Parental Anxiety and Post-Traumatic Stress Symptoms in Pediatric Food Allergy

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Abstract

Objective The purpose of this study was to explore anxiety, worry, and post-traumatic stress symptoms (PTSS) in parents of children with food allergies, and to evaluate whether these three psychological outcomes could be predicted by allergy severity, intolerance of uncertainty, and food allergy self-efficacy. Methods Participants were 105 parents who reported their children to have medically diagnosed food allergies. Participants were recruited to a study on parent wellbeing through an allergy clinic and social media advertisements. Participants completed online questionnaires assessing anxiety, worry, PTSS, intolerance of uncertainty, food allergy self-efficacy, and demographic and allergy information. Results In this sample, 81.0% of parents reported clinically significant worry, 42.3% met the clinical cut-off for PTSS, and 39.1% reported moderate-extremely severe anxiety. Greater intolerance of uncertainty and lower food allergy self-efficacy were associated with poorer psychological outcomes, with mixed results for allergy severity. However, intolerance of uncertainty was the only variable to consistently account for unique variance within regression models. **Conclusions** This study highlights the need for greater awareness of mental health in parents of children with food allergy. The study also indicates that factors impacting on parents' perception of threat may be most strongly predictive of psychological outcomes, warranting further research. Finally, the study indicates that intolerance of uncertainty may be a promising target for psychological interventions within this population.

Key words: food allergy, pediatric, parental anxiety, post-traumatic stress, worry

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Food allergies are a common childhood health condition, with a prevalence of around 6-8% (Luyt et al., 2016). Physical symptoms can include changes to the skin, gastrointestinal and respiratory systems, and in the most severe cases anaphylaxis. Caring for a child with food allergy can be challenging, as even with careful management exposure to allergens can occur (Boyce et al., 2010). Research exploring the psychosocial impact of caring for a child with food allergy has found increased anxiety and stress, particularly in mothers (e.g. Cummings, Knibb, King, & Lucas, 2010; Lau et al., 2014). However, there has been limited research on the nature of anxiety experienced by parents or predictors of psychological wellbeing.

Previous qualitative and case series studies have suggested that parents of children with food allergy may specifically experience increased worry (e.g. Akeson et al., 2007; Sanagavarapu et al., 2016; Knibb, 2015), which may not be captured in past research that has typically used general measures of anxiety. General anxiety measures often assess both somatic anxiety symptoms (more typical in panic; World Health Organisation, 2019) and worry (a primary feature of generalized anxiety disorder, GAD; World Health Organisation, 2019), but are not designed to differentiate between these. Understanding the type of anxiety experienced by parents is important, as it allows the wider adult anxiety literature to be better utilized when designing psychological interventions for this population.

Furthermore, both qualitative research (e.g Akeson et al., 2007; Rouf et al., 2012) and a review of food allergy literature (Kelsay, 2003) have highlighted the need for posttraumatic stress symptoms (PTSS) to be investigated in parents of children with food allergies. Despite this, to the best of the authors' knowledge, no previous research has specifically assessed either worry or PTSS in a larger quantitative study of parents of children with food allergy. The present study therefore considered three psychological outcomes in this population: worry, physiological anxiety symptoms, and PTSS. The study explored three factors that may predict these psychological outcomes. Such research has the potential to aid the identification of more at risk parents and the development of psychological models and treatments. Selection of predictors was guided by Clark and Beck's (2010) transdiagnostic cognitive model of anxiety. This model incorporates common features across CBT-based anxiety disorder models (including PTSD) and proposes that the nature of the anxiety-provoking event, individuals' perception of an event as threatening, and individuals' perceived capacity to cope are predictors of the experience of anxiety. One exemplar from each of these categories was included in the present study.

Firstly, indicators of food allergy severity were explored, to represent the nature of the anxiety provoking event. Indicators of allergy severity have been included in previous research with inconsistent findings. For example, Cummings, Knibb, Erlewyn-Lajeunesse et al. (2010) found mothers of children at risk of anaphylaxis experienced significantly greater anxiety, whilst Marklund et al. (2006) found the lowest emotional wellbeing in parents of children who primarily experience gastrointestinal symptoms, typically a less severe allergy. PTSS has not previously been researched in parents of children with food allergy; however, medical factors have often been considered in the wider paediatric medical traumatic stress literature. While this research tends to find parent and family factors are stronger predictors of pediatric medical traumatic stress (Price et al., 2016), a recent meta-analysis found illness severity to still be a significant predictor of PTSS in parents of children with chronic illnesses (Pinquart, 2019). Allergy severity indicators were therefore retained in the present study, despite previous mixed findings, as the study explores parental psychological outcomes that have not previously been assessed in food allergy.

