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Global availability and uptake of psychological services for adults, caregivers and children with food allergy

R. C. Knibb[1] | L. J. Herbert[2,3] | C. J. Jones[4] | J. L. P. Protudjer[5,6,7] | C. Screti[1] | C. Roleston[1,8] | H. A. Brough[9,10,11] | C. Warren[12] | L. Lombard[12,13] | A. F. Santos[9,10,11] | R. Gupta[14,15] | B. P. Vickery[16,17] | M. J. Marchisotto[18]

Correspondence
R. C. Knibb, Aston Institute of Health and Neurodevelopment, Aston University, Birmingham, UK.
Email: r.knibb@aston.ac.uk

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Abstract

Background: Food allergy (FA) is associated with poor health-related quality of life and high levels of psychological distress. Psychological support is extremely important but not always available. As part of the Global Access to Psychological Services for Food Allergy (GAPS) study, we aimed to assess psychological distress and service use among adults, caregivers and children with FA in a global survey.

Methods: Participants ($n = 1329$ adults with FA; $n = 1907$ caregivers of children with FA) from >20 countries were recruited through patient organisations, social media advertisements and online survey panels to complete an online survey. Surveys were available in six languages.

Results: A total of 67.7% of adults and 77.2% of caregivers reported direct experience, and 51.6% of caregivers said their child had experienced FA-related psychological distress. The most commonly reported issue was anxiety about having an allergic reaction. Less than 20% had been assessed for FA-related psychological distress. There were significant differences across countries for levels of distress, screening for distress, seeing a mental health professional and being diagnosed with a FA-related mental health disorder (all $p < .001$). The United Kingdom, Australia and Brazil had the highest number of participants reporting distress. The most commonly reported barrier to seeing a mental health professional was cost.

Conclusions: FA-related distress is common across countries, but with substantial country-to-country variability. Allergy providers are encouraged to routinely assess families for psychological distress and provide access to appropriate mental health resources. Development and implementation of evidence-based, patient-informed accessible, affordable FA interventions in multiple languages is urgently needed.

KEYWORDS
adult, caregiver, child, food allergy, mental health, psychological, support

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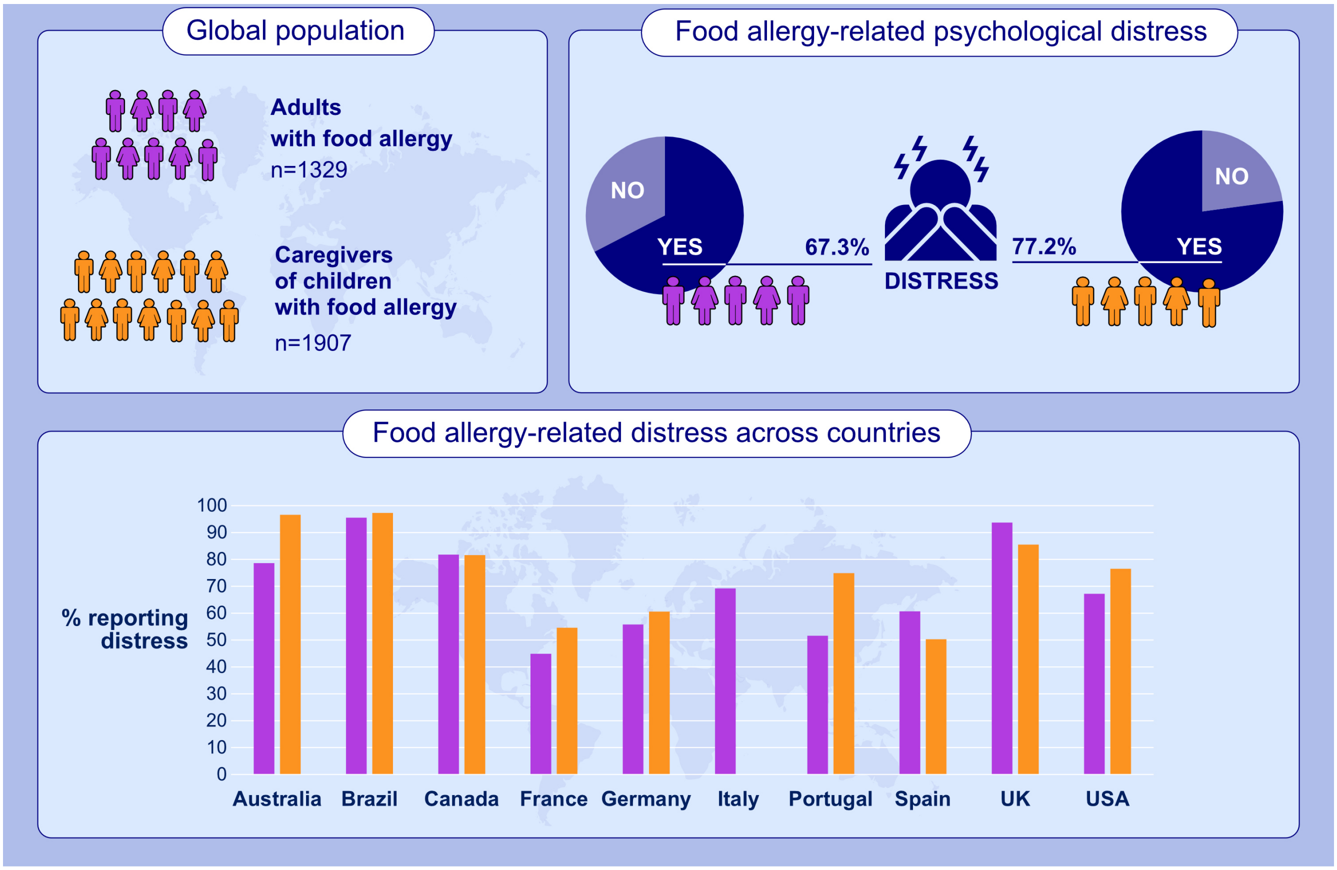
R. C. Knibb and L. J. Herbert shared the joint first authorship.

