

The Psychosocial Impact of Life-Threatening Childhood Food Allergies

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The issue of life-threatening food allergy in the pediatric population is notable and demands attention. In 2011, approximately 5.9 million children under 18 years of age in the United States had a reported food allergy (Gupta et al., 2011). Once signs and symptoms of food allergy appear, the threat of death following repeated exposure to an otherwise innocuous substance is always present. Because of the severity of the condition, it is expected that the child and family will feel significant psychosocial impact, and it is essential to understand the perspectives from all of those involved. To assist the family unit in adaptation, it is imperative that health care professionals not only understand the biomedical implications of the problem, but also the overall psychosocial impact that may be experienced after diagnosis.

Food Allergy: Overview

Food allergy, or food hypersensitivity, can be defined as an adverse or exaggerated immunological response to food proteins resulting in a myriad of clinical symptoms (Sampson, 2004; Sicherer & Sampson, 2006). Reactions can involve the skin, gastrointestinal tract, and respiratory tract, and may be due to either an immunoglobulin E (IgE) or non-IgE mediated response (Sampson, 2004). IgE mediated responses are accountable for the allergic reactions experienced by individuals with life-threatening food allergies (Sicherer & Sampson, 2006).

Various explanations attempt to highlight the epidemiological origin of IgE and non-IgE mediated food allergies. Of the more well-known explanations, genetics has long been thought to influence sensitization and subsequent development of food allergy. Studies involving both monozygotic and dizygotic twins have provided reliable evidence to support this hypothesis (Sohi & Warner, 2008).

The purpose of this integrated literature review was to bring understanding to medical professionals of the psychosocial impact of parenting a child with life-threatening food allergies. Prevalence of life-threatening food allergy among children is increasing, and families continue to navigate the effects it can have on all members of a family. A comprehensive literature review was performed related to chronic childhood illnesses and life-threatening food allergies. Commonalities among the conditions exist related to stress, coping, and adaptive responses when parental perceptions and experiences are considered. This information may provide a conceptual context for the adaptation process involved with parenting a young child with life-threatening food allergies, revealing areas where nursing can serve to intervene and support this process.

However, the increase in prevalence of food allergies suggests that environmental factors may play a role in their development, and the hygiene hypothesis has become a new model researchers are exploring.

The hygiene hypothesis was first exposed in the late 1980s during a study on hay fever that revealed an increased number of older siblings was associated with a decreased risk of developing hay fever and eczema (Sohi & Warner, 2008). Findings from this study led scientists to believe that older siblings created an opportunity for infection to occur through unhygienic contact with younger siblings, thus creating an effective level of resistance to development of atopic disorders, such as asthma, eczema, and allergies (Sohi & Warner, 2008). Researchers have suggested that decrease in family size coupled with increased emphasis on hygienic practices in Westernized nations may explain the increasing prevalence of allergies and other atopic manifestations (Sohi & Warner, 2008).

Prevalence

Food allergy among children is now recognized as a worldwide issue in Westernized nations, and prevalence appears to be increasing (Nowak-Węgrzyn, 2003; Sampson, 2004; Shimamoto & Bock, 2002). In the United States alone, from 1997 to 2007, there was an 18% increase in prevalence of food allergy among children under the age of 18 years (Branum & Lukacs, 2008). More recent statistics reveal 8% of young children in the United States suffer

from food allergy. Of these children, approximately 30% have multiple food allergies, and 38.7% have a history of severe food-induced reactions (Gupta et al., 2011).