Secondly, intolerance of uncertainty was considered, as this may impact on parents' perception of food allergies as threatening. Parents of children with food allergy frequently manage uncertainty relating to their child's health, as illustrated in a qualitative study where parents described anxiety relating to the impossibility of completely controlling their child's

exposure to food allergens (Rouf et al., 2012). Within the adult anxiety literature, intolerance of uncertainty has been widely associated with worry (e.g. Dugas et al., 2001), and more recently with both panic (e.g. Shapiro et al., 2020) and PTSS (e.g. Oglesby et al., 2016). Uncertainty is also inherent in many chronic health conditions, with a meta-analysis finding parents who report their child's condition as more uncertain tend to report higher levels of anxiety (Szulczewski et al., 2017). Despite this, parents' tolerance of uncertainty has been less commonly explored within pediatric literature.

Finally, parents' food allergy related self-efficacy was assessed, as this may have an impact on perceived ability to cope, which in turn would be expected to reduce anxiety (Clark & Beck, 2010). It has also been suggested that self-efficacy could contribute to inconsistent results found between allergy severity and anxiety in past research, as parents of children with more severe allergies may receive more medical support or be more likely to develop family management plans (Cummings, Knibb, King, & Lucas, 2010). This may lead to greater confidence in allergy management, in turn reducing anxiety.

In summary, the aim of the study was to address significant gaps in the literature by investigating PTSS and the nature of anxiety experienced by parents of children with food allergy. The study also aimed to contribute to the current understanding of psychological outcomes in this population by exploring three factors that may be related to parents' experience of anxiety, worry and PTSS. It was hypothesised that greater intolerance of uncertainty and lower food allergy self-efficacy would be associated with significantly greater psychological distress (worry, anxiety, and PTSS); these variables were also expected to remain individually significantly predictive within multiple regression models. Given inconsistencies in past research, no hypotheses were made for the relationship between allergy severity indicators and psychological distress.

Method

Design and Inclusion Criteria

The study involved an online survey completed at a single time point. Inclusion criteria were having main caring responsibility for a child (age 0-16 years) with a medically diagnosed food allergy, being a resident of the United Kingdom, and having sufficient understanding of English language to be able to complete the questionnaires.

Procedure

Ethical approval for the study was granted by the NRES Committee East of England – Essex. A priori power calculations were conducted using G*Power to indicate the sample size needed for linear regression to detect a medium effect, with alpha of .05. This indicated a sample size between 77 (three predictors) and 103 (seven predictors) would be needed to achieve power of 0.80, dependent on the number of allergy severity indicators included in the models.

Potential participants were invited to take part in a study investigating parent wellbeing in pediatric food allergy, with recruitment occurring through both social media advertisements and a pediatric allergy clinic. All participants completed the study online between April and November 2018. Participants recruited through the allergy clinic were given information about the study and completed a consent to contact form, which gave permission to send potential participants two emails with a link to the online survey. Social media advertisements were shared through Twitter and Facebook groups relevant to food allergy in the UK.

At the start of the online survey participants were given study information, asked to provide consent for participation, and informed of sources of further information and support. Participants then completed the questionnaires outlined below. At the end of the study participants were reminded of sources of further support, and had the opportunity to enter a prize draw for one of ten £20 gift vouchers and to request a summary of the study's results.

