

Development of a Tool to Measure Youths' Food Allergy Management Facilitators and Barriers

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Abstract

Objective This study's aims are to identify factors related to allergen avoidance and epinephrine carriage among youth with food allergy, develop a tool to measure food allergy management facilitators and barriers, and investigate its initial reliability and validity. **Methods** The Food Allergy Management Perceptions Questionnaire (FAMPQ) was developed based on focus groups with 19 adolescents and young adults with food allergy. Additional youth with food allergy ($N=92$; ages: 13–21 years) completed food allergy clinical history and management questionnaires and the FAMPQ. **Results** Internal reliability estimates for the FAMPQ Facilitators and Barriers subscales were acceptable to good. Youth who were adherent to allergen avoidance and epinephrine carriage had higher Facilitator scores. Poor adherence was more likely among youth with higher Barrier scores. **Conclusions** Initial FAMPQ reliability and validity is promising. Additional research is needed to develop FAMPQ clinical guidelines.

Key words: adherence; barriers; facilitators; food allergy.

Introduction

Food allergy is a common, time-consuming pediatric chronic illness that impacts daily life. Approximately 4–8% of children in the United States have a food allergy diagnosis (Gupta et al., 2011). Prevalence estimates in the past decade among children have increased by 18% for general food allergy diagnoses and 80% for peanut allergy (Branum & Lukacs, 2009; Sicherer & Sampson, 2007). Severe food allergic reactions, such as anaphylaxis, can be life-threatening and even fatal (Ben-Shoshan & Clarke, 2011). There is no cure for food allergy, so it is necessary to avoid allergens to prevent allergic reactions. Among reported food allergy fatalities in case series, two potentially risky health behaviors have been identified: nonadherence with food allergen avoidance and nonadherence with epinephrine carriage (Bock, Munoz-Furlong, &

Sampson, 2001; Sampson, Mendelsohn, & Rosen, 1992). Indeed, in a survey of epinephrine carriage, only 56% of parents reported that they carried epinephrine with them at all times, and only 71% of those parents had epinephrine with them in clinic (DeMuth & Fitzpatrick, 2011).

As many as 67% of adolescents and young adults with food allergy report having experienced an allergic reaction in the past 5 years, and 71% report having experienced anaphylaxis during their lifetime (Sampson, Munoz-Furlong, & Sicherer, 2006). This is not surprising given the transfer of food allergy management responsibility from parents to children as youth gain independence (Bock et al., 2001; Munoz-Furlong & Weiss, 2009; Pumphrey, 2004; Sampson et al., 2006; Turner et al., 2015). Food allergic

reactions may be more likely during this time owing to a higher likelihood of engagement in risk-taking behavior (Greenhawt, Singer, & Baptist, 2009; Sampson et al., 2006). In one study of adolescents with food allergy, half admitted to purposefully ingesting an allergen and more than one-third reported not always carrying epinephrine (Gallagher, Worth, Cunningham-Burley, & Sheikh, 2011). In another study regarding food allergy adherence among college students, only 33% reported always avoiding allergens and only 10% with a history of anaphylaxis reported carrying epinephrine (Greenhawt et al., 2009). Qualitative interviews have also indicated that many adolescents only carry their auto-injectable epinephrine when they believe they are at risk of a food allergic reaction (Monks et al., 2010).

Understanding the reasons that youth engage in food allergy management behaviors may be crucial to decreasing the frequency of food allergic reactions and promoting healthy food allergy management as youth transition to independent adults. According to the Health Belief Model (HBM; Sheeran & Abraham, 1996) and the Theory of Planned Behavior (TPB; Ajzen, 1991) there are many facilitators and barriers to allergen avoidance and epinephrine carriage. The HBM posits that an individual's intention to avoid allergens and carry epinephrine is dependent on his/her perceptions of susceptibility to an allergic reaction, severity of the perceived allergic reaction, likelihood that allergen avoidance and epinephrine carriage will prevent a severe food allergic reaction, and barriers to allergen avoidance and epinephrine carriage. Actual adherence is dependent on self-efficacy—the individual's food allergy management skills, belief that he/she can enact those skills, and food allergy social support. The TPB is similar, theorizing that an individual's intention to avoid allergens and carry epinephrine is based on his/her attitudes about food allergy, perceived subjective norms regarding adherence and subjective pressure to avoid allergens and carry epinephrine, and perceived ability to engage in allergen avoidance and epinephrine carriage. There are likely multiple layers of facilitators and barriers to healthy food allergy management, including individual beliefs, social factors (e.g., parent/peer support), and institutional factors (e.g., size of epinephrine auto-injector).