Sensitization

Although food allergy can develop at any age, it most often appears within the first 1 to 2 years of life after the process of sensitization has occurred (Wood, 2003). Sensitization occurs in susceptible individuals during initial exposure to a food antigen. Specific IgE antibodies to that antigen form and attach to receptors on the surface of mast cells and basophils. When the food antigen is subsequently ingested, the antigen binds to the IgE antibodies and causes both mast cells and basophils to release histamine, an inflammatory mediator. Inflammatory mediators bring about the classic symptoms of swelling (especially facial), urticaria, palatal itching and tingling, throat itching and tightness, nasal pruritis and congestion, rhinorrhea, hoarseness, stridor, dry cough, dyspnea and/or wheezing, cyanosis, dizziness, hypotension, tachycardia, colicky abdominal cramps, generalized erythema, nausea, vomiting, diarrhea (often bloody), chest pain, circulatory collapse, coma, and death (Butt & Macdougall, 2008; Kagy & Blaiss, 1998; Mandell, Curtis, Gold, & Hardie, 2005; Neuget, Ghatak, & Miller, 2001; Sampson, 2004; Sicherer & Sampson, 2006; Shimamoto & Bock, 2002). Ninety percent of sensitized children react to one of eight common offenders: cow's milk, egg, wheat, soy, tree nuts, ground nut

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(peanut), fish, and shellfish (Anderson, 1997; Kurkowski & Boxer, 2008; O'B Hourihane, 2006; Sicherer & Sampson, 2006; Sohi & Warner, 2008). Although it is common for children to outgrow these allergies, some may endure for a lifetime (Wood, 2003).

Anaphylaxis

Anaphylaxis is a serious result of an IgE mediated allergic response and can occur within minutes after ingesting a food antigen to which the child has been previously sensitized (Shimamoto & Bock, 2002). Commonly, a sensitized child need only ingest a very small amount of the food allergen to produce symptoms. Food-induced anaphylaxis (FIA) is currently the leading cause of anaphylactic reactions occurring outside of the hospital setting (Bollinger et al., 2006; Clark & Camargo, 2005; Shimamoto & Bock, 2002), and the myriad of symptoms can vary greatly in onset, presentation, and course.

Standard of Care

Currently, no definitive treatment or cure exists for food allergies (Bollinger et al., 2006; Gillespie, Woodgate, Chalmers, & Watson, 2007; Jones & Scurlock, 2006), and the course of food-induced anaphylaxis cannot be predicted (Mandell et al., 2005). Standard of care suggests health care professionals educate caregivers on how to avoid food antigens as the primary method of preventing life-threatening reactions in sensitized children. Families must be counseled on how to carefully read food labels to identify offending allergens. Muñoz-Furlong (2003) suggests that label reading is the foundation of food allergy management.

Education on recognizing early symptoms of an allergic reaction is also critical to enable caregivers to initiate appropriate emergency therapy through the use of self-injected epinephrine (Butt & Macdougall, 2008; Mandell et al., 2005; Neuget et al., 2001; Sampson, 2004; Shimamoto & Bock, 2002). Epinephrine is the gold-standard treatment for anaphylaxis because it suppresses histamine release from the mast cells and basophils, and works on vasodilatation, edema, and bronchoconstriction. To maximize benefit of treatment, epinephrine should be administered as soon as symptoms, such as itching, swelling, tightening of the throat, or nausea, present (Gillespie, 2002). Therefore, it is imperative that all children at risk for life-threatening food allergies are

prescribed self-injected epinephrine, and they and their families are instructed on appropriate use.

The Family and Chronic Medical Conditions

Although food-induced anaphylaxis does not conform to the conventional definition of chronic illness, the condition itself is a chronic deviation from what is considered normal (Gillespie et al., 2007). However, the Americans with Disabilities Act (ADA) recognizes severe food allergies as a disability because food allergies can create physical impairment that substantially limits one or more major life activities (Asthma and Allergy Foundation of America [AAFA], 2005). Eating, breathing, and going to school – all major life activities – can each become compromised in the presence of an anaphylactic reaction. Parents must understand how best to advocate for their child using federal regulations to collaborate with educators so absences from school can be minimized. Of note, even when controlled by medications, severe food allergies remain classified as a disability under the ADA guidelines (AAFA, 2005).

Chronic illnesses, however, affect more than the child's physical well-being. Parents often perceive high levels of stress, and this, in turn, may affect their parenting efficacy and own sense of well-being (Gillespie et al., 2007; Mandell et al., 2005). According to Sicherer, Noone, and Muñoz-Furlong (2001), the general health perception and emotional impact of parenting a child with food allergy is consistent with that of chronic conditions. It is anticipated that the condition will produce a major upheaval in the lives of the entire family, and how each member experiences and responds to the condition will greatly vary (Nuutilla & Salanterä, 2006).

