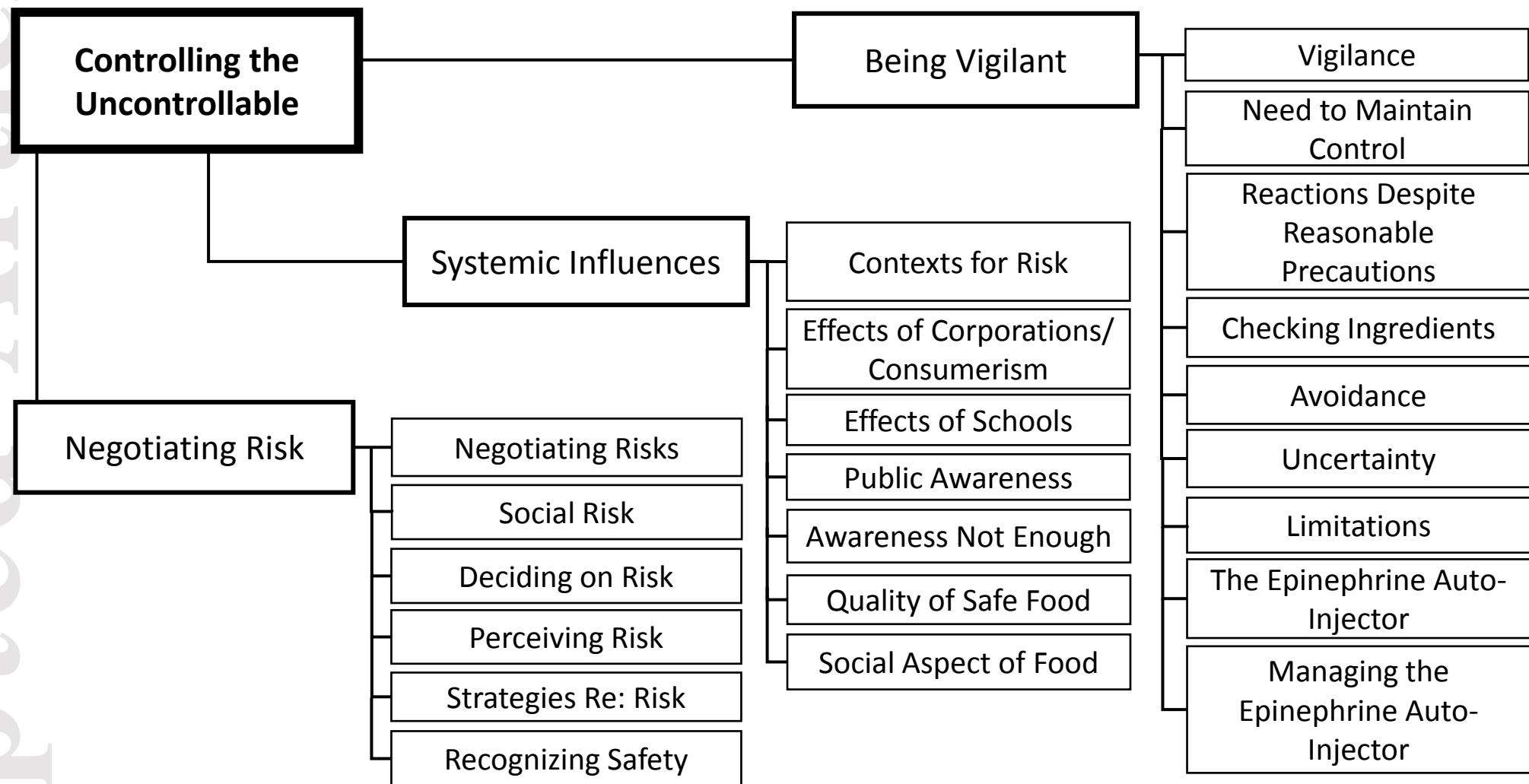


Figure 4: Synthesis Statement 3, Controlling the Uncontrollable