The extant food allergy literature regarding adherence to allergen avoidance and epinephrine carriage supports the HBM and TPB models, although only the HBM model has been assessed among this population (Jones et al., 2014, 2015). Food allergy medical experiences and perceptions of food allergy severity, such as less time since an allergic reaction, history of a severe food allergic reaction, and/or higher food allergy anxiety, may facilitate allergen avoidance and

epinephrine carriage (Cummings, Knibb, King, & Lucas, 2010; DeMuth & Fitzpatrick, 2011; Mullins, 2003). Food allergy-related peer experiences also impact adherence; youths' decisions to carry epinephrine auto-injectors depend on how noticeable they are to others (Marrs & Lack, 2013; Gallagher et al., 2011). Health vigilance frequently conflicts with peer norms, and some youth with food allergy feel embarrassed by and/or disempowered regarding food allergy management (Monks et al., 2010; Sampson et al., 2006; Fenton et al., 2011). Understanding the reasons for avoiding allergens and carrying epinephrine among a range of age-groups (i.e., preadolescents, adolescents, and young adults) may be crucial to promoting appropriate food allergy management, decreasing the frequency of food allergic reactions, and increasing the likelihood of appropriate treatment of severe allergic reactions with epinephrine. However, previous studies regarding food allergy management are limited by small samples, and the majority of the studies described above explore patterns of nonadherence rather than facilitators; identification of food allergy management facilitators is a primary gap in the literature that may provide insight regarding the development of interventions for this population.

Although food allergy quality of life and knowledge measures exist, to our knowledge, there is only one reliable and valid measure of food allergy management. Klinnert and colleagues (2015) developed the Food Allergy Management and Adaptation Scale (FAMAS), an eight-dimension scale administered via semi-structured interview, which assesses the family's balanced integration of food allergies into daily life. This measure may facilitate identification of families who would benefit from clinical intervention and provide unique insight regarding the promotion of healthy adjustment to food allergies. Furthermore, initial results indicated that families with a high balanced integration score were rated by their physician as more likely to avoid allergens and to be ready to respond to an allergic reaction appropriately. However, the FAMAS is time intensive, designed to assess family functioning primarily through parent report, and may not be practical for daily use in busy clinics. A questionnaire-based measure that quickly assesses food allergy management facilitators and barriers among youth with food allergy is needed, particularly because this population is more likely to be nonadherent to allergen avoidance and epinephrine carriage.

Following Holmbeck and Devine's (2009) guidelines for measure development, the current study's goal is to provide researchers and clinicians with a tool for the assessment of food allergy management among youth. The study's aims are to (1) identify factors related to allergen avoidance and epinephrine carriage among youth with food allergy, to (2) develop a

tool to measure facilitators of and barriers to food allergy management, and (3) investigate the measure's initial reliability and concurrent validity. We hypothesized that (1) the measure would demonstrate adequate internal reliability, (2) a greater number of perceived food allergy management facilitators would be related to greater food allergy management adherence, and (3) a greater number of perceived food allergy management barriers would be related to less food allergy management adherence.

Methods

Development of the Measure

The Food Allergy Management Perceptions Questionnaire (FAMPQ) was developed at a Mid-Atlantic hospital within the Division of Pediatric Allergy and Immunology using focus groups. The senior author and two additional allergists relied on the empirical literature regarding food allergy and engagement in medical care, including the HBM (Sheeran & Abraham, 1996) and the TPB (Ajzen, 1991), to generate a list of topics related to allergen avoidance and epinephrine carriage. Nineteen patients, ages 13–21 years, diagnosed with food allergies (47% male, 58% Caucasian), were recruited from the Pediatric Allergy clinic to participate in one of two 3-day interactive online focus groups. Informed consent and assent were obtained electronically, and parental consent was obtained from all participants <18 years of age. This study had institutional review board approval.

