

Availability of mental health services for patients with food allergy

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Clinical Implications

- Despite frequent food allergy–related psychosocial concerns, even among Food Allergy Research & Education’s Centers of Excellence, there are few mental health professionals to whom allergists can refer patients. Clinicians are encouraged to develop pathways to connect patients to mental health professionals.

TO THE EDITOR:

Approximately 8% of children in the United States are diagnosed with food allergy.¹ Complete allergen avoidance is the only current treatment,² but daily adherence to allergen avoidance and epinephrine carriage may be difficult due to the ubiquity of food in daily life and a lack of public knowledge.^{3–5} Fear about allergen exposure and stress related to daily food allergy management practices contribute to increased stress and anxiety and decreased quality of life among children and caregivers.^{3–6} Access to mental health services to address psychosocial concerns may be crucial to supporting families in successful food allergy management,⁶ yet the availability of mental health professionals with food allergy experience is unknown. To address this knowledge gap, this project evaluated the availability of mental health services for patients with food allergy among Food Allergy Research & Education (FARE) Clinical Network Centers of Excellence (CEs).

FARE has established a Clinical Network of CEs that provide state-of-the-art clinical care and research to food allergy patients. CEs serve a racially and economically diverse allergy population throughout major metropolitan areas across the United States, with demographic characteristics of each CE’s patient population reflective of its respective location.⁷ For this project, CE site coordinators were asked to complete an online survey created by the research team via Research Electronic Data Capture (REDCap)⁸ that assessed (1) the number of mental health professionals employed within their division, (2) the availability of mental health professionals in their institution and community, (3) mental health professional inclusion in food allergy clinical trials, and (4) perceptions of mental health concerns related to food allergy. Mental health professionals were grouped into 3 categories: (1) psychologists (PhD or PsyD), (2) psychiatrists (MD), and (3) social workers or masters-level mental health professionals (MA). All surveys were completed in January and February 2018. Frequencies were calculated across variables.

Overall, 28 of 29 CEs (97%) completed the survey. Most were hospital outpatient settings ($n = 22$), but multispecialty ($n = 3$), single specialty practices ($n = 1$), and academic institutes ($n = 2$) were also represented. Fifty-seven percent of CEs ($n = 16$) provided clinical care to pediatric patients only. There

was variability among CEs regarding the number of annual pediatric food allergy patients (mean, 2365 ± 1887 ; range, 40–7000) and adult food allergy patients (mean $\pm$ SD, 394 ± 294 ; range, 50–1000).

Five CEs (21%) had a mental health professional in their division; however, there was variability as to the amount of time that each CE had a mental health professional dedicated to its division. Regarding psychologists, 1 CE had 2 full-time psychologists in its division (full-time equivalent [FTE] = 2.0), 1 CE had 1 full-time psychologist (FTE = 1.0), and another CE had a part-time psychologist (FTE = 0.50 or 2.5 d/wk). Regarding psychiatrists, 1 CE had 2 full-time psychiatrists (FTE = 2.0), and regarding social worker/masters-level mental health professionals, 1 CE had a part-time MA (FTE = 0.15 or <1 d/wk). Some CEs had a psychologist ($n = 18$; 86%), psychiatrist ($n = 19$; 68%), or MA ($n = 9$; 31%) in their institution to whom they could refer patients. Fewer CEs had a psychologist ($n = 15$; 54%), psychiatrist ($n = 5$; 18%), or MA ($n = 3$; 11%) in the community to whom they could refer patients. Only 4 CEs (14%) had students receiving training in food allergy–related mental health concerns.

Most CEs reported they observed food allergy–related mental health concerns in their divisions, including child anxiety ($n = 27$; 96%) and parent anxiety ($n = 26$; 93%). CE coordinators also indicated that mental health services would be most beneficial at the time of diagnosis ($n = 25$; 89%), before notable developmental transitions ($n = 22$; 79%), and before oral food challenges ($n = 20$; 71%). See [Tables 1 and II](#).

Eighteen CEs (61%) did not have mental health support for clinical trial participants, yet 13 (81%) of these CEs indicated they would like to have them. In response to an open-ended question, respondents indicated they had observed mental health concerns related to clinical trials including anxiety related to oral food challenges ($n = 7$), dosing ($n = 7$), allergic reactions ($n = 5$), blood draws ($n = 4$), and epinephrine use ($n = 2$), treatment adherence concerns ($n = 3$), psychosomatic symptoms ($n = 2$), and food aversions ($n = 1$).

CE respondents reported that anxiety and other food allergy psychosocial concerns are common, but there were few mental health professionals with food allergy knowledge to whom to refer patients. Project limitations include the sole use of CE site coordinators as respondents. Although their knowledge about mental health services within their division/institution is likely accurate, they may not be aware of all the community referral options used by other clinicians in their divisions. Furthermore, results regarding their perceptions of mental health needs should only be interpreted as their impressions, not the opinions of the entire division. We encouraged respondents to reach out to colleagues to gather information as needed, but acknowledge that future studies should implement a more systematic approach. In addition, these results are only representative of FARE CEs, not all allergy clinics across the United States, and do not reflect patients’ own perceptions of their mental health needs. Regardless, the FARE CEs represent a geographically, racially, and economically diverse population, and to our knowledge, these are the only available data about mental health service availability for food allergy patients in the United States.

TABLE I. Mental health concerns among food allergy patients observed by CE site coordinators

Mental health concern	n (%)
Parent anxiety about living with a food allergy	26 (92.90)
Child anxiety about living with a food allergy	27 (96.40)
Needle phobia or other medical procedure anxiety	23 (82.10)
Avoidance of safe foods or unnecessarily restricted diets	25 (89.30)
Food allergy–related bullying	20 (71.40)
Parent/child anxiety about oral food challenges	27 (96.40)
Panic attacks	19 (67.90)
Minimization of food allergy severity	17 (60.70)
Adherence concerns	20 (71.40)

TABLE II. CE Coordinators' perceptions of when patients would benefit from mental health services

Time point	n (%)
At time of diagnosis	25 (89.30)
After an allergic reaction	19 (67.90)
Before an oral food challenge	20 (71.40)
During an oral food challenge	10 (35.70)
Once a year	6 (21.40)
Before notable developmental transitions	22 (78.60)
Only if clinically indicated	4 (14.30)

Although most CEs reported that food allergy–related mental health concerns were significant, less than a quarter had the needed patient support. The fact that there is such a marked deficit of mental health support among sites recognized as exemplar food allergy programs suggests that other allergy clinics and general practitioners who provide allergy care may face equal, if not greater, challenges accessing mental health services for their patients. Additional research regarding the types of mental health services available to patients at CE sites (ie, general allergy clinics, oral food challenge clinics, clinical trials), the availability of mental health services among non-CE sites, and patients' perceptions of their needs is warranted. Clinicians are encouraged to consider developing pathways to connect their patients to mental health professionals when needed. The allergy and mental health communities should work together to create educational programs about food allergy for mental health professionals and

general medical practitioners, and facilitate the creation of an expanding pool of mental health professionals with food allergy expertise.

Acknowledgments

We acknowledge and thank FARE's Centers of Excellence for their participation.

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This work was supported by the Eugene Washington PCORI Engagement Award Program (Agreement # 3017), "Empowering Patient Partners and Key Stakeholders to Develop a Patient-Centric Food Allergy Research Program."

Conflicts of interest: The authors declare that they have no relevant conflicts of interest.

Received for publication January 27, 2019; revised April 30, 2019; accepted for publication April 30, 2019.

Available online May 14, 2019.

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2213-2198

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<https://doi.org/10.1016/j.jaip.2019.04.045>

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