



Letters

Psychosocial needs of adolescents with food allergies registering for a national online social program



Food allergy (FA) directly affects 1 in 13 children,¹ and accumulating research has highlighted a plethora of psychosocial difficulties faced by families of children with FA.^{2–5} However, psychosocial research and interventions to date have tended to focus on young children and caregivers, with a dearth of literature dedicated to the unique psychosocial needs of adolescents with FA.^{5,6} Existing research on adolescents with FA has largely focused on medical risk, as the highest rates of anaphylaxis and fatalities occur among this population.^{7,8} Although it is important to acknowledge risk taking, it is also necessary to more broadly explore how FA interact with the developmental context of adolescence. As the prevalence of FA increases, and more children with FA become adolescents with FA, it is imperative to (1) identify the psychosocial needs of adolescents with FA and (2) subsequently develop resources to meet these needs. The current project seeks to preliminarily identify these psychosocial needs in a large sample of adolescents who registered for a national online social program for youth with FA.

This evaluation involved secondary data analysis of 9 months (January–September 2021) of registration responses for Food Allergy Research and Education (FARE) Teen Talks, an online video-based social program for youth with FA aged 11 to 22 years. Teen Talks occur monthly, last 1 hour in length, are freely available, are advertised through FARE's e-mail listserv, and are developed and led by the first author. When participants register for Teen Talks, they are asked, “What do you hope to gain from Teen Talks? If you have specific topics/activities you'd like to see covered, please include those here.” The current study analyzes these responses. In consultation with the Emory University Institutional Review Board, it was determined that this project did not meet the federal definition of Human Subjects Research and therefore was not advanced for further Institutional Review Board review.

The 9 months of registration responses was combined such that each individual registrant was given a unique identification number, followed by their cumulative responses. Individuals were identified by dates of birth and e-mail addresses provided, resulting in a total of 461 unique youth. Registrants ranged from 10 to 23 years of age ($M = 15$, $SD = 2.58$). More than 85% of the registrants reported 2 or more food allergen categories (each of the top 9 allergens, fruits, vegetables, other; $M = 3.47$, $SD = 2.00$).

Data on allergy history, racial and ethnic background, and socioeconomic status were not available.

Thematic analysis was applied to these responses. With consultation from a qualitative analysis expert, responses were reviewed by the team and divided into 6 broader themes, plus “other” and “no response.” Responses most often contained multiple themes and could be coded as such. Team members independently coded responses from 20% of the registrants. Kappas for each theme ranged from 0.82 to 1.00, indicating high interrater reliability. For the remaining 80%, team members frequently communicated and discussed uncertain responses until thematic consensus was reached.

Analysis of registration responses from 461 unique youth identified the following 6 key psychosocial needs: connect with other adolescents with FA ($n = 183$, 39.70%); share experiences ($n = 148$, 32.10%); learn how to navigate social situations (eg, dating, restaurants, school; $n = 127$, 27.55%); cope with emotional challenges (eg, anxiety, bullying, guilt; $n = 55$, 11.93%); increase FA knowledge ($n = 53$, 11.50%); and gain confidence, independence, and communication skills ($n = 37$, 8.03%). An additional 19 responses were classified as “other” and 99 as “no response.” Table 1 provides examples of participant responses representing each psychosocial need. Psychosocial needs did not differ by age or number of allergens.

In this large, qualitative evaluation of adolescents with FA who registered for an online social program, we identified 6 unique psychosocial needs. This preliminary work lays the foundations for future systematic research with adolescents with FA, a population that has been understudied in previous research yet is increasing in numbers. Needs identified by means of the present thematic analysis included connecting with peers, sharing experiences, navigating social situations, coping with emotional challenges, increasing knowledge, and gaining confidence. Given that Teen Talks are marketed as a social program, it is not surprising that the most common themes involved getting to know others with FA and sharing stories. Many registrants mentioned feeling alone in their everyday FA struggles and seeking to develop friendships with a community of relatable peers.

Considering that we did not explicitly ask adolescents about any difficulties, it is striking that such a large number indicated wanting to learn how to navigate social situations, cope with emotional challenges, and gain confidence. This is likely an underestimate of the psychosocial difficulties faced by adolescents with FA and suggests that this population greatly needs support. Registrants most often cited the centrality of food to teenage social life and the associated anxiety, exclusion, and uncomfortable situations with friends, family,

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Table 1
Examples of Participant Responses Falling Into Each Thematic Category of Psychosocial Needs