For affiliations refer to page 9.



GRAPHICAL ABSTRACT

Food allergy-related distress reported by adults and caregivers across countries. Abbreviations: AAI, adrenaline auto-injector; FA, food allergy; FARE, Food Allergy Research & Education; GAPS, Global Access to Psychological Services; HCPs, healthcare Professionals; HRQoL, health-related Quality of life; IgE, immunoglobulin E.

1 | INTRODUCTION

Food allergy (FA) is an IgE-mediated reaction to predominantly protein in food which affects approximately 4%–8% of children, with higher rates observed in younger children.[1–3] Up to 10% of adults also have the condition, with some evidence suggesting an increase in the numbers of patients diagnosed with FA in adulthood.[4,5] Most research to date has focused on the impact of FA on children and their parents, with poor health-related quality of life (HRQoL)[6,7] and poor mental health being consistently reported.[8,9] A systematic review identified FA-specific anxiety to be the most frequently endorsed form of FA-specific distress.[8] Qualitative research has reported that parents feel they lack support from healthcare professionals (HCPs), have uncertainties regarding their child's FA management and experience anxiety, turmoil and isolation as they seek to integrate the FA into daily life.[10]

There is much less research on the experiences of adults with FA; however, evidence suggests they are similarly affected. For example, in a survey of 153 adult patients in the United States with peanut allergy, almost a third reported that their FA substantially interfered with their life, with all observed domains of HRQoL significantly worse than population norms.[11] Mental health may also be affected in adults, with a recent survey of university students reporting those with a FA had higher levels of anxiety and depression than those without FA.[12] Significant associations have also been observed between poor HRQoL in adults and clinical characteristics such as a history of severe reaction,[13,14] being allergic to multiple foods,[14,15] being female[13,15] and allergen type.[13,14] Qualitative research has further elucidated the experiences of adults living with FA, with eating out being one of the most frequently endorsed challenges to successfully managing FA.[16–18]

Given the challenges of managing FA, its noted impact on HRQoL and the overall mental health burden it imposes,[6–8,11] access to FA-related mental health resources and professionals equipped with FA expertise may be crucial to supporting patients and caregivers. However, recent research conducted by our team regarding access to mental health care among Food Allergy Research & Education's (FARE) Centers of Excellence in the United States indicated that there are few mental health professionals to whom allergists can refer patients, even among sites recognised as providing exemplar clinical FA care.[19] Similar unmet needs have been recognised in the United Kingdom, with very few allergy clinics having access to specialist psychologists to support their patients.[20]

The Global Access to Psychological Services for Food Allergy study (GAPS) was established to characterise FA-specific psychological needs and access to care globally in order to inform health care leaders about the psychosocial needs of the FA population and their families, and encourage educated decisions about resource allocation. The first phase of this project aimed to assess the psychological healthcare needs of patients with FA and caregivers of children with FA, and the availability and uptake of psychological resources via on online survey. This article reports on the results of a large international sample of adults with FA and caregivers of children with FA. The main aim of this article was to determine the rates of psychological distress and support needs across different countries, to inform what efforts are necessary to support patients.

2 | METHODS

2.1 | Design

This study used a cross-sectional online survey design. The study received ethical approval from Aston University Research Ethics Committee (REC ID number 1621) and all participants provided informed consent.

2.2 | Measures

Current validated scales of HRQoL and anxiety were determined to be too narrow to assess the range of psychological distress under investigation in this study and no scales exist to measure access to and experience of mental health services. Therefore, a questionnaire developed by members of our team's prior study on mental health provider access in the United States[19] was adapted by the study team. The revised questionnaire was based on a review of the current literature, the aims of the GAPS study and iterative input from the full research team which includes psychologists, allergists, methodologists, primary care physicians, health services researchers, patients and patient organisation representatives. The questionnaire was translated into further languages: French (European and Canadian), German, Italian, Portuguese (European and Brazilian) and Spanish, by a professional translation company. It was then piloted with native speakers of each language from across our network, who checked the translations and provided feedback on any inaccuracies. Questionnaires were then successfully back translated to confirm accuracy.

Questionnaires assessed adult, caregiver and child sociodemographic characteristics, FA characteristics, FA-related psychological distress, screening for FA-related psychological distress at allergy appointments, FA-related mental health appointments, and barriers to seek mental health care for FA. Skip logic was used within the survey so that participants only answered questions relevant for them.

