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A survey examining the impact of COVID-19 on food protein–induced enterocolitis syndrome

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Clinical Implications

To assess the burden of coronavirus disease 2019 (COVID-19) on patients and caregivers with food protein–induced enterocolitis syndrome (FPIES), an anonymous survey was distributed online from March to June 2020. Respondents reported heightened stress with regard to food access, financial security, and health concerns related to FPIES.

Over the past year and a half, the coronavirus disease 2019 (COVID-19) pandemic has set off a cascade of new challenges to the health, safety, and economic stability of families around the world. Given limitations in accessing safe food and decreased options for emergency assistance, food-allergic individuals have been identified as particularly vulnerable to food insecurity during COVID-19.¹ Whereas prior studies have considered this issue in the context of immunoglobulin E (IgE)–mediated food allergies, food protein–induced enterocolitis syndrome (FPIES) is another serious food allergy affecting over 900,000 North Americans, which should be considered as a risk factor for food insecurity during times of disruption.² The FPIES is a non–IgE-mediated food allergy that frequently presents with protracted vomiting 1 to 4 hours after eating a trigger food, sometimes followed by watery diarrhea, and with severe symptoms including lethargy, hypotension, and shock in up to 15% of cases.³ In prior studies, parents of children with FPIES reported significant stress and decreased quality of life related to this condition.⁴ With this survey, we examined whether the widespread disruption caused by the COVID-19 pandemic contributed to increased difficulty obtaining safe food and other stressors in a population affected by FPIES.

To assess the impact of COVID-19 on caregivers and patients with FPIES, an anonymous survey was distributed online via the website of the International FPIES Association (fpies.org), a 501(c)3 nonprofit organization that provides education and advocacy for families affected by FPIES. Surveys were collected from March to June 2020 (Appendix 1; available in this article's Online Repository at www.jaci-inpractice.org). During the study period, the survey link was opened 357 times. One hundred fifty-one surveys were completed, 142 of which were submitted by mothers of children affected by FPIES. The 9 additional responders were mothers of children with FPIES who also reported being affected by FPIES themselves (median age 37 years). Children affected by FPIES ranged in age from infancy to adolescence (median age 2.0 years), lived in suburban/urban

areas, resided in the United States, and were primarily non-Hispanic White. Demographic characteristics of the respondents are reported in Table I.

As reported in Table I, the burden and clinical manifestations of FPIES prior to the pandemic were substantial in this study group, with a majority of responders reporting prior use of the emergency department owing to FPIES and about one-third requiring treatment with intravenous fluids. Of note, these clinical findings suggest a study population with more severe FPIES than average, with possible implications for study generalizability.³ There were no known or suspected COVID-19 cases among the 151 respondents of all ages. However, secondary impacts of COVID-19 were widespread (Table II). A majority of responders reporting increased difficulty buying safe, nutritious food and having to utilize multiple stores/online retailers to buy safe foods during the pandemic. Most responders also reported spending more money on food during the COVID-19 pandemic than previously, and many reported having to modify their diet or find alternative foods owing to the pandemic. These findings are in line with prior research showing that FPIES (and in particular, multifeed-trigger FPIES) can result in onerous dietary restrictions that may be complicated owing to food shortages during times of disruption.⁵

We hypothesized that caregivers managing multifeed-trigger FPIES, or those dealing with both FPIES and IgE-mediated food allergy, would report higher level of stress related to obtaining adequate nutrition owing to the difficulty in managing multiple food restrictions. However, although mean stress levels were higher for those reporting multifeed FPIES compared with single-food FPIES (6.52 vs 6.10 on a 10-point scale), and for families reporting both FPIES and IgE-mediated food allergies compared with FPIES alone (6.70 vs 6.31), these results were not statistically significant (independent samples *t* test, $P = .430$ and $.4165$, respectively). This survey may have been underpowered to detect these differences.