The impact felt by a child once diagnosed with a chronic medical condition cannot be segregated from the impact felt by the child's family. The child's illness influences the family unit just as the family affects the way in which the condition is managed. Pediatric nursing literature describes a familial response to chronic illness, including its impact, coping strategies used, and adaptation to the condition (Ray, 2002). Although considered a normal part of life, stress, in the context of chronic illness, may adversely affect the adaptive process (Hockenberry & Wilson, 2009).

For parents of children with chronic illness, common sources of stress stem from a lack of understanding about the illness, demanding management strategies, and developmental needs (Yoos, 1987). Nuutilla and Salanterä (2006) interviewed parents of children with asthma, epilepsy, muscular dystrophy, leukemia, diabetes, meningomyelocele, cerebral palsy, food allergy, and metabolic syndrome. They found that parents of children with each diagnosis expressed strong emotional responses, including feelings of anxiety, shock, anger, guilt, fear, and powerlessness. In addition, Goble (2004) found in her study of fathers of children with cerebral palsy, osteogenesis imperfecta, and autism that disbelief was a common expression post-diagnosis. Kurnat and Moore (1999) cited excessive demands on parental time and energy, fear of the child dying, financial burden, uncertainty regarding the future, marital strain, interference with routines, social and emotional isolation, and dealing with health care providers as sources of parental stress.

Cohen (1993) explored stress in parents of chronically ill children, noting that to live with a child with chronic illness is to live in a state of sustained uncertainty. She found the ambiguity of the disease can cause confusion and disorganization within the family system. Previously held knowledge, beliefs, expectations, and values become obsolete, and what is now unknown is feared:

It is not the struggle, but the unknown that we fear the most, for even if the disease is under control or in remission, the knowledge that the child's status could change with little or no warning robs parents of any respite from the reality of the threat (Cohen, 1993, p. 84).

Stressors require action, and the desired response is effective coping. Lazarus and Folkman (1984) describe coping as the process by which cognitive and behavioral strategies are employed to manage the excessive demands of chronic illness. How an individual appraises the stressful situation is a key factor in coping with the event. The appraisal will be mediated by the "personal characteristics of individuals, such as patterns of motivation, beliefs about themselves and the world, and personal recognition of resources for coping" (Lewes & Lyne, 1999, p. 134). Previous experience with a stressful event may also aid or hinder the coping process, in-

fluencing the utilization of coping resources and strategies (Gillespie, 2002).

Coping with the child's chronic illness requires both resources and strategies. Coping strategies are used to adjust to a stressful situation and have been divided into problem-focused and emotion-focused (Lazarus & Folkman, 1984). Each has both positive and negative implications depending on the chosen strategy. Parents of children with a chronic illness using problem-focused strategies to change or manage a stressful situation may define the problem, seek potential solutions, and learn new skills to handle the diagnosis and new methods to manage the environment. Parents who opt to employ emotion-focused strategies may distance themselves from stress through minimization, avoidance, self-blame and punishment, drug and alcohol use, or exercise and relaxation techniques (Gillespie, 2002). Holaday (1984) suggests parents assign meaning to the illness, normalize the child's life, and establish a social support system as additional means of coping.

Parental Perspectives Related to Food Allergy

Currently, there is limited information in medical, nursing, psychological, and social work journals regarding the psychosocial impact of parenting a young child with a life-threatening food allergy (Mandell et al., 2005). Further, prevalence is increasing, and research findings are needed to establish practice guidelines. Although an abundance of literature exists that briefly mentions the familial impact of having a young child with a life-threatening food allergy, there were only nine articles found that explicitly focused, in some way, on the psychosocial impact of parenting a young child with this condition (Bollinger et al., 2006; Bunce, 1997; Gillespie et al., 2007; Hu, Loblay, Ziegler, & Kemp, 2008; Kelsay, 2003; Klinnert & Robinson, 2008; Mandell et al., 2005; Sicherer et al., 2001; Williams, Parra, & Elkin, 2009).