2.3 | Participants and study procedures

Adults aged 18 years or over and caregivers (ages 18+ years) of children (aged 0–17 years) who self-reported a FA diagnosed by a HCP were eligible to participate. Participants were recruited via advertisements shared by patient organisations via their websites, newsletters, emails, and social media and advertisements posted on social media by the study team. Advertisements asked for participation in a study looking at psychological service needs for people with FA. An online survey panel, supplied by Qualtrics, was also used for recruitment. Additionally, the caregiver questionnaire was distributed as an optional survey to participants in the Food Allergy Outcomes Related to White and African American Racial Differences (FORWARD) Study, a prospective, multicentre cohort study investigating clinical and psychosocial FA factors in a socioeconomically, racially, and ethnically diverse sample of children with allergist-diagnosed FA and their caregivers in the United States. Recruitment methods aimed to reach as many countries as possible, however specific advertising was focused on Australia, Brazil, Canada, France, Germany, Italy, Portugal, Spain, the United Kingdom and the United States. A link in the study advertisement took participants to a participant information sheet, a consent form and the survey, hosted on the Qualtrics online platform. All participants had to answer eligibility questions regarding the diagnosis of their FA and age and had to complete the consent form before being allowed access to the survey. Surveys were completed anonymously.

2.4 | Data analysis

Data were downloaded from the Qualtrics server into SPSS Version 28. Descriptive data on need for and use of psychological services are reported across the whole sample, split by adults and caregivers. Where there were sufficient participants, cross country-comparisons were conducted using chi-square analyses for categorical data.

3 | RESULTS

A total of 1329 adults and 1907 caregivers participated. Over 20 countries were represented; however, participants mostly came from Australia, Brazil, Canada, France, Germany, Italy, Portugal, Spain, the United Kingdom and the United States. The range of participants from these countries was 90 to 208 adults and 117 to 659 caregivers. Most adults identified as White (85.4%), over two-thirds were women (70.2%) and just under half were married (42.7%). Mean age was 38.14 ± 13.4 years. The most commonly reported allergy was to peanut (36.1%), followed by tree nut (30.6%) and cow's milk (26.9%). Half of the adult participants (49.1%) had a prescription for an adrenaline auto-injector (AAI), and half (50.1%) had a history of anaphylaxis.

Most caregivers also identified as White (79.2%); 80.9% reported they were the mother of a child with FA and were married (71.8%). Mean (SD) child age was 8.60 ± 4.66 years and over just half of children were male (60.6%, $N = 1157$). Caregivers reported that mean (SD) child age at time of FA diagnosis was 4.31 ± 3.68 years. Two-thirds of children (69.5%) had a prescription for an AAI, and half (47.9%) had a history of anaphylaxis according to the caregiver. Participant characteristics can be seen in Tables 1 and 2.

TABLE 1 Characteristics of the survey participants (adults $N=1329$; caregivers $N=1907$).

Participant characteristics	Adults *N* (%)	Caregivers *N* (%)
Country of residence		
Australia	120 (9.0)	118 (6.2)
Brazil	90 (6.8)	188 (9.9)
Canada	208 (15.7)	185 (9.7)
France	111 (8.4)	119 (6.2)
Germany	115 (8.7)	109 (5.7)
Italy	126 (9.5)	18 (0.9)
Portugal	130 (9.8)	171 (9.0)
Spain	145 (10.9)	151 (7.9)
United Kingdom	116 (8.7)	117 (6.1)
United States of America	122 (9.2)	659 (34.6)
Other	46 (3.4)	72 (3.8)
Age (years)	38.14 years (SD = 13.4)	38.45 years (SD = 8.05)
Gender (% female)	931 (70.2)	1028 (75.2)
Ethnicity		
Asian	25 (1.9)	43 (2.3)
Black, Black British, Caribbean, or African	23 (1.7)	140 (7.3)
Mixed or multiple ethnic groups	82 (6.2)	109 (5.7)
White	1135 (85.4)	1511 (79.2)
Other ethnic group	51 (3.8)	57 (3.0)
Unknown	2 (0.2)	18 (0.01)
Prefer not to say	11 (0.8)	29 (1.5)
Highest level of education		
No qualifications	4 (0.3)	25 (1.3)
School level	212 (16.1)	140 (7.4)
College level	359 (27.2)	383 (20.4)
University undergraduate level	382 (29.0)	527 (28.0)
University postgraduate level	259 (19.7)	491 (26.1)
PhD or MD	54 (4.1)	122 (6.4)
Other	48 (3.6)	32 (1.7)
Employment status		
Full-time employment	714 (55.0)	1110 (58.7)
Part-time employment	198 (15.3)	368 (19.5)
Not employed outside the home	208 (16.0)	244 (12.9)
Student	146 (11.2)	48 (2.5)
Marital status (% married)	558 (42.7)	1359 (71.8)
How would you pay for mental health services		
My health insurance	491 (40.1)	550 (30.6)
I would pay privately for this	427 (34.9)	887 (49.3)
Government insurance	307 (25.1)	290 (15.6)

TABLE 2 Food allergy characteristics of adults and children (adults $N=1329$; children $N=1907$).