Measures

Demographic and Allergy Questions

For the purpose of the study a questionnaire was developed to gather information about the participant and their child(ren) with food allergy. For parents, this included their age, gender, whether they had any allergies (food or otherwise), whether anyone else in their close family had a food allergy, and the number of children they had caring responsibility for. Regarding their child(ren), participants were asked their age, gender, allergens, how the allergy was diagnosed, when the diagnosis was made, and symptoms their child(ren) had experienced during an allergic reaction (16 common symptoms were listed with an additional 'other' option). Where participants had more than one child with food allergy, they were asked to complete the questions for each child. The questionnaire also included five questions pertaining to the severity of each child's food allergy: having an adrenaline auto-injector (AAI) prescribed, an AAI having been administered during an allergic reaction, history of anaphylactic reaction, having attended a hospital Emergency Department (ED) with an allergic reaction, and parent reported anaphylaxis symptoms (in line with action plans endorsed by the Royal College of Paediatrics and Child Health and the British Society for Allergy and Clinical Immunology; BSACI, 2013). Anaphylaxis symptoms comprised of seven of the 16 allergy symptoms included in the survey that are considered to be indicators of an anaphylactic reaction (e.g. breathing difficulties, swollen tongue), parents answered 'yes' or 'no' as to whether their child had experienced each symptom during an allergic reaction. The questionnaire was developed based on past research and consultation with allergy clinicians.

Penn State Worry Questionnaire (PSWQ; Meyer et al., 1990)

The PSWQ is a 16-item measure of worry, scored on a five-point Likert scale from one 'not at all typical of me' to five 'very typical of me'. Total scores range from 16-80 (a higher score indicating greater levels of worry). The PSWQ has been found to have good reliability and validity in general and clinical populations, both for measuring worry as a transdiagnostic construct and for identifying GAD (Meyer et al., 1990; Brown et al., 1992). As such, the PSWQ has two previously established cut-offs, a score of 45 has been shown to discriminate clinical from non-clinical samples, and a score of 64 to have discriminative validity for GAD compared to other anxiety and mood disorders (Behar et al., 2003; Chelminski & Zimmerman, 2003). Within the current study Chronbach's Alpha was 0.92, indicating good reliability.

Depression Anxiety Stress Scales 21 (DASS-21) - Anxiety subscale (Lovibond & Lovibond, 1995)

The DASS-21 anxiety subscale is a seven-item measure of anxiety experienced in the past week, predominantly focused on somatic symptoms. Responses are given on a four-point Likert scale, from zero 'did not apply to me at all' to three 'applied to me very much, or most of the time'. Responses are totaled and doubled, resulting in a score from 0-42 with a higher score indicating greater anxiety. Based on a general population sample, five categories of scores have been developed to indicate increasing severity (Lovibond & Lovibond, 1995). In a large general population sample (Henry & Crawford, 2005), the DASS-21 anxiety subscale has been found to have good reliability and convergent validity with the anxiety subscale of the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983). Within the current study Chronbach's Alpha was 0.89, indicating good reliability.

Impact of Events Scale – Revised (IES-R; Weiss & Marmar, 1997)

The IES-R is a 22-item measure of trauma symptoms experienced over the past seven days, with responses scored on a five-point Likert scale, from zero 'not at all' to four 'extremely'. Scores vary from 0-88 with a higher score indicating more trauma symptoms. A score of 33 or more has been suggested to have the best diagnostic accuracy for PTSD

(Creamer et al., 2003); however, a score of 24 or more has been suggested as indicative of clinically significant PTSS (Asukai et al., 2002). Participants were asked to complete the IES-R in reference to the most stressful experience they could recall related to their child's allergy, and were asked to briefly indicate what this event was and when it occurred. The IES-R has been found to have good reliability (Weiss & Marmar, 1997), and has been used in much research exploring PTSS in parents of children with health conditions, including asthma (Kean et al., 2006). Reliability in the present study population was good, Chronbach's alpha = 0.96.

Intolerance of Uncertainty Scale – Short Form (IUS-S; Carleton et al., 2007)

The IUS-S is a 12-item measure of an individual's attitudes towards uncertainty. The IUS-S is scored on a five-point Likert scale, from one 'not at all characteristic of me' to five 'entirely characteristic of me', with total scores ranging from 12-60, higher scores indicating less tolerance of uncertainty. The IUS-S has good reliability and validity in clinical and non-clinical samples (e.g. Khawaja & Yu, 2010). Within the current study Chronbach's alpha = 0.93, indicating good reliability.

Food Allergy Self-Efficacy Scale for Parents (FASE-P; Knibb et al., 2015)

The FASE-P is a 21-item scale designed to measure parents' confidence in managing their child's food allergy. Each item is rated from zero 'cannot do at all' to 100 'highly certain can do', an average confidence rating is then calculated, with a higher score indicating greater confidence in allergy management. A score under 70 indicates further support with allergy management is needed. An online survey of parents of children with food allergy found the scale to have good reliability and construct validity (Knibb et al., 2015). Within the current study Chronbach's alpha = 0.90, indicating good reliability.

