



Becoming the Parent of a Child With Life-Threatening Food Allergies¹

Susan Brantlee Broome, PhD, RN^{a,*},
Barbara J. Lutz, PhD, RN, CRRN, APHN-BC, FAHA, FNAP, FAAN^b,
Christa Cook, PhD, MSN, RN, APHN-BC^a

^aDepartment of Health Care Environments and Systems, University of Florida College of Nursing, Gainesville, FL

^bUniversity of North Carolina at Wilmington, School of Nursing, Wilmington, NC

Received 1 May 2014; revised 12 September 2014; accepted 15 October 2014

Key words:

Life-threatening childhood food allergies;
Anaphylaxis;
Chronic illness;
Family;
Parenting;
Competence;
Grounded theory;
Qualitative methods

Food induced anaphylaxis (FIA) is a serious medical event and managing it can place tremendous mental, emotional and financial burdens on parents of children with FIA. Using grounded theory methods, the experiences of parents caring for a child with FIA and the adjustments and strategies used to effectively manage a child's diagnosis were examined. Findings revealed once a child is diagnosed with FIA, parental competency is often severely challenged, calling into question parents' ability to succeed in the parenting role. To regain parental competency, parents engage in a 3 phase process to learn how to parent a child with FIA.

© 2015 Elsevier Inc. All rights reserved.

FOOD ALLERGIES ARE among the fastest growing public health concerns without cure, affecting 8% of children (Gupta et al., 2011). Food-induced anaphylaxis (FIA) is caused by a severe allergic response to a food allergen, which results in rapid reactions that can end in circulatory collapse, coma, and even death (Mandell, Curtis, Gold, & Hardie, 2005). A recent sample of nearly 40,000 United States households estimated that 3.1%, or 2.2 million children, have one or more severe food allergies (Gupta et al., 2011). Although food-induced anaphylactic reactions in children are rare, they account for approximately 53,700 episodes of anaphylaxis, 125,000 emergency department visits (Sicherer & Sampson, 2010) and 150 deaths each year in the United States (Gupta et al., 2010).

Currently, standard of care for FIA is limited to dietary avoidance of allergenic foods and prompt response after accidental ingestion, creating the need for constant vigilance. The ability of parents to adhere to this standard may be compounded by factors outside their control, including cross-contamination of food products (e.g., during manufacturing or in restaurants), reliance on others for supervision in their absence (e.g., teachers, family and childcare professionals), and lack of consistency in food labeling. All of these factors contribute to the uncertainty in managing a severe food allergy and might impact a parent's experience of caring for a child with FIA. Indeed, parents of children with FIA risk experiencing tremendous mental and emotional burdens manifested as psychological distress, including stress, anxiety, and depression (Cummings, Knibb, King, & Lucas, 2010).

Research suggests that health care providers are underprepared to address the needs of parents of children with severe food allergies as very little is known regarding the parental

* Corresponding author: S. Brantlee Broome, PhD, RN.
E-mail address: sbroome1@ju.edu.

experience of this phenomenon (Broome-Stone, 2012). Only a few recent studies have explored the parental experience. Gillespie, Woodgate, Chalmers, and Watson (2007) described the essence of the parental 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” (p. 33). Fear was incorporated throughout all of the themes, and underscores the importance of the nurse in offering anticipatory guidance to meet the ever-changing needs of parents as they adapt to caring for their child in different developmental stages.

In a similar study by Mandell et al. (2005), the authors interviewed parents regarding their experiences of adaptation following a diagnosis of severe food allergy in their child. Findings resembled those of Gillespie et al. (2007) with the addition of a high level of anxiety as a major obstacle to coping. Anxiety was noted to influence a family’s ability to adjust and remain vigilant to risk of accidental exposure to allergens. In a study of 253 parents, Sicherer, Noone, and Munoz-Furlong (2001) found that parents of children with food allergies had significantly higher levels of distress and worry, and more limitations on family activities than parents from the general population. Though some anxiety may be protective, disproportionate anxiety may become detrimental and lead parents to unnecessarily restrict a child’s social activities (Cohen, Noone, Munoz-Furlong, & Sicherer, 2004; Klinnert & Robinson, 2008). King, Knibb, and Hourihane (2009) suggested the familial impact related to a child’s diagnosis of food allergy included stress on the entire family, constant vigilance, parental difficulty in leaving the child in the care of another, and sibling concern that the brother or sister with allergies may die. While many families are able to manage the challenges of severe food allergies, others struggle to achieve balance between ensuring a child’s safety and attaining a normative developmental status leading to increased distress and/or maladaptive coping (Klinnert & Robinson, 2008).