Participants were allocated into two online focus groups based on age (13–16 years; 17–21 years). Online focus groups have been used successfully with other medical populations (de Jong et al., 2012). Online focus groups provide the same amount of unique ideas as in person focus groups, but may not offer the same degree of depth of information (Bruggen & Willems, 2009; Underhill & Olmsted, 2003). Despite this drawback, online focus groups may give the moderator less control, which provides space for unique ideas, give all participants equal opportunity to voice opinions, facilitate more diverse participant inclusion, and save time and money (Abrams, Wang, Song, & Galindo-Gonzalez, 2015).

Focus groups were facilitated by a professional market research company, Cogent Research LLC (now Market Strategies International), using CoRE Board™ technology, and were asynchronous (i.e., participants were not required to log in simultaneously). Participants anonymously logged into secure discussion board sites three times per day for 3 days to answer predetermined questions exploring food allergy clinical and reaction history, allergen avoidance and epinephrine carriage, and individual-, community-, and structural-level factors underlying these

behaviors. Participants responded to each question before gaining access to others' responses and were then encouraged to comment on others' responses. Probing questions were privately posed to individual participants by the senior author and the CoRE Board facilitator as needed. The sample reported a median number of three food allergies (range = 1–9); 47% reported they occasionally ingested foods they "should" avoid, and 58% reported they do not "always" carry epinephrine.

Standard content analysis was applied to the verbatim transcripts of the online focus groups (Hsieh & Shannon, 2005). Using inductive approaches common to qualitative content analysis, the senior author classified the data into codes to organize participants' descriptions of food allergy experiences. Transcripts were reviewed five times and *in vivo* coded by the senior author to obtain an understanding of overarching ideas. These codes were then categorized into broader individual, social, and institutional themes related to the facilitators and barriers to food allergy management, and the frequency of each code was noted. Item generation and reduction was completed by two allergists, based on focus group results, and an initial FAMPQ draft was developed. Five patients from a Mid-Atlantic pediatric hospital's Division of Allergy and Immunology completed a test version of the measure; items were revised based on patients' feedback, resulting in a 25-item final version of the FAMPQ. See Table I.

The final FAMPQ includes statements that describe food allergy management facilitators and barriers. Respondents indicate their agreement or disagreement using a 5-point Likert scale ranging from "Strongly disagree" to "Strongly agree." Ten items refer to food allergy management facilitators: five items refer to allergen avoidance, four items refer to epinephrine carriage, and one item is applicable to both. Fifteen items refer to food allergy management barriers: four items refer to allergen avoidance, six items refer to epinephrine carriage, and five items are applicable to both. Two subscales, Facilitators and Barriers, are calculated by summing the items. The Facilitators subscale has a possible range of 10–50; the Barriers subscale has a possible range of 15–75. Higher scores indicate a greater number of perceived food allergy management facilitators or barriers.

Initial Administration of the FAMPQ

Participants

Patients with food allergy were recruited from a Mid-Atlantic pediatric hospital's allergy clinics, the Food Allergy and Anaphylaxis Network (now Food Allergy Research & Education; FARE), and Allergic Living magazine to participate in an online survey. After completion of the focus groups, the age range was

Table I. Themes Identified During Focus Groups Related to Allergen Avoidance and Epinephrine Carriage and Corresponding Item Information Based on Initial Administration of the Food Allergy Management Perceptions Questionnaire (FAMPQ; N = 92)