Participants

Parents

Participants were 106 parents who reported having a child(ren) with medically diagnosed food allergy. However, one parent was excluded from the analyses as no psychological outcome measures were completed. The age of the remaining 105 participants (102 mothers, 3 fathers) ranged from 23-55 years (M = 38.96, SD = 6.53). Seventeen participants (16.2%) had more than one child with a medically diagnosed food allergy, of whom 16 had two children with food allergy and one had three children with food allergies. Ten participants (9.5%) also had a food allergy themselves.

Participants predominantly found out about the study through social media advertisements (88.6%), with 7.6% recruited through allergy clinic and 2.9% hearing about the study through other means (word of mouth and allergy charities). Eight out of 13 parents who gave consent to contact in allergy clinic took part.

Children

The 123 children with food allergies reported on by parents were 67 boys and 55 girls (1 gender not reported), aged from 6-months to 16 years 10 months (M = 6.13 years, SD = 4.23). The most commonly reported food allergens were peanuts (56.1%), milk (55.3%), and egg (51.2%), for all allergens see Supplementary Material 1 (S1). The total number of different foods participants' children were allergic to ranged from 1-15 (M = 4.07, SD = 3.05). All parents reported that their child's food allergies had been medically diagnosed, mainly by specialist allergy clinics (79.7%, N = 98), but also GPs (7.3%, N = 9), and other healthcare professionals including paramedics, dieticians, gastroenterologists, private consultants, general pediatricians, and dermatologists (13.0%, N = 16). The method of diagnosis reported included skin prick testing (74.0%), medical history (56.1%), blood tests (42.3%), and other (primarily food challenges or elimination diets; 11.4%). Adrenaline auto-injectors (AAIs) had been prescribed for 67.5% of children (N = 83). Sixty children (48.8%) had been taken to ED because of an allergic reaction, with 50.4% reported to have

experienced at least one anaphylactic reaction. Symptoms parents reported their children experiencing during an allergic reaction are displayed in S1.

Data Treatment

Where parents had more than one child with food allergy, the five dichotomous allergy severity indicators were included as 'yes' if at least one child met the criteria. An approximate median split was used to dichotomise anaphylaxis symptoms, resulting in a cutoff of having at least one child with at least three anaphylaxis symptoms.

One participant was excluded from the PTSS analyses, as they reported on a non-food allergy related event. For the PSWQ, IES-R and DASS-21, individual mean substitution was used up to a maximum of 30% of missing items (Roth et al., 1999). Less than 1% of data was replaced using this approach. There was no missing data for the IUS-S or FASE-P.

Data Analysis

Data analysis was conducted using IBM SPSS Statistics v25. Firstly, for the five dichotomous allergy severity indicators, differences in the three psychological outcomes were assessed using t-tests or non-parametric alternatives. To account for multiple testing, a Holm (1979) correction was applied to these analyses . Correlation coefficients were calculated to assess whether intolerance of uncertainty and food allergy self-efficacy were significantly associated with the three psychological outcomes. Finally, regression analyses were run for each of the three psychological outcomes including all significant predictor variables. For worry, assumptions of multiple linear regression were adequately met. For anxiety, the DASS-21 anxiety subscale was heavily positively skewed (in line with general population norms; Henry & Crawford, 2005). A square root transformation was therefore applied to the DASS-21 before running linear regression to resolve problems with heteroscedasticity and the distribution of standardized residuals (Manikandan, 2010). For PTSS, the IES-R showed a bimodal distribution with the dip in the distribution approximately coinciding with the

clinical cut-off score of 24. As such, a logistic regression using this cut-off was thought to better represent the data. Due to the small number of fathers who completed the study, it was not possible to examine fathers responses separately,, regression analyses were therefore rerun excluding male participants, and controlling for maternal age.