Widespread changes in the utilization of health care services have occurred throughout the COVID-19 pandemic, particularly with relation to the use of emergency services and telemedicine. During infection surges, concerns about potential exposure to severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) in medical settings, and particularly while seeking medical care in the emergency department, were widespread. Indeed, responders in our survey reported significant concern about potentially having to go to the emergency department for FPIES reactions during the pandemic, with a high number of families utilizing telemedicine during this period, consistent with broader trends toward increased telehealth during COVID-19 (Table II).⁶ Around three-quarters also reported significant concerns about introducing new foods during COVID-19, as well as concern about managing FPIES or anaphylactic reactions during COVID-19. These findings are unsurprising, given the high levels of anxiety that often accompany the introduction of new foods in this patient/caregiver population. This highlights the need for proactive management of FPIES, including assisting and empowering caregivers to expand the diet and remove unnecessary restrictions as much as possible. Concerns about exposure risk have recently prompted changes to the

TABLE I. Survey participant demographics*

Demographics	Value
Current age of child, median (range) (n = 151)	2.0 y (2 mo–16 y)
Age of child at diagnosis of FPIES, median (range) (n = 151)	12.5 mo (birth–9 y)
Current age of parent, median (range) (n = 143)	39.5 y (24–65 y)
Age of parent diagnosed with FPIES, median, (range) (n = 9)	37 years (24–65 y)
Country of residence	
United States	73.5% (n = 111)
Canada	12.6% (n = 19)
Other	11.3% (n = 17)
Area of residence†	
Suburban	56.3% (n = 85)
Urban	26.5% (n = 40)
Rural	14.6% (n = 22)
Race and ethnicity	
Non-Hispanic White	80.7% (n = 122)
Hispanic	7.9% (n = 12)
Non-Hispanic Black	1.4% (n = 2)
Other	2.0% (n = 4)
Prefer not to state	4.0% (n = 6)
Annual household income, median (range)	\$100,000–149,000 (\$12,000–\$200,000)
Clinical manifestations of FPIES	
Protracted vomiting following trigger	91.8% (n = 135)
Prior ED or inpatient admission for FPIES	68.2% (n = 103)
Required IV fluids for treatment of FPIES during ED/inpatient	42.4% (n = 64)
Prior use of epinephrine autoinjector for FPIES	7.9% (n = 12)
Top reported trigger foods	
Cow's milk	48.3% (n = 71)
Oat	47.7% (n = 70)
Rice	35.1% (n = 52)
Egg	14.5% (n = 22)
Banana	12.6% (n = 19)
Multifood FPIES	24.5% (n=37)
Patient-reported comorbidities‡	
Atopic dermatitis	51.7% (n = 76)
IgE-mediated food allergy	29.9% (n = 44)
Asthma	23.1% (n = 34)

ED, Emergency department; IV, intravenous.

*All available data were used when available. Missing data values were excluded.

†Self-reported.

‡Diagnosed by a physician.

recommended management of both anaphylaxis and severe FPIES reactions during the pandemic, with at-home management recommended in nonsevere cases.^{7,8}

This survey suggests that individuals affected by FPIES experienced stress during the COVID-19 pandemic across multiple psychosocial domains. As a cross-sectional survey, we are unable to determine how stress levels in this survey group may have evolved over time (including in the prepandemic era), or how they compare with populations unaffected by FPIES.⁴ Furthermore, this study population reported more severe manifestations of FPIES than average, suggesting that the survey responders may

TABLE II. Impact of COVID-19

Survey question	Positive response
Known or suspected cases of COVID-19	0% (n = 0)
Supply of safe foods (compared with pre-COVID)	
Had to use multiple stores/online retailers to buy safe foods during the pandemic	82.3% (n = 121)
Spent more money on food during the COVID-19 pandemic	80.9% (n = 119)
Increased difficulty buying safe, nutritious food	57.1% (n = 84)
Had to modify diet or find alternative foods owing to inability to find safe foods	42.2% (n = 62)
Consulted with dietician for meal planning during COVID-19	16.3% (n = 24)
Stress/concern about acute FPIES reaction (compared with pre-COVID)	
Concern about needing to go to ED for FPIES reaction during pandemic	82.3% (n = 121)
Fear of introducing new foods owing to FPIES	77.6% (n = 114)
Concern that FPIES will result in severe COVID-19 infection	64.6% (n = 95)
Experienced increased stress owing to FPIES	59.1% (n = 87)
Access to care (compared with pre-COVID)	
Had physician appointment canceled owing to COVID-19	59.9% (n = 88)
Utilized telemedicine to contact physician	58.5% (n = 86)
Contacted physician with questions on managing FPIES during COVID-19	36.1% (n = 53)