Domain	Factor	Definition	FAMPQ item(s)	Correlation with total subscale score
Individual	Food allergy knowledge	Understanding the negative outcomes of eating an allergenic food or not having epinephrine	I know how to use my epinephrine auto-injector. (F)	.39***
			A fear of having an allergic reaction helps me avoid eating foods that I am allergic to. (F)	.50***
			I follow my diet because I am afraid of the consequences of eating the food I am allergic to. (F)	.56***
			The fear of not having my epinephrine in the event of an allergic reaction forces me to carry my epinephrine everywhere with me. (F)	.81***
	Disease normalization	A sense that food allergy is a normal part of life	I carry my epinephrine because it can save my life. (F)	.63***
			I understand enough about my food allergy. (F)	.35***
			My food allergy keeps me from experiencing what “normal” people experience. (B)	.73***
			I regularly plan ahead to avoid foods to which I have allergies. (F)	.59***
	Planning	Preparing for food allergy needs in advance of activities	I always carry my epinephrine auto-injector because I never know when I may need it. (F)	.74***
			I want to be able to eat what everyone else is eating. (B)	.43***
			Because of my food allergy, I feel different from everyone else. (B)	.70***
			I take chances with foods I am allergic to because I want to fit in. (B)	.43***
	Annoyance	Aggravated and jaded about food allergy	I do not stick to my diet because trying to avoid certain foods is annoying. (B)	.27**
	Forgetting	Not remembering to carry epinephrine at all times	Included as an adherence question, not an FAMPQ item	N/A
	Not eating/Being careful	Intentionally not bringing epinephrine due to confidence that allergens will be avoided	I do not need to carry my epinephrine auto-injector because I am cautious and avoid foods that I am allergic to. (B)	.47***
			When I am not planning on eating, I do not bring my epinephrine auto-injector. (B)	.40***
Social	Parental involvement	Parents assist with food allergy management	My parents help me avoid foods that I am allergic to. (F)	.31**
	Friend involvement	Friends assist with food allergy management	Having a food allergy helps me find my true friends because they help me avoid foods that I am allergic to. (F)	.49***
	Peer Victimization	Food allergy-related teasing or bullying	I am not very strict avoiding foods I am allergic to because I do not want to be teased by other kids. (B)	.32**
			I feel left out because of my food allergy. (B)	.65***
	Social embarrassment	Concern about social perceptions of allergen avoidance or epinephrine carriage	I feel “high maintenance” because of my food allergy since I have to take precautions to avoid eating certain foods. (B)	.54***
			I am embarrassed by my food allergy. (B)	.66***
			I do not carry my epinephrine auto-injector because it is embarrassing to have it with me. (B)	.57***
	Fashion	Carrying epinephrine compromises personal style	Carrying my epinephrine auto-injector is difficult because it is not fashionable. (B)	.57***
Institutional	Insufficient allergen information	Eating in places without adequate food labels or ingredient lists	Included as an adherence question, not an FAMPQ item	N/A
	Epinephrine inconvenience	Size of the epinephrine device is too big to routinely carry	There is no easy way to keep my epinephrine auto-injector with me at all times. (B)	.56***
			I do not carry my epinephrine auto-injector because it is too big to carry everywhere. (B)	.58***

Note. F = Facilitator subscale item; B = Barrier subscale item. Please contact the corresponding author to obtain a copy of the Food Allergy Management Perceptions Questionnaire.

** $p < .01$. *** $p < .001$.

expanded for this component of the study to capture a full range of preadolescence through young adulthood. Therefore, youth between ages 11 and 22 years who were diagnosed with at least one food allergy, had access to the Internet, and provided electronic assent/consent and parental consent were eligible to participate. Those who were not fluent in English or did not have parental consent were excluded from participation. Furthermore, youth who did not have an epinephrine auto-injector prescription were excluded because several adherence questions and FAMPQ items reference epinephrine carriage. One hundred twenty participants were preliminarily identified as eligible. Nine youth (8%) did not have a prescription for an epinephrine auto-injector and 19 additional youth (16%) did not complete all portions of the online survey. The final survey sample included 92 participants.

Procedure

Participants were recruited over the course of 1 year (May 2012–April 2013). Participants received information about the study and how to access the survey Web site via printed advertisements and announcements at allergy clinics, the Food Allergy and Anaphylaxis Network (now FARE)'s annual Teen Summit, and Allergic Living magazine. Informed consent/assent was obtained electronically. Parents of children <18 years of age were emailed two links, one for parental informed consent and one for child assent. Participants who were ≥18 years were emailed a link to an informed consent form. After providing consent/assent, participants completed the online survey through SurveyMonkey®. This portion of the study had institutional review board approval.

Measures

Demographic and Medical Questionnaire

As part of the online survey, participants first completed a self-report demographic and medical questionnaire developed by the study team that assessed participant age, location, caregiver education level, and food allergy clinical history. Participants responded to questions regarding specific food allergies (peanut, tree nut, cow's milk, egg, soy, wheat, shellfish, fish, and sesame), food allergy diagnosis method, epinephrine auto-injector prescriptions, age at the time of the first food allergic reaction, the length of time since the most recent food allergic reaction, food allergic reaction symptoms, and food allergic reaction treatment methods. "Don't know" options were included for all items.