Theme	Description	Examples
Connect	• Meet other teens with food allergies • Make new friends with food allergies • Find or offer support • Build community	• <i>I want to feel supported by a community of people that relate to my allergies. I have yet to meet anybody EVER with allergies like mine. I genuinely just want to feel less alone when dealing with my allergy.</i> • <i>I want to see that I am not alone.</i> • <i>I hope to gain new friendships and people I can talk to that understand what I am going through.</i> • <i>I'd love just to connect with other teens like me and build friendships!</i>
Share experiences	• Share personal stories • Learn from the experiences of others • Give or get tips or advice	• <i>I hope to hear from other people my age about how they are handling having food allergies in their day-to-day lives.</i> • <i>Just other kids my age thoughts about life and how they deal with it. Not doctors and parents' opinions.</i> • <i>Just hearing other people's stories.</i> • <i>I hope to help those with food allergies feel comfortable, related to, and heard.</i>
Emotions	• Cope with the emotional challenges of food allergies, such as: ◦ Anxiety and fear ◦ Guilt ◦ Bullying or teasing ◦ Stigma or discrimination ◦ Exclusion	• <i>I have extreme anxiety and would love to discuss ways to cope.</i> • <i>I'd like to talk to people who understand what it's like to sit at a peanut free table, who have been food allergy bullied, who knows what it's like to be forced into an uncomfortable situation because of their allergy/allergies, who have felt excluded just because they can't have a food.</i> • <i>How to have a more positive outlook about my food allergies... do you feel/get excluded from parties and sleepovers because of your food allergies?</i> • <i>How anxieties may be worse after COVID again because right now the rest of the world knows how we feel every day.</i> • <i>How to not drag down the mood/ decline food without making people feel bad.</i> • <i>I'd really like to cover how to deal with bullying. I myself have been bullied and would find it useful to see how others have dealt/coped with it.</i> • <i>To be more comfortable talking to people. Less anxiety about all things revolving around food, trying new items or going out to eat. Fears of dating with allergies.</i> • <i>Anxiety over food and feeling excluded around my peers during activities or at school.</i>
Confidence	• Learn how to communicate needs effectively • Gain independence from adults • Self-advocacy skills	• <i>I am looking to feel more confident about my allergies and embrace it more as a part of me, rather than feeling ashamed when talking about it in certain scenarios, like at social scenes or at restaurants when the managers act "too busy."</i> • <i>How to ask others to clean their hands and take precautions for your safety without making them uncomfortable and confused.</i> • <i>How to become more confident when people mention my food allergies or when I need to speak up, how to not feel embarrassed or bad about my food allergies.</i> • <i>I hope to gain skills on how to be confident in saying to friends that want to go out and eat I can't eat there without feeling bad.</i> • <i>How to deal with questions from others about my food allergies, how to keep myself safe at school and advocate for myself, what to do if I go out to a restaurant with friends.</i> • <i>Confidence I feel like the ugly duckling sometimes.</i>
Social situations	• Learn how to navigate common social situations, such as: ◦ Travel ◦ Dating ◦ Friends and family ◦ School/college ◦ Restaurants	• <i>I hope we could talk about how food allergies can put up a barrier in social events and how to deal with that.</i> • <i>How to successfully navigate social situations with my allergies. It has become harder as I have gotten older.</i> • <i>I hope to know more about handling allergies in social situations such as eating out with friends or going on a trip with a school! I just want to know tips and tricks to make it easier in social situations!</i> • <i>How others deal with allergies around friends and teachers that are non-allergic and don't understand.</i> • <i>I'd like to discuss how to start a relationship with someone who doesn't have allergies: coming up with rules, trusting them, and not feeling guilty about having to change their lifestyle for me.</i> • <i>Making friends in college when so much of a social life revolves around food and eating activities.</i> • <i>Staying safe in college with food allergies, addressing roommates, dating.</i> • <i>I'd love to hear how people have managed traveling/studying abroad... I avoided going abroad because of my allergies yet still want to travel.</i>
Facts	• Increase food allergy knowledge • Learn about research, treatment, and advocacy • Get recommendations for safe products/ restaurants	• <i>Understanding of how I can better deal with my allergies being accommodated at school and what my rights are as a student with allergies.</i> • <i>I hope to gain advice on how to spread awareness about food allergies.</i> • <i>I want to see how much scientists currently know about the nature of food allergies in kids and what's unknown in studies like this or the research needed to get there.</i>

teachers, restaurant employees, and prospective romantic partners. One registrant mentioned feeling like the “ugly duckling,” and several mentioned feeling guilty, ashamed, or making others feel bad for needing to accommodate. FA anxiety has traditionally been conceptualized as fear of anaphylaxis⁹; however, our findings suggest that adolescents may also experience FA-related *social anxiety*. The themes we uncovered provide novel groundwork for future research to systematically investigate and build on in more demographically representative, generalizable samples.

Messaging from physicians often focuses on preventing youth from having serious allergic reactions. Although protecting physical health is paramount, providers need resources to support the complex psychosocial needs of adolescents with FA (eg, increased independence, heightened social reward, greater reliance on peers, emergence of romantic relationships) to improve emotional well-being. One study found that positive aspects of having a FA included self-advocacy, empathy for others, and healthier eating. These benefits were all stronger when supported by peers, parents, and school personnel.¹⁰

Although there are several community resources for parents of children with FA to connect (ie, local and virtual support groups), we know of few initiatives that specifically targeted toward adolescents. Providers, support groups, and allergy organizations could consider creating teen-only social programs, videos focused on communication, role-playing social scenarios, and simply asking adolescent patients about their greatest FA challenges. Creating virtual communities for adolescents with peers and trained professionals could support and empower adolescents with FA.

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Melissa L. Engel, MA*

Sabra K. Rich*

Christopher M. Warren, PhD[†]

Ruchi S. Gupta, MD, MPH^{†,‡}

* Department of Psychology

Emory University

Atlanta, Georgia

[†] Center for Food Allergy and Asthma Research and Institute for Public

Health and Medicine

Feinberg School of Medicine

Northwestern University

Chicago, Illinois

[‡] Advanced General Pediatrics and Primary Care

Ann & Robert H. Lurie Children's Hospital of Chicago

Chicago, Illinois

mlengel@emory.edu

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