ED, Emergency department.

have been at increased risk of the adverse impacts of COVID-19 (and may also have greater need of intervention/support). Because we used an internet-based survey, this population may also have greater access or experience with technology than the general public, with potential implications for generalizability. However, clinicians should be aware of these potential added burdens in families affected by FPIES even in the absence of acute COVID-19 infection in this population. In particular, respondents reported difficulty obtaining safe, nutritious food during the pandemic, a finding that is in line with prior research identifying food-allergic individuals as particularly vulnerable to food insecurity.¹ In response to this finding, guidelines on the dietary management of FPIES during a pandemic (including recommendations regarding food label reading, ingredient selection, new food introduction, and supplementation) were recently published, and can act as an important resource for families affected by this condition.⁵ As the economic and systems-wide effects of the pandemic continue, particular attention should be paid to the issues of food security, health education, and access to health care among those affected by FPIES and food allergies.

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ONLINE REPOSITORY

Appendix 1: Survey Material

Dear Patients, Parents, and Caregivers,

We hope you are doing well and staying healthy during the COVID-19 pandemic. These unprecedented circumstances pose many challenges, especially to the individuals with food-allergic disorders, including FPIES. We ask you to answer a series of anonymous questions focusing on your experience during the pandemic. Our goal is to understand your daily struggles and to identify the strategies how to counteract the detrimental effects of the pandemic. We also ask you to let your friends and family members without FPIES know about the survey and to encourage them to complete the survey, serving as controls and providing a point of reference. The survey takes about 10 to 15 minutes to complete.

Thank you for taking time out of your busy lives to contribute to the well-being of the FPIES community!

Take good care and stay healthy,

The Research Team

This survey was exempt from review by the Institutional Review Board of the New York University School of Medicine, New York, NY.

Demographics

- 1) Are you responding for yourself or your child?
 - a. Myself
 - b. My child
 - c. Both myself and my child have FPIES
- 2) If responding for a child, please indicate your role:
 - a. Mother
 - b. Father
 - c. Other caregiver
- 3) If you are responding for your child, how old is your child?
(Free text)
- 4) How old are you? (Free text)
- 5) Which country do you reside in?
 - a. Drop down menu of all countries in alphabetical order
- 6) Is the area that you live in:
 - a. Urban
 - b. Suburban
 - c. Rural
- 7) How many people live in your household?
 - a. Two
 - b. Three
 - c. Four
 - d. Five
 - e. Six or more
- 8) If you reside in the US, what was the combined annual household income in 2019? This should include income (before taxes) from all sources, including wages, rent from properties, social security, disability and/or veteran's benefits, unemployment benefits, workman's compensation, help from relatives (including child payments and alimony), etc.
 - a. \$12,760 or less
 - b. \$12,761–\$17,240
 - c. \$17,241–\$26,200
 - d. \$26,201–\$30,680
 - e. \$30,681–\$35,160
 - f. \$35,161–\$39,640
 - g. \$39,641–\$44,120
 - h. \$44,121–\$74,999
 - i. \$75,000–\$99,999
 - j. \$100,000–\$149,999
 - k. \$150,000–\$199,999
 - l. Over \$200,000
- 9) Please indicate your race and ethnicity: (Select all that apply)
 - a. White
 - b. Black
 - c. Asian
 - d. Hispanic
 - e. Non-Hispanic
 - f. Prefer not to state
- 10) Have you or your child been diagnosed by a physician with FPIES?
 - a. Yes
 - b. No [if selected, jump to question 20]
- 11) How old were you or your child when you were diagnosed?
(Free text)
- 12) Do you or your child have active FPIES at this time?
 - a. Yes
 - b. No
 - c. Not sure
- 13) Which food(s) have caused an FPIES reaction? (Select all that apply)
 - a. Cow's milk
 - b. Soy
 - c. Rice
 - d. Oatmeal
 - e. Other
- 14) If other, please specify: (Free text)
- 15) Did a food cause vomiting 1 to 4 hours after eating?
- 16) What other symptoms were present? (Select all that apply)
 - a. Diarrhea
 - b. Lethargy
 - c. Floppiness
 - d. Dusky appearance
 - e. Other
- 17) If other, please specify: (Free text)
- 18) Have you or your child been admitted to the hospital or went to the emergency department after FPIES reaction?
 - a. Yes
 - b. No
- 19) Did you or your child receive intravenous fluids to treat FPIES reaction?
 - a. Yes
 - b. No
- 20) Do you/your child carry an epinephrine autoinjector for food allergy?
 - a. Yes
 - b. No
- 21) Have you ever used epinephrine after an allergic reaction?
 - a. Yes
 - b. No
- 22) If yes, which food(s) caused a reaction that was treated with epinephrine? (Free text)
- 23) Have you or your child been diagnosed by a physician with the following conditions: (Select all that apply)
 - a. Asthma
 - b. Eczema (atopic dermatitis)
 - c. Hay fever (allergic rhinitis)