Food Allergy Management Perceptions Questionnaire

Participants completed the 25-item FAMPQ by rating their agreement with 10 food allergy management

facilitator items and 15 food allergy management barrier items.

Food Allergy Management Adherence

Participants responded to four items that assessed allergen avoidance and epinephrine carriage. Three items were rated on a 5-point Likert scale ranging from "Never" to "Always." These items were used to assess the frequency at which participants ate foods without labels, carried epinephrine, and forgot to carry epinephrine. An additional item was rated on a 5-point Likert scale ranging from "I do not do this" to "Almost daily." This item was used to capture the frequency at which participants intentionally tried a food that they knew they were allergic to or might be allergic to (i.e., they were uncertain owing to insufficient ingredient information). A total allergen avoidance adherence score and a total epinephrine carriage adherence score were calculated as continuous variables by summing the two allergen avoidance items and the two epinephrine carriage items; higher scores indicated greater self-reported adherence.

Analyses

All statistical analyses were based on the 92 participants who completed the online survey and were conducted using SPSS (20th edition). Preliminary descriptive statistics were generated for demographic/medical characteristics and the frequency of allergen avoidance and epinephrine carriage. Pearson product moment and Spearman rho correlational analyses were conducted regarding the relationships between demographic/medical characteristics and food allergy management behaviors. We then examined the measure's reliability by conducting two Cronbach's alpha internal consistency estimates (Facilitators and Barriers subscales). We then assessed the measure's concurrent validity by conducting Pearson product moment and Spearman rho correlational analyses to determine the relationships between the FAMPQ Facilitators and Barriers subscales and demographic/medical characteristics, allergen avoidance, and epinephrine carriage (DeVillis, 2003). Two linear regressions were conducted to determine whether the FAMPQ subscales were predictive of adherence to allergen avoidance and epinephrine carriage. Participant age, caregiver education, whether the participant had multiple food allergies, and the recency of last food allergic reaction were included as covariates.

Results

Participant Characteristics

The 92 participants who completed the online survey reported their age according to categories: 29% were between 11 and 13 years, 34% were between 14 and

16 years, 20% were between 17 and 19 years, and 17% were between 20 and 22 years. Ninety-one percent lived in the United States, representing 28 states; 9% lived in Canada. Sixty-eight percent reported their parents had earned an undergraduate college degree or more. Participants reported a range of food allergies; peanut (79%) and tree nut (72%) allergies were most common. Eighty-three percent had more than one food allergy, and 69% were diagnosed during infancy. Eighty-seven percent were diagnosed by an allergist and only 2% could not remember experiencing an allergic reaction, indicating that almost all participants had a clinical history consistent with IgE-mediated food allergy and were not diagnosed solely based on positive test results. Participants reported a range of time since their most recent food allergic reaction; 13% did not remember their most recent allergic reaction or reported that it occurred when they were too young to remember, whereas 9% had an allergic reaction during the past week. Fifty-nine percent reported having received epinephrine to treat an allergic reaction. See Table II for additional details.

Food Allergy Management

Participants reported variable adherence to allergen avoidance and epinephrine carriage. Fifty-eight percent of youth reported they “never” eat foods without labels, 67% “do not” intentionally try food that they know they are allergic to or might be allergic to (i.e.,

Table II. Food Allergy Characteristics for Participants Who Completed the Food Allergy Management Perceptions Questionnaire (N = 92)

Medical variable	Percentage (n)	Cumulative percentage (n)
Food allergies		
Peanut	79.30 (73)	
Tree nuts	71.70 (66)	
Shellfish	40.20 (37)	
Cow's milk	32.60 (30)	
Egg	28.30 (26)	
Sesame	23.90 (22)	
Fish	21.70 (20)	
Soy	13.00 (12)	
Wheat	12.00 (11)	
>1 food allergy	82.60 (76)	
Age of first allergic reaction		
Can't remember/Never	2.20 (2)	2.20 (2)
Infancy (0–2 years)	68.50 (63)	70.70 (65)
Toddler (3–5 years)	16.30 (15)	87.00 (80)
School age (5–12 years)	7.60 (7)	94.60 (87)
Adolescence (13–21 years)	5.40 (5)	100.00 (92)
Most recent allergic reaction		
Can't remember/Too young when it happened to remember	13.00 (12)	13.00 (12)
Within the past 5–10 years	29.40 (27)	42.40 (39)
Within the past 6–12 months	38.00 (35)	80.40 (74)
Within the past month	10.90 (10)	91.30 (84)
Within the past week	8.70 (8)	100.00 (92)