Results

Levels of Worry, Anxiety and PTSS in Our Sample

For worry (measured using the PSWQ), the mean score was 56.77 (SD = 12.69), 85 participants (81.0%) scored over the cut-off of 45 (found to distinguish clinical to nonclinical samples), and 37 participants (35.2%) scored above 64 (found to have good discriminatory validity for generalized anxiety disorder). On the DASS-21 Anxiety Subscale, the mean score was 9.42 (SD = 9.54), 46.7% showed 'normal' levels of anxiety, 14.3% 'mild', 14.3% 'moderate', 8.6% 'severe', and 16.2% 'extremely severe'. For PTSS (measured using the IES-R), the mean score was 22.28 (SD = 20.34), 44 parents (42.3%) scored above 24 (the recommended cut-off for clinically significant PTSS), with 33.7% (N = 35) scoring over 33, the suggested clinical cut-off for PTSD. The stressful events reported by parents for the IES-R included witnessing anaphylactic reactions in their child (51.0%), witnessing non-anaphylactic allergic reactions in their child (39.4%), and other events (9.6%) such as finding out their child was exposed to allergens. For parents who reported clinically significant PTSS, time since the traumatic event varied from less than one week to ten years, with a median of 11 months. The mean score for intolerance of uncertainty was 34.30 (SD = 10.66), and for food allergy self-efficacy was 72.11 (SD = 14.10).

Are Allergy Severity Indicators Associated with Parental Worry, Anxiety, and PTSS?

Differences in worry, anxiety, and trauma symptoms between food allergy severity groups are shown in Table 1. Parents who reported at least one of their children had experienced at least three anaphylaxis symptoms reported significantly greater worry, anxiety, and PTSS than parents that reported their children to have experienced less than three anaphylaxis symptoms. Parents who reported their child(ren) to have had an AAI administered at least once during an allergic reaction reported significantly greater worry and PTSS than parents of children who had not had an AAI administered. Finally, parents whose child(ren) had attended ED at least once for an allergic reaction reported significantly higher PTSS than those who had not attended ED. However, following a Holm (1979) correction to account for multiple testing, the only difference that remained statistically significant was the difference in PTSS for whether or not parents' children had an AAI administered. Therefore only this indicator of allergy severity was included in logistic regression predicting PTSS. [Table 1]

Are Greater Intolerance of Uncertainty and Lower Food Allergy Self-Efficacy Associated with Greater Parental Worry, Anxiety, and PTSS?

As predicted, greater intolerance of uncertainty and lower food allergy self-efficacy were significantly correlated with worry, anxiety and PTSS (Table 2).

[Table 2]

Regression Models of Parental Psychological Distress Worry

Multiple linear regression was used to predict parental worry (PSWQ score), with the variables food allergy self-efficacy (FASE-P) and intolerance of uncertainty (IUS-S). The model was significantly predicative of parental worry, F(2,102) = 40.93, p < .001, explaining 44.5% of variance in worry scores. Within this model, intolerance of uncertainty was individually significantly predictive ($\beta = .70$, p < .001), but food allergy self-efficacy was not ($\beta = .08$, p = .347). This pattern of results was maintained when excluding fathers from the analysis and controlling for maternal age.

Anxiety

Multiple linear regression was used to predict anxiety (DASS-21 anxiety subscale with a square root transformation applied), with the predictor variables food allergy selfefficacy and intolerance of uncertainty. The model was significantly predictive of anxiety, F(2,102) = 13.98, p < .001, explaining 21.5% of variance in anxiety scores. Within this model, intolerance of uncertainty was individually significantly predictive ($\beta = .44$, p < .001), but food allergy self-efficacy was not ($\beta = -0.05$, p = .610). This pattern of results was maintained when excluding fathers from the analysis and controlling for maternal age. **PTSS**

Binary logistic regression to predict whether parents experienced clinically significant PTSS symptoms (i.e. IES-R above 24), found a model including only an AAI having been administered led to a significant improvement in the classification of clinical cases, $\chi^2(1) =$ 12.53, *p* < .001. However, when intolerance of uncertainty and food allergy self-efficacy were added to the regression model, there was a significant improvement in the number of participants correctly classified, $\chi^2(3) = 31.24$, *p* < .001, and a Hosmer and Lemeshow test indicated the model was a good fit of the data, $\chi^2(8) = 8.29$, *p* = .406, Nagelkerke *R*² = 0.35. Within this model an AAI having been administered and intolerance of uncertainty were individually significantly predictive of PTSS, but food allergy self-efficacy was not (Table 3). The model correctly classified 76.9% of participants. This pattern of results was maintained when removing fathers from the analysis, and controlling for maternal age. [Table 3]