- 24) Have you or your child been diagnosed with other conditions?
a. Yes
b. No
- 25) If yes, please specify what conditions: (Free text)
- 26) Do you or your child have an IgE-mediated food allergy?
a. Yes
b. No
- 27) If yes to IgE-mediated food allergy, what food(s) do you avoid? (Select all that apply)
a. Cow's milk
b. Egg
c. Fish
d. Crustacean/shellfish
e. Tree nuts
f. Peanuts
g. Wheat
h. Soy
i. Other
- 28) Have you or your child been diagnosed with the pandemic virus COVID-19?
a. Yes
b. No [if selected, jump to question 46]
- 29) Was the COVID-19 infection confirmed with swab?
a. Yes
b. No
- 30) What was the date (month/day/year) of COVID-19 infection onset/diagnosis? (Free text)
- 31) Did you or your child have symptoms of COVID-19 infection?
a. Yes
b. No (if selected, jump to 38)
- 32) Did you or your child have diarrhea during COVID-19 infection?
a. Yes
b. No
- 33) Did you or your child have vomiting during COVID-19 infection?
a. Yes
b. No
- 34) Did you or your child have fever during COVID-19 infection?
a. Yes
b. No
- 35) Did you or your child have runny nose during COVID-19 infection?
a. Yes
b. No
- 36) Did you or your child have cough during COVID-19 infection?
a. Yes
b. No
- 37) Did you or your child have pneumonia during COVID-19 infection?
a. Yes
b. No
- 38) Did you activate emergency services by calling an ambulance?
a. Yes
b. No
- 39) Did you or your child have go to emergency department during COVID-19 infection?
a. Yes
b. No
- 40) How long did the COVID-19 infection last? (Free text)
- 41) Did you or your child fully recover?
a. Yes
b. No
- 42) If no, please specify the outcome: (Free text)
- 43) Did you or your child have an FPIES reaction to new food introduction after COVID-19 infection?
a. Yes
b. No
c. Not applicable
- 44) Did you or your child have new food allergy that required epinephrine administration after COVID-19 infection?
a. Yes
b. No
c. Not applicable
- 45) Did you or your child start to carry epinephrine autoinjector after COVID-19 infection?
a. Yes
b. No
- 46) Did you or your child experience FPIES or immediate IgE-reaction reaction to a known food trigger during COVID-19 pandemic?
a. Yes
b. No
- 47) If yes: what food/what symptoms/how was it managed?
- Compared with times before the onset of the COVID-19 pandemic:**
- 48) Do you have difficulties buying safe, nutritious foods for yourself or your child?
a. Yes
b. No
- 49) Can you order food online for home delivery to your address?
a. Yes
b. No
- 50) Do you have to utilize multiple stores/online retailers to buy safe foods?
a. Yes
b. No
- 51) Have you had trouble accessing your child's formula?
a. Yes
b. No
c. Not applicable
- 52) Are you spending more money on food during the COVID-19 pandemic than before?
a. Yes
b. No
- 53) If yes, please estimate how much more money you spend per week shopping for food for your child compared with before the pandemic? (Free text)
- 54) If yes, please select all additional costs that apply:
a. Ordering more expensive products online
b. Shipping fees
c. Less expensive food alternatives were sold out
d. Have to drive around to locate safe foods
e. Ordering for takeout or delivery