Food allergy characteristics	Adult *N* (%)	Child *N* (%)
Age of food allergy diagnosis (years)	17.9 years (SD = 13.62)	4.31 years (SD = 3.68)
Allergens		
Peanut	480 (36.1)	1025 (53.7)
Tree nut	407 (30.6)	797 (41.8)
Cow's milk	357 (26.9)	788 (41.3)
Crustaceans	244 (18.4)	251 (13.2)
Cereals containing gluten	182 (13.7)	171 (9.9)
Egg	171 (12.9)	756 (39.6)
Molluscs	159 (12.0)	117 (6.8)
Wheat	152 (11.4)	197 (10.3)
Fish	147 (11.1)	222 (11.6)
Soy	146 (11.0)	261 (13.7)
Sesame	84 (6.3)	239 (12.5)
Sulphites and sulphur dioxide	76 (5.7)	25 (1.5)
Mustard	57 (4.3)	54 (3.1)
Lupin	44 (3.3)	29 (1.7)
Celery	39 (2.9)	28 (1.6)
Other	429 (32.3)	386 (20.2)
Food allergy diagnosis method		
Skin test	698 (52.5)	784 (45.5)
Blood test	575 (43.3)	764 (44.3)
Oral food challenge	212 (16.0)	336 (19.5)
History	544 (40.9)	627 (36.4)
Elimination diet	220 (16.6)	251 (14.6)
Other	59 (4.4)	43 (2.5)
Don't remember/unsure	89 (6.7)	17 (0.1)
Other allergic diseases		
Drug allergy	309 (23.3)	143 (7.5)
Eosinophilic esophagitis	58 (4.4)	98 (5.1)
Eosinophilic gastritis or other gastrointestinal disorder	130 (9.8)	104 (5.5)
Eczema	384 (28.9)	935 (49.0)
Asthma	442 (33.3)	640 (33.6)
Environmental allergies	486 (36.6)	576 (30.2)
Oral allergy syndrome	175 (13.2)	106 (5.6)
Adrenaline auto-injector prescription	652 (49.1)	1310 (69.5)
History of anaphylaxis	666 (50.1)	743 (47.9)
History of treatment for allergic reaction (% yes)	541 (40.7)	657 (43.8)

* This question was not asked for participants of the FORWARD study as they formed a cohort already identified as having a medical diagnosis for food allergy (n=183). Numbers and % for this question were out of a base of 1724.

3.1 | Food allergy-related psychological distress

Just over two thirds of adults (67.7%, $n=900$) and three-quarters of caregivers (77.2%, $n=1473$) reported experiencing psychological distress related to their or their child's FA. The distress reported by most participants was anxiety about an allergic reaction (64.1% of adults; 74.4% of caregivers). For adults, this was closely followed by anxiety about living with their FA (62.5%). Over half felt sadness about the impact of FA on their lives (54.1%) and just over one-third of adults were worried about bullying related to their FA (35.2%). Caregivers reported fear of trusting others with care of their child (71.0%). Over half of caregivers reported worry that people do not understand the seriousness of their child's FA even though the caregiver tried to explain it to them (59.7%) and, similar to adults, sadness about the impact of FA on life (55.6%) was also commonly reported.

Approximately half of caregivers (51.6%) reported that their child had experienced psychological distress related to FA. The most commonly reported types of distress experienced by children were sadness about the impact of FA on life (57.4%) and anxiety about having an allergic reaction (56.4%). A complete list of reported types of FA-related distress is provided in Tables 3 and 4

Cross-country comparisons were made for 10 countries where there were sufficient sample sizes (see Tables 5 and 6). There were significant associations between FA-related distress and country of residence for adults ($\chi^2(9)=142.85$, $p<.001$), caregivers ($\chi^2(8)=168.55$, $p<.001$) and children ($\chi^2(8)=75.55$, $p<.001$). Proportions of adults from Brazil (95.5%), the United Kingdom (93.7%) Canada (81.8%) and Australia (78.6%) reporting FA-related distress were significantly greater than proportions of adults from countries such as Germany (55.8%) and France (44.9%) (see Table 4). Similarly, proportions of caregivers from Brazil (97.3%), Australia (96.6%), and the United Kingdom (85.6%) reporting their own FA-related psychological distress were higher than other countries. In comparison, proportions of caregivers in Germany (60.6%), France (54.6%) and Spain (50.3%) reporting their own FA-related psychological distress were lower (Table 5). Proportions of caregivers in Australia (72.0%) and the United Kingdom (70.9%) reporting FA-related psychological distress in their child were higher than other countries. In contrast, proportions in Spain (35.1%) and Portugal (42.4%) were lower (Table 6).

3.2 | Screening for food allergy-related distress

Only one fifth of adults (19.4%, $n=258$) had been screened or assessed for FA-related psychological distress during a FA appointment. Similarly, very few caregivers reported that they (13.9%) or their child (15.8%) had been screened or assessed for FA-related psychological distress during a FA appointment (Tables 5 and 6).

There was significant cross-country variability for patient-reported screening of FA-related distress for adults ($\chi^2(9)=106.89$, $p<.001$), caregivers ($\chi^2(8)=157.64$, $p<.001$) and children, ($\chi^2(8)=108.64$, $p<.001$). In the United Kingdom and Canada, only 2.7% and 7.1% of adults reported being screened for FA-related distress, respectively, compared to almost half of the US adults (45.9%) and just over a third of those from Germany (34.5%) (Table 5). For caregivers in Australia (0.8%), Brazil (8.0%) and the United States (8.5%), a smaller proportion were screened for FA-related distress compared to Germany, where over half of caregivers were screened (51.5%). Similarly, less than 10% of children were screened for FA-related distress in Australia (3.4%), Brazil (9.0%) and Canada (9.7%), whereas in Germany almost half of children were screened (40.7%) (Table 6).