Parents of children with food allergies reveal fear and uncertainty as themes in the literature related to the process of familial adaptation. Gillespie and colleagues (2007) performed a phenomenological study aimed at ascertaining the central meaning of the mother's experience of parenting a child with a life-threatening food allergy. The study results found the essence of the experience as

"living with risk," supported by five themes: "living with fear," "worrying about well-being," "looking for control," "relying on resources," and "it is hard, but it is not." The author notes that fear was a constant thread that entwined all of the themes and highlights the importance of the nurse in supporting mothers of children with food-induced anaphylaxis.

Parents of children with food allergies also describe "constant vigilance" as a supporting theme in the literature. Bunce (1997) offers an anecdotal account of one mother's experience parenting a child with a life-threatening food allergy. The mother's experience began with observing her child suffering a severe anaphylactic reaction. The mother stated: "It takes over your life. You need to be constantly vigilant and can't afford to let up for even a moment because it could be fatal" (Bunce, 1997, p. 28). Eventually, the child's food allergy became such an overwhelming factor that the mother quit her job to manage her child's condition. When the mother returned to work, she carried a pager so that in the event of an emergency, she would be accessible. Throughout the adaptation process, the mother stated normalization of the family as an important goal and means of coping.

Bollinger et al. (2006) demonstrated a significant impact of food allergy on the daily activities of parents. Using the Food Allergy Impact Scale, Bollinger and colleagues (2006) asked 87 caregivers to rate the degree to which their child's food allergy affected meal preparation, family social activities, caregiver-supervised child social activities, autonomous child social activities, school activities, family relations, caregiver stress and free time, and employment and finances. Findings showed that almost 70% of parents felt an impact from food allergy on meal preparation activities. Approximately 60% of parents reported the child's and/or family's social activities were significantly altered as a result of the food allergy. In addition, 41% of parents indicated their stress level had increased since their child was diagnosed, particularly when it was necessary to separate from their child. Bollinger et al. (2006) also determined that parents of children with two or more food allergies reported decreased quality of life likely related to the additional burden of monitoring for more than one food allergen. Using the Children's Health Questionnaire (CHQ-PF50) in their study of 253 parents, Sicherer and col-

leagues (2001) also noted parental distress and worry, perception of health, and limitations to family activities as a result of parenting a child with food allergy are significantly greater than in the general population. These differences existed to a greater degree for parents of children diagnosed with two or more food allergens and concurrent diagnosis of other atopic diseases.

Implications for Nursing

Chronic in nature, the prevalence of life-threatening food allergy among children is increasing, and the diagnosis puts a child's life at risk from ingestion of common foods. As a result, life-threatening childhood food allergies can present a significant burden to both children and their parents. Research suggests that parents of children with life-threatening food allergies and children themselves are subject to a variety of psychosocial effects. Although many of the effects are normal and anticipated, parents must be prepared to effectively navigate the food allergy experience or risk increased psychological distress or maladaptive coping (Klinnert & Robinson, 2008).

Health care providers are in a unique role that may serve to assist families in successful adaptation to the diagnosis. However, it is imperative they understand more than just the biomedical component. Health care providers must take into account the psychosocial impact food allergies have on families to properly intervene and support the adaptive process. Thus, a comprehensive approach to the care of children with life-threatening food allergies and their families should occur wherein health care providers routinely assess psychosocial care needs during each encounter.

Current literature suggests that health care providers are underprepared to address the needs of families of children with life-threatening food allergies. Additional research related to the experience of parenting a child with life-threatening food allergies is urgently needed to better understand how health care professionals currently assess and meet the psychosocial needs of these families. Research specific to the parental psychosocial impact post-diagnosis may be beneficial because an increased level of burden and distress could impair a parent's ability to effectively navigate and adapt to their child's diagnosis. ■

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Additional Readings

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