- f. Other
- 55) If other, please specify additional food-related costs: (Free text)
- 56) If yes, please estimate how much more money you spend per week shopping for food for your child compared with before the pandemic? (Free text)
- 57) Have you had to modify the diet to substitute alternative foods for the safe foods you could not find?
- Yes
 - No
- 58) On a scale of 1 to 10 (1 = no stress, 10 = maximum stress), please rate your level of stress about being able to provide adequate nutrition for yourself or your child. [Likert scale]
- 59) Do you have adequate support from members of your family?
- Yes
 - No
- 60) Have you consulted with a registered dietitian during COVID-19 pandemic to come up with a meal plan?
- Yes
 - No
- 61) Have you contacted your or your child's physician with any questions regarding managing FPIES or food allergies during COVID-19 pandemic?
- Yes
 - No
- 62) If yes, was it easy to reach your physician?
- Yes
 - No
- 63) On a scale of 0 to 10 (0 = not applicable, 1 = no worry, 10 = maximum worry), rate your level of worry that you/your child might develop more severe symptoms because of FPIES or IgE food allergies should you/your child become ill with COVID-19. [Likert scale]
- 64) On a scale of 0 to 10 (0 = not applicable, 1 = no worry, 10 = maximum worry), rate your level of worry about introducing new foods to your child/yourself during the COVID-19 pandemic. [Likert scale]
- 65) On a scale of 0 to 10 (0 = not applicable, 1 = no worry, 10 = maximum worry), rate your level of worry about managing food allergic reaction (FPIES or anaphylaxis) during COVID-19 pandemic. [Likert scale]
- 66) On a scale of 0 to 10 (0 = not applicable, 1 = no worry, 10 = maximum worry), rate your level of worry about having to go to the emergency department owing to a food-allergic reaction (FPIES or anaphylaxis) during COVID-19 pandemic. [Likert scale]
- 67) Do you have FPIES or anaphylaxis emergency treatment letter?
- Yes
 - No
- 68) Have you introduced new foods to your child during the COVID-19 pandemic?
- Yes
 - No
- 69) If yes, what foods? Please specify: (Free text)
- 70) Did you have to interrupt the new food introduction owing to troublesome symptoms that did not reach the full FPIES or IgE-mediated allergic reaction?
- Yes
 - No
 - Not applicable
- 71) If yes, what were the symptoms that led to interruption of the food introduction? Select all that apply:
- Gas
 - Abdominal discomfort
 - Vomiting
 - Reflux/spitting up
 - Persistent hiccups
 - Skin eczema rash
 - Foul-smelling stools
 - Loose stools or diarrhea
 - Hives
 - Other
- 72) If other, please specify: (Free text)
- 73) Have your or your child's office visits been cancelled owing to COVID-19?
- Yes
 - No
- 74) If yes, please indicate whether the cancellations affected visits with:
- Pediatrician
 - Allergist
 - Gastroenterologist
 - Physician of another specialty
 - Registered dietitian
 - Urgent care
 - Social worker
- 75) Have you utilized telemedicine to contact your or your child's health care professional during the COVID-19 pandemic?
- Yes
 - No
- 76) If yes, please select all that apply:
- Pediatrician
 - Allergist
 - Gastroenterologist
 - Physician of another specialty
 - Registered dietitian
 - Urgent care
 - Social worker
- 77) If you utilized telemedicine, were you satisfied with the quality of the telemedicine encounter with (rate all that are applicable, on a scale of 1 to 5 with 1 = least satisfied and 5 = most satisfied):
- Pediatrician
 - Allergist
 - Gastroenterologist
 - Physician of another specialty
 - Registered dietitian
 - Urgent care
 - Social worker
- 78) How likely would you utilize telemedicine encounters during normal times, once the pandemic is over? (On a scale 1 to 5, where 1 = definitely not, 5 = definitely yes)?
- Pediatrician
 - Allergist
 - Gastroenterologist
 - Physician of another specialty
 - Registered dietitian
 - Urgent care
 - Social worker