Recently, Gupta et al. (2013) estimated the economic burden of food allergies in the U.S. at \$24.8 billion annually. The burdens may have a cumulative negative impact on the family, especially when they impair parental competency. Thus, parents need substantial support following a food allergy diagnosis (Williams, Parra, & Elkin, 2009). To provide this support, healthcare professionals must understand the challenges faced by parents of children with severe food allergies (Klinnert & Robinson, 2008). Therefore, this study seeks to understand parents’ perspectives about the impact of having a child with severe food allergies and adjustments required to effectively manage the condition. The research will provide initial data to promote development and testing of family-centered interventions to address the needs of parents, siblings, and the afflicted child, thus improving the quality of life for the entire family.

Methods

The study employed the grounded theory method (Glaser & Strauss, 1967), which uses a hierarchal coding structure

and comparative analysis to generate concepts, themes, and relationships from participant interviews. Data were analyzed using dimensional analysis within a symbolic interactionist perspective (Bowers & Schatzman, 2009; Schatzman, 1991). Inclusion criteria consisted of English reading and writing adults able to give informed consent and who assumed the active role of parent/caregiver for a 6-month to 12-year-old child diagnosed by a physician as at risk for a life threatening food allergy and who carry auto-injectable epinephrine in case of a reaction. Parents were excluded if the child had other prominent chronic conditions such as diabetes, seizures, cancer, behavior disorders, etc. Children with asthma and/or other allergies were not excluded as these conditions commonly exist in conjunction with the diagnosis of food allergy.

Participant recruitment and data collection occurred exclusively using an electronic format. Prior to initiation of study activities, study approval was obtained from the institutional review board at a large southeastern university. Participant recruitment was initiated using a study advertisement posted in the bi-weekly electronic newsletter of the Food Allergy Research and Education (FARE) organization. FARE is a Web-based, 501(c) (3) nonprofit designed to provide information, programs, and resources related to food allergy and anaphylaxis. The newsletter is distributed to over 60,000 individuals via email. If interested, participants were consented utilizing Qualtrics™ survey software, a secure data collection portal with SAS 70 certification for rigorous privacy standards. Participants were presented an informed consent waiver and asked to answer a set of demographic questions. Demographic information was used for inclusion and exclusion and to contextualize study results.

Once participants were consented, asynchronous interviews were conducted utilizing Qualtrics™ software. Initially, all participants were asked to provide 2–3 written narratives focusing on the parents’ experiences and understanding of the implications of severe food allergies, through open-ended questions loosely structured around Kleinman’s (1988) explanatory model to elicit the meaning of an illness. The initial interview questions were the same for each participant. The parents’ narrative responses were analyzed and subsequent interview questions were developed by the research team to explore themes, concepts, and categories identified during analysis. Subsequent questions were specific to each participant based on their answers to the previous set of questions. Each participant responded to 4 sets of questions during the study with each set containing approximately 4–6 narrative type questions. Table 1 includes a description of the topics and focus areas for each set of interview questions.

Analysis began with open coding, which generated data fragments such as “terrifying” and “stressful” and “just don’t know or understand.” Axial coding consisted of relating these concepts to researcher memos and theoretical discussions by the research team during analysis into sub-concepts such as “emotional upheaval,” “becoming the expert,” and “establishing a new normal.” As categories achieved density

Download English Version:

<https://daneshyari.com/en/article/2666771>

Download Persian Version:

<https://daneshyari.com/article/2666771>

[Daneshyari.com](https://daneshyari.com)