3.3 | Mental health appointments and diagnosis

Similar to proportions reported for screening, 22.9% of all adults ($n=304$) and 22.0% ($n=411$) of caregivers reported they had visited a mental health professional for treatment for FA-related concerns. For caregivers who had seen a mental health professional, 27.5% reported they visited a provider for themselves, 48.0% for their child, and 24.6% for both themselves and their child.

TABLE 3 Psychological distress related to food allergy reported by adults ($N=1329$).

Type of FA-related psychological distress	Adults *N* (%)
Anxiety about an allergic reaction	656 (64.1)
Anxiety about living with my FA	612 (62.5)
Anxiety about avoiding unsafe foods	557 (60.3)
Worry about getting allergen free/safe foods	447 (54.9)
Sadness about the impact of FA on my life	432 (54.1)
Worry of a potentially fatal reaction because of my FA	396 (51.9)
Loss of a normal life due to my FA	385 (51.2)
Fear of trusting others to know what to do if I have an allergic reaction	381 (50.9)
Worry about not being able to take part in social activities because of my FA	356 (49.2)
Stress of managing my health because of my FA	334 (47.6)
Worry about telling people I have a FA	305 (45.4)
Anxiety about having an unnecessarily restricted diet	287 (43.9)
Anxiety about administering an AAI	237 (39.2)
Worry about carrying my AAI	223 (37.8)
FA-related bullying	199 (35.2)
Panic attacks because of my FA	192 (34.3)
Anxiety about oral food challenges	173 (32.0)
Worry about access to AAIs	159 (30.2)
Worry about finding an intimate partner because of my FA	154 (29.6)
Worry about finding or keeping a safe job because of my FA	150 (29.0)
Needle phobia or other medical procedure anxiety	83 (18.4)

Abbreviations: AAI, adrenaline autoinjector; FA, food allergy.

TABLE 4 Psychological distress related to food allergy reported by caregivers for them and their children ($N=1907$).

Type of FA-related psychological distress	Caregiver *N* (%)	Child *N* (%)
Anxiety about me/my child having an allergic reaction	676 (74.4)	544 (56.4)
Fear of trusting others with care of my child	645 (71.0)	N/A
Fear for my child's safety	613 (67.4)	N/A
Anxiety about living with FA	590 (64.9)	524 (54.3)
Worry that people won't understand the seriousness of my child's allergies even though I try to explain them	543 (59.7)	N/A
Worry about me/my child experiencing of a potentially fatal reaction	513 (56.4)	326 (33.8)
Sadness about the impact of FA on my life	505 (55.6)	554 (57.4)
Worry about getting allergen free/safe foods	436 (48.3)	N/A
Worry after my child has a severe reaction	420 (46.2)	N/A
Worry about not being able to take part in social activities because of my/my child's FA	381 (41.9)	387 (40.1)
Social isolation during routine activities due to my child's FA	370 (40.7)	364 (37.7)
Stress of managing my/my child's health because of my FA	358 (39.4)	163 (16.9)
Anxiety about administering AAI	328 (36.1)	305 (31.6)
Anxiety about oral food challenges	313 (34.4)	314 (32.5)
Me/My child experiencing FA-related bullying	312 (34.3)	218 (22.6)
Fear of restricting my child's diet	303 (33.3)	N/A
Worry about carrying my/my child's AAI	268 (29.5)	191 (19.8)
Worry about access to AAIs	230 (25.3)	N/A
Worry about telling people about FA	209 (23.0)	285 (29.5)
Worry about cost	205 (22.6)	N/A
Panic attacks because of my/my child's FA	136 (15.0)	126 (13.1)

Abbreviations: AAI, adrenaline autoinjector; FA, food allergy.

Again there were significant associations between proportions of those seeing a mental health professional for FA-related distress and country of residence for adults ($\chi^2(9)=42.30$, $p<.001$) and caregivers ($\chi^2(8)=.50.13$, $p<.001$) (Tables 5 and 6). The proportion of adults seeing a mental health professional were lowest in the United Kingdom (11.5%) compared to countries such as the United States (35.1%), Brazil (34.4%), Spain (30.3%) and Australia (30.2%). The pattern was slightly different for caregivers, with greater proportions of caregivers in Germany (35.5%) and the United Kingdom (39.7%) reportedly attending mental health appointments than proportions of caregivers in Portugal (14.6%) or the United States (17.9%).

A minority of adults (10.6%, $n=141$) said they had been diagnosed with a mental health disorder that was related to their FA, with significant associations across country of residence ($\chi^2(9)=32.70$, $p<.001$). A larger proportion of adults in the United States (24.2%) reported a diagnosis compared to other countries, with Portugal reporting the lowest proportion (5.4%). (Table 5). Of the caregivers who reported on their and their child's mental health history, 29.3% reported they had been diagnosed with a mental health disorder and 12.6% reported their child had been diagnosed. There were significant associations for mental health diagnoses across countries for both caregivers ($\chi^2(8)=36.07$, $p<.001$) and children ($\chi^2(8)=33.48$, $p<.001$). Higher proportions of caregivers in the United States (43.0%) and the United Kingdom (39.0%) reported mental health diagnoses than compared to other countries, such as France which had the lowest (12.3%). Higher proportions of children in the United Kingdom (21.6%) and Germany (19.3%) had mental health diagnoses compared to other countries, with Australia reporting the lowest (0.0%) (Table 6).

