Student and Parent Perspectives on Severe Food Allergies at College

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ABSTRACT

Introduction: Constant vigilance to manage severe food allergies (FAs) can lead to high stress. Additional stress may develop during life-course transitions, such as the transition to college. However, few studies have evaluated everyday and FA-related stress in college students with FA and their parents. This analysis examined experiences of 26 college students with FA and their parents.

Methods: Students and parents completed online surveys in a mixed-methods exploratory study of everyday and FArelated stressors, potential contributing factors, and FA management.

Results: FA affected nearly all areas of students' lives. Management required constant vigilance because of issues of trust in others. However, nearly 40% of students did not consistently carry emergency medication to counteract reactions. Parents worried from a distance while learning to trust their child's FA management capabilities.

Discussion: Additional preparation and support for college students with severe FA and their parents may help improve stress and FA management. J Pediatr Health Care. (2018) ■■,

KEY WORDS

Anxiety, college students, food allergies, stress, transition to adulthood

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Food allergy (FA) management requires constant vigilance to avoid allergen exposure and potentially fatal reactions (Fenton, Elliott, & Clarke, 2013; Klinnert & Robinson, 2008; Mandell, Curtis, Gold, & Hardie, 2005; Stjerna, Worth, Harden, & Olin Lauritzen, 2017); however, this can lead to stress and anxiety (Duncan & Annunziato, 2018; Fenton et al., 2013; Gallagher, Worth, Cunningham-Burley, & Sheikh, 2016; Klinnert & Robinson, 2008; MacKenzie, Roberts, van Laar, & Dean, 2010; Mandell et al., 2005; Shanahan, Zucker, Copeland, Costello, & Angold, 2014; Stjerna et al., 2017). These may be particularly evident during developmental transitions, such as the transition to college. Substantial life changes in multiple domains during this transition, coupled with taking primary responsibility for independent FA management, could generate stress and anxiety (Arnett, 2000, 2007; Guidicessi, Rubes, Kim, & Annunziato, 2015) and could contribute to observed high rates of anaphylaxis and fatalities in this age group (Gupta, 2014).

Some anxiety facilitates appropriate vigilance (Mandell et al., 2005; Skinner & Edge, 1998), but the additional chronic and acute stress generated by FA and its management may lead to poor mental and physical health later in life (Compas, Jaser, Dunn, & Rodriguez, 2012; McEwen & McEwen, 2015). Despite high rates of stress among emerging adults with FA, few studies have examined their experiences or those of their parents (Greenhawt, Singer, & Baptist, 2009; Guidicessi et al., 2015; Karam, Scherzer, Ogbogu, Green, & Greenhawt, 2017). College students, in particular, face multiple potential FA-related stressors, including real or perceived reluctance to implement requested accommodations, difficulty creating a safe environment, and sharing important FA-related information with others who could provide support and assistance (Choi & Rajagopal, 2013; Lessa, Lozano, Esteve, & Frigola, 2016; Mandell et al., 2005; Olarnyk & Elliott, 2016; Panzer et al., 2012). Findings from other studies indicate that parents of children with FA experience substantial stress

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related to keeping their children safe (Annunziato et al., 2013; Broome, Lutz, & Cook, 2015); however, few have examined parental experiences of sending a child with an FA to college. This is a critical developmental transition, anticipation of which can lead to stress in parents of children with other chronic health conditions, such as Type 1 diabetes mellitus (T1DM; Ersig, Tsalikian, Coffey, & Williams, 2016). Parents of teens and college students with FA may have similar experiences, although these have not been described. Students and their parents may also experience sustained high stress and anxiety, particularly when allergic reactions occur (Ferro et al., 2016; Herbert & Dahlquist, 2008; Shanahan et al., 2014). To better understand the experiences of college students with FA and parents, this exploratory study examined their everyday and allergyrelated stressors.

METHODS

Procedure

College students with FA and parents participated in a descriptive exploratory study approved by the University of Iowa institutional review board. Participants included 18- to 21-year-old college students with a selfreported severe FA and biological parents, stepparents, or parental figures of 18- to 21-year-old college students with severe FA. Both paired and nonpaired students and parents participated; although not identified by name, participant codes indicated which parents and students were paired. Students were recruited via mass e-mails at a public university, private college, and community college and through invitations on the Food Allergy Research & Education (FARE) Facebook page. Parents were recruited through participating students and the FARE Facebook page. Because this was an exploratory study, a formal power analysis was not completed (Sim & Lewis, 2012; Browne, 1995).

Instruments

Anonymous online surveys assessed students' state and trait anxiety, perceived FA severity, perceived likelihood of allergic reactions and negative outcomes, quality of life, and FA management routines and explored their everyday and FA stressors. Parents provided data on state and trait anxiety, perceived FA severity, and everyday and FA stressors.

The State–Trait Anxiety Inventory assessed state and trait anxiety (Barnes, Harp, & Jung, 2002; Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1983). Perceived FA severity was measured using the Perception of the Severity of Chronic Illness survey, which was adapted for parents (Leung et al., 1997; Sebold, Lovell, Hopkin, Noll, & Schorry, 2004). The Food Allergy Independence Measure (van der Velde et al., 2010) evaluated perceived likelihood of allergen consumption, experiencing a reaction, and negative outcomes. The Food Allergy Quality of Life instrument assessed FA-related

quality of life (Flokstra-de Blok et al., 2008). Investigator-developed questions, reviewed by FA clinicians to ensure applicability, assessed FA management, including allergen avoidance, crisis response, navigating social situations, and accessibility of emergency medication. Finally, everyday and FA-related stressors were explored with open-ended questions based on earlier studies: What in your everyday life stresses you out? and What about your (child's) food allergy stresses you out? (Ersig et al., 2016).

Analyses

We explored everyday and FA-related stressors using qualitative description (Sandelowski, 2000, 2010). The first author read all text and generated preliminary codes using Atlas.ti (Scientific Software Development GmbH, 2018). Similar codes were merged, after which the first author assessed coding consistency and identified overarching themes. The second author reviewed 25% of coded transcripts for completeness and codes lacking support. After this review, one code was added. Discussion of overarching themes led to consensus on minor revisions and exemplar quotes.

Descriptive statistics were generated for quantitative measures. Scale scores were calculated for the State—Trait Anxiety Inventory, Perception of the Severity of Chronic Illness survey, Food Allergy Independence Measure, and Food Allergy Quality of Life. Scores were compared with available normative data. Scores from scales without normative data were compared with scores from individuals with other chronic health conditions or their parents. When possible, we also compared results within families. Frequencies were generated for crisis situations and availability of medication, health care, and emergency care. Relationships among these results were examined using correlations.

RESULTS

Participants

Twenty-six college students with FA and 16 parents participated (14 student-parent pairs). Participants were primarily female (76% students, 76.9% parents) and White (92.3% students, 92.9% parents; Table 1, Table 2). Although the study intended to enroll students with severe FA, three students indicated in their responses that they had celiac disease, and the remainder referred directly to anaphylactic reactions and specific severe allergies. Students were not asked to specify the foods to which they were allergic; however, those who did volunteer this information indicated allergies to common allergens including peanuts, tree nuts, dairy, soy, and fruit. Some students identified multiple triggering allergens in their responses.

Unifying Theme

One unifying theme emerged from student and parent responses: having an FA in college has a *Significant*

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