Discussion

In the present sample, a large proportion of parents of children with food allergy reported clinically significant worry, anxiety, and/or PTSS. As predicted, within regression analyses, greater intolerance of uncertainty was a consistent significant predictor of worry, anxiety, and PTSS. In contrast, whilst food allergy self-efficacy was significantly negatively correlated with all three mental health outcome measures, it did not remain significant in any of the planned regression analyses. Finally, mixed results were found for the relationship between allergy severity and parent mental health.

These findings supplement previous qualitative studies that have indicated worry (e.g. Akeson et al., 2007; Sanagavarapu et al., 2016) and trauma symptoms (e.g. Akeson et al., 2007; Rouf et al., 2012) in parents of children with food allergy. Whilst it is not possible to draw conclusion on prevalence, given the possible biases in our sample, it is interesting to note that clinically significant levels of PTSS were also observed in 42.3% of participants. This is similar to the rate of PTSS observed in a pilot study of children with food allergy (36%; Weiss & Marsac, 2016). In the present study, PTSS was observed in parents of children with both life-threatening and milder allergies. Furthermore, the disparity between the rates of clinically significant anxiety (39.0%) and worry (81.0%) found in the study highlight the benefit of considering different types of anxiety rather than exploring anxiety as a unitary construct. This suggests that parents may be more likely to experience persisting anxious cognitions than acute somatic symptoms. Clinically, this may indicate that drawing on generalized anxiety disorder literature may be helpful when planning psychological interventions.

The strong relationship found between intolerance of uncertainty and mental health outcomes (r = 0.45 - 0.66) is congruent with the high rates of worry in the sample, a presentation where intolerance of uncertainty has been suggested to play a central role (Dugas et al., 2001). This finding is also in keeping with qualitative parent reports (e.g. Rouf et al., 2012) and the nature of food allergy, due to the impossibility of guaranteeing non-exposure to allergens. However, contrary to anxiety models (Clark & Beck, 2010), and suggestions in past research (e.g. Quach & John, 2018), food allergy self-efficacy was not a significant predictor in any of the regression analyses. This may be partially explained by

shared variance with intolerance of uncertainty, due to the moderate negative correlation between these variables (i.e. parents who were more intolerant of uncertainty reported significantly lower confidence in allergy management). It may be that intolerance of uncertainty is a barrier to increasing parents' confidence, or that parents' perception of threat may be too great to be counteracted by their confidence in allergy management. This is an important clinical finding, as whilst confidence is important for medical management, the present study indicates psychological interventions may be more effective if they focus on factors that impact on parents' threat perception (e.g. intolerance of uncertainty).

Mixed results for allergy severity are also in keeping with previous literature (e.g. Cummings, Knibb, Erlewyn-Lajeunesse et al., 2010; Marklund et al., 2006). These inconsistencies may be compounded due to the absence of a single reliable method to quantify allergy severity. Given the early stage of research in the field, the present study managed this by including multiple indicators of severity, but this introduces difficulties associated with multiple testing. It may be beneficial for future research to formulate hypotheses based on specific allergy related symptoms and events, rather than assessing severity more broadly. For example, this study raised a novel finding regarding parents who reported their child to have had an AAI administered, who were around seven times more likely to report clinically significant PTSS (OR = 7.41). Whilst an AAI having been administered has been discussed in some previous research (e.g. Ogg et al., 2017; Williams et al., 2009), it has been considered less frequently than an AAI having been prescribed, particularly in relation to anxiety. In the wider pediatric psychology literature, parents of children with Type I diabetes have reported giving injections to be the second most distressing diabetes related event, with the most distressing being having their child rushed to hospital (Horsch et al., 2007). Given AAI administration involves giving an injection during a potentially life-threating reaction, likely to lead to an ED admission, it is in keeping with

this research that parents may find this particularly distressing. It may therefore be helpful for future research to further assess the relationship between AAI administration and parental psychological outcomes, as if this finding is supported it may be beneficial to introduce targeted brief psychological assessments for parents whose children have had an AAI administered. However, at this stage caution is needed due to the limitations of the current study.