3.4 | Barriers to accessing mental health services

The most commonly reported barrier to seeking mental health services for those who had seen and those who had not seen a mental health professional was cost (33.0% of adults and caregivers who had seen a mental health professional, and 33% of adults and 25% of caregivers who had not) (Table 7). A lack of insurance coverage, doctors not providing a referral, practitioners not available, time constraints and childcare difficulties were other common barriers reported (Table 7).

Barriers were ranked based on the number of endorsements for each barrier by participants in each country. Cost was ranked as the biggest barrier in almost all countries by adults and caregivers. Fewer people endorsed a reluctance to seek mental health care due to potentially receiving a mental health label apart from the United Kingdom and Spain, where this was the most commonly endorsed barrier by those who had seen a mental health professional. The online data (Data S1) show barrier rankings by country for those who had or had not seen a mental health professional.

4 | DISCUSSION

This is the first study to report on the global level of psychological distress experienced by adults, caregivers and children with FA. Two thirds of all adults and almost three-quarters of all caregivers in this large sample from over 20 countries reported FA-related psychological distress, but there was significant variability across countries.

TABLE 5 Number (%) of adults reporting psychological distress, screening and diagnosis of mental health disorders related to FA across countries.

Country	FA-related distress	Screened for FA-related distress	Seen a mental health professional for FA-related distress	Diagnosed with a FA-related mental health disorder
	Yes	Yes	Yes	Yes
Australia (*n* = 120)	92 (78.6)	18 (16.2)	35 (30.2)	15 (12.5)
Brazil (*n* = 90)	85 (95.5)	18 (20.9)	31 (34.4)	9 (10.0)
Canada (*n* = 208)	162 (81.8)	14 (7.1)	34 (16.7)	17 (8.2)
France (*n* = 111)	48 (44.9)	30 (27.8)	21 (19.1)	8 (7.3)
Germany (*n* = 115)	58 (55.8)	38 (34.5)	33 (29.2)	10 (8.8)
Italy (*n* = 126)	83 (69.2)	29 (23.8)	24 (19.5)	9 (7.1)
Portugal (*n* = 130)	63 (51.6)	22 (17.2)	22 (17.3)	7 (5.4)
Spain (*n* = 145)	85 (60.7)	32 (22.4)	44 (30.3)	18 (12.4)
United Kingdom (*n* = 116)	104 (93.7)	3 (2.7)	13 (11.5)	14 (11.0)
United States (*n* = 122)	78 (67.2)	51 (45.9)	40 (35.1)	29 (24.2)
Total	858 (70.1)	255 (20.7)	297 (23.7)	136 (10.6)

TABLE 6 Number (%) of caregivers reporting psychological distress, screening for psychological distress, and diagnosis of mental health disorders related to food allergy across countries.

	Food allergy-related psychological distress *N* (% yes)		Screened for food allergy-related distress *N* (% yes)		Seen a mental health professional for food allergy-related distress *N* (% yes)			Diagnosed with a food allergy-related mental health disorder *N* (% yes)	
Country	Caregiver	Child	Caregiver	Child	Caregiver	Child	Both	Caregiver	Child
Australia (*n* = 118)	114 (96.6)	85 (72.0)	1 (0.8)	4 (3.4)	3 (13.0)	16 (69.6)	4 (17.4)	42 (36.8)	0 (0.0)
Brazil (*n* = 188)	183 (97.3)	102 (54.3)	15 (8.0)	17 (9.0)	16 (39.0)	10 (24.4)	15 (36.6)	50 (27.3)	12 (6.4)
Canada (*n* = 185)	151 (81.6)	105 (56.8)	21 (13.9)	18 (9.7)	11 (29.7)	13 (35.1)	13 (35.1)	47 (31.1)	23 (12.4)
France (*n* = 119)	65 (54.6)	61 (51.3)	21 (32.3)	33 (27.7)	5 (15.2)	17 (51.5)	9 (27.3)	8 (12.3)	8 (6.9)
Germany (*n* = 109)	66 (60.6)	55 (50.5)	34 (51.5)	44 (40.7)	7 (18.4)	21 (55.3)	10 (26.3)	21 (31.8)	21 (19.3)
Portugal (*n* = 171)	128 (74.9)	72 (42.4)	22 (17.2)	30 (17.5)	1 (4.0)	18 (72.0)	6 (24.0)	21 (16.4)	17 (9.9)
Spain (*n* = 151)	76 (50.3)	53 (35.1)	20 (26.3)	31 (20.5)	12 (35.3)	13 (38.2)	9 (26.5)	23 (30.2)	13 (8.6)
United Kingdom (*n* = 117)	100 (85.5)	83 (70.9)	23 (23.0)	30 (25.6)	17 (37.0)	19 (41.3)	10 (21.7)	39 (39.0)	25 (21.6)
United States (*n* = 659)	504 (76.5)	304 (48.8)	54 (8.4)	79 (12.7)	32 (27.4)	63 (53.8)	22 (18.8)	46 (43.0)	88 (14.0)
Total (*N* = 1817)	1387 (76.3)	920 (50.6)	211 (11.6)	286 (15.7)	104 (5.7)	190 (10.5)	98 (5.4)	297 (16.3)	207 (11.4)

In most countries very few had been screened for FA-related psychological distress during a FA appointment. These new data highlight the scale of the unmet need for psychological support among patients with FA and their caregivers, which supports that already noted for children and caregivers in countries such as the United States[19] and the United Kingdom.[20]

The types of distress reported by adults in this study are similar to what has been found in children and caregivers, particularly the anxiety that accompanies living with FA as well as anxiety about unsafe foods and having an allergic reaction.[6–9] Over half of adults also reported sadness about the impact of FA on their lives, supporting previous findings on a sample of undergraduate students in the United States.[12] Adults in this study also reported anxiety and worry over procedural aspects of their FA such as carrying and administering an AAI or having an oral food challenge. Assessment of adults for FA-related distress and referral to appropriate support should therefore not be overlooked. Over a third also reported worry about FA-related bullying. This has been reported in children[21–23] and is often associated with bullying at school, but has not previously been shown in adults. It is not clear what the source of bullying might be

TABLE 7 Barriers to seeking mental health treatment for food allergy-related concerns.