they are uncertain owing to insufficient ingredient information), 69% “always” carry epinephrine, and 30% “never” forget their epinephrine (See Table III). Mean total allergen avoidance adherence was 9.11 ($SD = 1.42$, range = 3–10). Mean total epinephrine carriage adherence was 8.66 ($SD = 1.38$, range = 4–10). Nineteen participants (21%) reported that they were always adherent to both allergen avoidance and epinephrine carriage.

A series of correlational analyses was conducted to assess the relationships between key demographic and medical characteristics. Participants whose caregivers had a higher education level ($r = -.24$, $p < .05$), who had multiple food allergies ($r_s = -.21$, $p < .05$), and who had experienced an allergic reaction less recently ($r = -.22$, $p < .05$), were less likely to eat foods without labels. Participants who were older ($r = .31$, $p < .05$) were more likely to intentionally eat food that they knew they were allergic to or might be allergic to. More recent allergic reactions were associated with less frequent epinephrine carriage ($r = .25$, $p < .05$). Participants who reported they were more adherent to allergen avoidance also reported they were more adherent to epinephrine carriage ($r = .31$, $p < .01$); associations with other demographic/medical variables were not significant ($ps > .05$) (Table IV).

Perceived Food Allergy Management Facilitators and Barriers

Participants reported a mean score of 44.36 on the FAMPQ Facilitators subscale ($SD = 4.34$, range = 29–50) and a mean score of 37.85 on the FAMPQ Barriers subscale ($SD = 9.26$, range = 15–57). This sample perceived a high number of food allergy management facilitators and a moderate number of food allergy management barriers. With respect to reliability, the Cronbach's alpha internal consistency estimate for the Facilitators subscale was $\alpha = .73$, which is acceptable, and the Cronbach's alpha internal consistency estimate for the Barriers subscale was $\alpha = .82$, which is good (George & Mallery, 2003). The Facilitators and Barriers subscales were negatively correlated ($r = -.38$, $p < .001$); participants who reported a greater number of food allergy management facilitators reported fewer food allergy management barriers.

A series of correlational analyses was conducted to investigate the relationship of the FAMPQ with demographic characteristics, medical characteristics, and food allergy management. A greater number of perceived facilitators was related to higher caregiver education ($r = .23$, $p < .05$) and a less recent food allergic reaction ($r = .28$, $p < .01$). A greater number of perceived barriers was related to older current child age ($r = .22$, $p < .05$), lower caregiver education ($r = -.26$, $p < .05$), and a more recent food allergic reaction ($r = -.39$, $p < .001$). Participants who reported greater adherence to allergen avoidance reported more food

Table III. Self-Reported Frequency of Allergen Avoidance and Epinephrine Carriage for Participants Who Completed the Food Allergy Management Perceptions Questionnaire (N = 92)

How frequently do [you] . . .	I do not do this/ never Percentage (<i>n</i>)	I have only done this once/ rarely Percentage (<i>n</i>)	I do this less than once a week/sometimes Percentage (<i>n</i>)	I do this 1–2 times a week/ usually Percentage (<i>n</i>)	I do this almost daily/ always Percentage (<i>n</i>)
Intentionally try foods to which I am or might be allergic to	72.80 (67)	13.00 (12)	10.90 (10)	1.10 (1)	2.20 (2)
Eat foods that do not have labels	71.70 (66)	18.50 (17)	6.50 (6)	2.20 (2)	1.10 (1)
Forget to carry my epinephrine	30.40 (28)	48.90 (45)	17.40 (16)	3.30 (3)	0.00 (0)
Carry my epinephrine	2.20 (2)	2.20 (2)	4.30 (4)	16.30 (15)	75.00 (69)

allergy management facilitators ($r = .48, p < .001$) and fewer barriers ($r = -.42, p < .001$). Participants who reported greater adherence to epinephrine carriage reported more food allergy management facilitators ($r = .66, p < .001$) and fewer barriers ($r = -.43, p < .001$).

Predictors of Food Allergy Management Adherence

Two regression analyses were conducted to assess the relationships of allergen avoidance adherence and epinephrine carriage adherence with the FAMPQ Facilitators and Barriers subscales. Key medical and demographic variables (participant age, caregiver education, whether the participant has multiple food allergies, recency of last food allergic reaction) were entered as predictors into the first step of each regression followed by the FAMPQ Facilitators and Barriers subscales. The overall model for allergen avoidance was significant ($F(6,79) = 5.92, p < .001, R^2 \text{ change} = .21, p < .001$). Allergen avoidance adherence was significantly associated with age ($\beta = -.23, p < .05$), the Facilitators subscale ($\beta = .35, p < .01$), and the Barriers subscale ($\beta = -.26, p < .05$). Other predictors were not significantly associated with allergen avoidance adherence ($ps > .05$). The overall model for epinephrine carriage was also significant ($F(6,79) = 12.97, p < .001, R^2 \text{ change} = 0.47, p < .001$). Epinephrine carriage adherence was significantly associated with the Facilitators subscale ($\beta = .64, p < .001$) and the Barriers subscale ($\beta = -.19, p < .05$). Other predictors were not significantly associated with epinephrine carriage adherence ($ps > .05$). Adherence to allergen avoidance and epinephrine carriage was more likely among adolescents and young adults who reported higher scores on the FAMPQ Facilitators subscale and lower scores on the FAMPQ Barriers subscale. Adherence was also more likely among younger participants.

Discussion

There is preliminary evidence that the newly developed FAMPQ is a reliable and valid measure of food

allergy management facilitators and barriers. The measure evidenced acceptable to good Cronbach's alpha internal consistency estimates and concurrent validity related to self-reported allergen avoidance and epinephrine carriage adherence (DeVillis, 2003; George & Mallery, 2003). Youth who reported a greater number of perceived food allergy management facilitators and fewer barriers were more likely to report engagement in allergen avoidance and epinephrine carriage. These results are consistent with the limited food allergy research that assesses food allergy management from an HBM framework (Jones et al., 2015), with TPB theory, and with other food allergy research that indicates food allergy medical experiences, individual food allergy perceptions, and food allergy-related peer experiences impact adherence (Allen, Campbell, & Kemp, 2009; Cummings et al., 2010; Demuth & Fitzpatrick, 2011; Fenton et al., 2011; Gallagher et al., 2011; Greenhawt et al., 2009; Marrs & Lack, 2013; Monks et al., 2010; Mullins, 2003). That being said, these results go beyond previous research by introducing a new measure that assesses multiple domains of food allergy perceptions, including ways to promote healthy food allergy management, and is predictive of self-reported adherence.

The literature regarding adherence to food allergy management among youth is still nascent, yet our study provided comparable total adherence rates to a report by Jones et al. (2015) and comparable epinephrine carriage rates to a report by Greenhawt and colleagues (2009). However, participants in our sample reported they were less likely to intentionally ingest allergens than adolescents in a sample conducted by Sampson et al. (2006). These differences may be attributable, in part, to a lack of standardized methods to assess food allergy management adherence. Additional longitudinal research regarding food allergy management adherence among this population is needed to elucidate adherence rates. Longitudinal research will also help clinicians to better understand the factors that contribute to healthy food allergy management and the successful transition of care from parent to child.

Table IV. Correlations Among Demographic/Medical Characteristics, Food Allergy Adherence, and Food Allergy Management Facilitators and Barriers for Participants Who Completed the Food Allergy Management Perceptions Questionnaire (FAMPQ; N = 92)