Barrier	Adults *N* (%)		Caregivers *N* (%)	
	Had seen a mental health professional (*N* = 304)	Had not seen a mental health professional (*N* = 997)	Had seen a mental health professional (*N* = 411)	Had not seen a mental health professional (*N* = 1475)
Cost	102 (33.6)	327 (32.8)	135 (32.8)	369 (25.0)
Lack of insurance coverage	78 (25.7)	151 (15.1)	97 (23.6)	191 (12.9)
Doctor would not provide referral	62 (20.4)	232 (23.3)	81 (19.7)	226 (15.3)
Practitioner not available in my area	58 (19.1)	142 (14.2)	53 (12.9)	217 (14.7)
Reluctant to seek help in case I was labelled as having a mental health problem	52 (17.1)	122 (12.2)	53 (12.9)	77 (5.2)
Time constraints	46 (15.1)	129 (12.9)	93 (22.6)	208 (14.4)
Finding childcare	N/A	N/A	52 (12.7)	211 (14.3)
I didn't have any challenges	54 (17.8)	N/A	82 (20.0)	N/A

but it could be in the workplace or from peers and so requires further investigation.

Types of distress reported by caregivers, such as anxiety about having a reaction, fear of trusting others, worry about not taking part in social activities or about using an AAI are also similar to worries reported in previous research.[6–9] The mean age of diagnosis for children in this study was over 4, which may indicate delayed access to care and medical support, which may contribute to distress. Caregivers' perceptions about their child's FA psychosocial distress are aligned with previous research about the impact of FA on children's QoL and mental health, with anxiety about allergic reactions and sadness about the impact on FA being prominent.[24] However, findings to date have been mainly from North America and a small number of countries in Europe. This study is the first to show that the impact of FA and the type of distress felt by families is not confined to these countries but is felt globally.

A strength of this study is the sample sizes achieved, making it possible to explore cross-country differences in the level of distress reported and the level of assessment and uptake of mental health services. There was significant variability in reported distress across countries, with higher numbers of participants from Brazil, Australia and the United Kingdom reporting distress compared to countries in Europe such as Germany and France. Similar variation was seen for those reporting assessment or screening for FA-related distress where this was less than 10% of adults for the United Kingdom and Canada, compared to countries such as the United States where almost half reported they had been assessed. For caregivers, those in Brazil, Australia and the United States reported much lower rates of screening compared to countries such as Germany. However, it should be noted that overall, very few participants reported that this screening had occurred at all. This lack of screening may be resulting in large numbers of patients and caregivers with FA-related distress not being identified and supported. This might be particularly the case in those countries where it appears that the need is greatest, such as Brazil and Australia. Reasons for the cross-country differences are unclear but may be due to cultural variations and different ways in which healthcare is accessed and paid for.

Only one fifth of caregivers and adults had visited a mental health professional for treatment for FA-related concerns. This highlights the global unmet need for psychological support for adults, children and caregivers. The reasons for variability across countries found in this study regarding visiting a mental health professional or receiving a diagnosis of a mental health disorder related to FA need further investigation. It could be due to differences in the level of mental health distress we found across countries or due to variability in level of referrals or available qualified psychologists. The barriers reported by participants included lack of practitioners available and doctors not making a referral. The most commonly reported barrier, however, across almost all countries, was the cost of seeking and paying for psychological support. Paying privately for such support is costly, making this route to support available only for those who can afford it. In comparison, very few caregivers reported a reluctance to seek mental health services due to concern about potentially being labelled with a mental health diagnosis. Therefore, the lack of assessment, referral and access to a mental health professional are clear areas that are in need of addressing, rather than any stigma that might be perceived regarding seeking such help. The notable exception to this is adults in the United Kingdom; however, numbers reporting barriers were low compared to the whole sample size and so this finding needs further investigation.

This is the first global survey of psychological distress and support for adults and caregivers of children with FA, reaching over 20 countries and over 3000 participants. Strengths of this study include that the survey was developed by a multidisciplinary research team with FA expertise in collaboration with FA patient organisations, and a rigorous translation process with native speakers that enabled participants to complete the survey in different languages. However, there are some limitations to consider. Despite the global reach of this study, the sample is still predominantly White and over two thirds female. Further, it is unclear if the demographic profiles of respondents within each country are representative of the country overall. More work is needed to understand the levels of distress and access to support that is experienced by more underserved populations. We were also only able to reach those who had internet access and saw adverts from patient organisations or were part of a survey panel. Although this methodology was the most appropriate to reach a large sample from a spread of countries, the results may not be applicable to those who do not have internet access to complete an online survey. The study was advertised as wanting to explore psychological service needs of those affected by FA and so respondents who had psychological distress related to FA may have been more likely to respond. However, significant cross-country differences in levels of distress reported demonstrate that this is not uniform across the whole sample. Additionally, the quantitative nature of the survey limits our ability to provide explanations as to why we have cross-country differences. In order to explore this, the GAPS study is currently undertaking in-depth interviews with adults and caregivers across nine countries and is planning a follow-up survey to explore these issues further. An online intervention toolkit guided by our findings to offer psychological support for caregivers is also planned.