Variable	Age	Caregiver education	Multiple allergy diagnoses	Age of first allergic reaction	Epinephrine use history	Allergic reaction recency	1	2	3	4	5
1. Frequency of eating a food without a label	.13	-.24*	-.21*	.13	-.05	-.22*	-	-	-	-	-
2. Frequency of intentionally trying a food you might be allergic to or know you are allergic to	.31**	.03	.01	.23*	.08	-.16	.39***	-	-	-	-
3. Frequency of carrying epinephrine	-.11	.17	-.07	.08	.12	.25*	-.17	-.17	-	-	-
4. Frequency of forgetting epinephrine	.09	-.05	.01	-.15	.02	.01	.26*	.26*	-.44***	-	-
5. FAMPQ Facilitators subscale	-.11	.24*	-.02	-.05	.18	.28**	-.43***	-.37**	.64***	-.47***	-
6. FAMPQ Barriers subscale	.22*	-.26*	-.09	.07	.05	-.39***	.30*	.40***	-.41***	.30**	-.38***

Note. Multiple Allergy Diagnoses: 0 = No, 1 = Yes; Anaphylaxis History: 0 = No, 1 = Yes; Epinephrine Use History: 0 = No, 1 = Yes.

Allergic Reaction Recency is coded such that a lower number indicates less time since the most recent allergic reaction. Correlations are Pearson product moment correlations or Spearman rho correlations, as appropriate.

* $p < .05$. ** $p < .01$. *** $p < .001$.

Strengths, Limitations, and Future Directions

This study has several notable strengths. The FAMPQ is one of the first measures to assess factors that are related to food allergy management behaviors, and represents a complement to the FAMAS, which provides a comprehensive assessment of parents' perceptions of overall food allergy-related family functioning (Klinnert et al., 2015). A rigorous set of focus groups and examination of health behavior theory were used to develop the measure and there is initial evidence of internal consistency and concurrent validity. All of the youth in this sample were prescribed epinephrine auto-injectors, and most had been diagnosed by an allergist and had a clinical history of a food allergic reaction, suggesting that this sample had true IgE-mediated food allergies. However, this study used a small sample and sex and ethnicity were not collected; thus, the impact of demographic variables on food allergy management facilitators and barriers is unclear at this time. Recruitment of participants from food allergy conferences and magazines likely affected the data as well; these participants may be more knowledgeable about food allergies, more adherent to allergen avoidance and epinephrine carriage, and more likely to perceive food allergy facilitators than participants from a general food allergy clinic.

Another limitation is that these data relied on youth self-report. However, use of self-report was crucial; most previous studies regarding food allergy management focus on parents' perspectives, so it was important to assess youths' perspectives during the focus groups. These data were also supplemented by the opinions of allergy experts and theoretical models of health behavior engagement. Self-report regarding adherence was used during initial administration of the FAMPQ as well because there is a dearth of adherence measures for this population and medical chart reviews are an inadequate way to assess adherence; there are no adherence biomarkers, and allergic reactions are frequently not documented unless patients remember to report them.

All limitations considered, the results of this study provide guidance regarding future research. Administration of the FAMPQ to a larger sample, which would include parents to substantiate food allergy management self-report, and collection of comprehensive demographic data should be a priority. Development of a food allergy management adherence measure should also be prioritized. Continued inclusion of a broad age range of participants (i.e., preadolescents, adolescents, and young adults) will also be an important next step, as it will provide rich information about food allergy management across several developmental stages. Future studies should include repeat administration of the FAMPQ to examine temporal stability, and inclusion of measures that can establish

the FAMPQ's discriminant and convergent validity, such as measures of quality of life, anxiety, and peer experiences. Exploratory factor analysis will also be an important component of future studies, once data have been collected from a larger sample, to provide further evidence of validity. Additionally, it will be important to investigate the relative impact of specific factors within the facilitators and barriers subscales and establish clinical guidelines regarding the meaning of specific scores. These scores could then be used by clinicians, along with the clinical history, to identify adolescents and young adults who are at high risk for nonadherence. It is expected that this measure will eventually allow providers to identify specific facilitators and barriers to appropriately guide food allergy management and inform intervention development. For example, youth who report a high number of social barriers may benefit from an intervention that targets social problem solving.

Conclusions

The FAMPQ is the first measure, to our knowledge, to assess food allergy management among youth by examination of facilitators and barriers to allergen avoidance and epinephrine carriage. The measure has demonstrated initial internal consistency and concurrent validity. Development of this measure is consistent with the growing trend to engage in health promotion rather than focus on nonadherent behaviors. Additional research with a more diverse population, examination via exploratory factor analysis, and development of clinical guidelines will increase the applicability of this measure to providers and may aid them in the provision of targeted food allergy self-management interventions.

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