5 | CONCLUSION

FA-related distress appears widespread among adults, children and caregivers. However, this psychosocial burden may be underappreciated and largely unrecognised due to a lack of clinical screening and linkage to appropriately trained mental health professionals. Clinicians should be aware that FA-related distress is not confined to children or adolescents and their caregivers and are encouraged to ask their adult patients about their worries so that targeted support or referral can be made where possible. Routine screening for psychological distress for patients of any age and caregivers would be optimal, particularly for anxieties about an allergic reaction, using an AAI, or having an oral food challenge. Adults also reported sadness about their FA and therefore low mood or depression should be assessed. The impact on other areas of adult life should also be part of a clinical consultation, particularly concerns regarding bullying, which might not be routinely discussed. Validated psychosocial measures of anxiety, depression and QoL could be utilised and should be FA-specific where possible and information and education delivered at the most appropriate times tailored to age could be helpful in reducing anxieties. Patients or caregivers who report high levels of psychological distress should be referred to, or connected with, a mental health professional where available and to mental health resources or sources of support such as the relevant patient organisation. Due to the barriers to support identified by this study, low-cost or free and accessible psychological support is needed. Further analysis of the current data is planned in order to explore differences in distress other than country of residence, based on clinical characteristics of allergy in our participant groups. The next phase of the GAPS study is to develop an online intervention, guided by our findings, to offer psychological support for adults and caregivers.

AUTHOR CONTRIBUTIONS

Study concept and design, R. C. Knibb, L. J. Herbert, C. J. Jones, J. L. P. Protudjer, H. A. Brough, C. Warren, L. Lombard, B. P. Vickery, M. J. Marchisotto; Data collection, R. C. Knibb, L. J. Herbert, C. J. Jones, J. L. P. Protudjer, C. Screti, C. Warren, A. F. Santos, R. Gupta; Analysis of data, R. C. Knibb, L. J. Herbert; Interpretation of data, all authors; Drafting of the manuscript, R. Knibb, L. J. Herbert; Critical revision of the manuscript for important intellectual content, all authors. All authors approved the final version to be published.

AFFILIATIONS

[1]Aston Institute for Health and Neurodevelopment, Aston University, Birmingham, UK
[2]Children's National Health System, Washington, DC, USA
[3]George Washington University School of Medicine, Washington, DC, USA
[4]School of Psychology, Faculty of Health and Medical Sciences, University of Surrey, Guildford, UK
[5]Department of Pediatrics and Child Health, University of Manitoba, Winnipeg, Manitoba, Canada
[6]Children's Hospital Research Institute of Manitoba, Winnipeg, Manitoba, Canada
[7]Institute of Environmental Medicine, Karolinska Institutet, Stockholm, Sweden
[8]Nuffield Department of Primary Care Health Sciences, University of Oxford, Oxford, UK
[9]Children's Allergy Service, Evelina Children's Hospital, Guy's and St. Thomas's NHS Foundation Trust, London, UK
[10]Department of Women and Children's Health (Pediatric Allergy), School of Life Course Sciences, Faculty of Life Sciences and Medicine, King's College London, London, UK
[11]Peter Gorer Department of Immunobiology, School of Immunology and Microbial Sciences, King's College London, London, UK
[12]Center for Food Allergy and Asthma Research, Northwestern University Feinberg School of Medicine, Chicago, Illinois, USA
[13]Private Practice, Chicago, Illinois, USA
[14]Ann & Robert H. Lurie Children's Hospital of Chicago, Chicago, Illinois, USA
[15]Institute for Public Health and Medicine, Northwestern Feinberg School of Medicine, Chicago, Illinois, USA
[16]Emory University School of Medicine, Atlanta, Georgia, USA
[17]Children's Healthcare of Atlanta, Atlanta, Georgia, USA
[18]MJM Advisory, New York, New York, USA

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RCK: research funding from the National Institute for Health Research, Aimmune, National Peanut Board, Novartis and the Food Standards Agency and honoraria from Nutricia, Viatris and DBV Technologies. RCK is also Chair of the British Society for Allergy and Clinical Immunology Psychology Special Interest Group for Psychology. JP: Section Head for Allied Health, and Co-Lead, Research Pillar, for the Canadian Society of Allergy and Clinical Immunology; sits on the steering committee for Canada's National Food Allergy Action Plan, and reports consultancy for Ajinomoto Cambrooke, Nutricia, Novartis and ALK-Abelló. HB: research funding from the NIH (NAIAD) and speaker honoraria from DBV Technologies. MJM Advisory, New York.

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ORCID

R. C. Knibb https://orcid.org/0000-0001-5561-0904

C. J. Jones https://orcid.org/0000-0003-3672-6631

H. A. Brough https://orcid.org/0000-0001-7203-0813

A. F. Santos https://orcid.org/0000-0002-7805-1436

B. P. Vickery https://orcid.org/0000-0002-7243-5543

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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