One of the main limitations of the study is the use of a self-selected sample, with primarily online recruitment; while this is a practical method to conduct preliminary research, it does introduce a risk of bias to the sample which impacts on the generalizability of the results. It could be helpful in the future for a large clinic base study to be conducted, which would be better placed to monitor the representativeness of the sample, and could also allow the prevalene of psychological distress in this population to be assessed. Additionally, the use of a cross-sectional design meant it was not possible to establish causality between food allergy and psychological outcomes. Whilst PTSS was measured in relation to the most stressful food allergy event parents could recall, inferring a degree of causality, as the IES-R only considers symptoms over the past week it does not account for the potential of resolved PTSS. It would be beneficial for future research to take a longitudinal approach, better suited to considering the temporal relationship between food allergy events and psychological distress. A further limitation is that parents self reported their child's food allergy to be medically diagnosed- However, detailed information about food allergy diagnostic and symptom history was recorded in order to try to mitigate this. Furthermore, there was an imbalance in the gender split of participants. While inclusion criteria were any adult with the main caring responsibility for a child with food allergy, only three fathers participated. In the future, a paired design may be helpful allowing both parents to report.

Finally, while the regression models in this study were significant, a large proportion of variance in psychological outcomes remained unexplained. Whilst this is to be expected, given the positive findings for intolerance of uncertainty, it may be beneficial for future research to examine additional parental factors that may influence threat perception (e.g. perceived life threat associated with allergy, Price et al., 2016; or attitudes towards risk). A better understanding of these factors could help lead to the development of a psychological model for the impact of food allergy, which in turn could guide treatment.

Despite its limitations, this study addresses a significant gap in the literature through assessing PTSS in parents of children with food allergies, a need highlighted in a 2003 review (Kelsay, 2003) that had remained unaddressed. It is important for clinicians to be aware that allergic reactions are potentially traumatic events for parents. As suggested in other pediatric health conditions (e.g. Price et al., 2016), it is important to normalize emotional responses to allergic reactions, while also assessing for signs that a parent may be experiencing or at risk of PTSS to allow appropriate intervention to be offered.

The study also provides useful information for the development of models and psychological treatments for parents of children with food allergy, through highlighting a strong relationship between intolerance of uncertainty and psychological distress. This is a positive finding as there are pre-existing therapies that target intolerance of uncertainty (e.g. Dugas & Ladouceur, 2000), and it may be helpful for future research to investigate the effectiveness of these interventions in this population.

Overall, the study highlights the importance of greater awareness of parents' mental health in pediatric food allergy, and offers direction for future research in this comparatively new field.

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References

- Akeson, N., Worth, A., & Sheikh, A. (2007). The psychosocial impact of anaphylaxis on young people and their parents. *Clinical and Experimental Allergy*, *37*(8), 1213–1220. https://doi.org/10.1111/j.1365-2222.2007.02758.x
- Asukai, N., Kato, H., Kawamura, N., Kim, Y., Yamamoto, K., Kishimoto, J., Miyake, Y., & Nishizono-Maher, A. (2002). Reliability and validity of the Japanese-language version of the impact of event scale-revised (IES-R-J): Four studies of different traumatic events. *The Journal of Nervous and Mental Disease*, *190*(3), 175–82. https://doi.org/10.1097/00005053-200203000-00006
- Behar, E., Alcaine, O., Zuellig, A. R., & Borkovec, T. D. (2003). Screening for generalized anxiety disorder using the Penn State Worry Questionnaire: a receiver operating characteristic analysis. *Journal of Behavior Therapy and Experimental Psychiatry*, 34(1), 25–43. https://doi.org/10.1016/s0005-7916(03)00004-1
- Boyce, J.A., Assa'ad, A., Burks, A. W., Jones, S. M., Sampson, H. A., Wood, R. A., Plaut, M., Cooper, S. F., & Fenton, M. J. (2010). Guidelines for the diagnosis and management of food allergy in the United States. *Journal of Allergy & Clinical immunology*, *126*, S1-58. https://doi.org/10.1016/j.jaci.2010.10.007
- British Society for Allergy and Clinical Immunology (2013, October). *Allergy Action Plan*. https://www.bsaci.org/about/download-paediatric-allergy-action-plans
- Brown, T. A., Antony, M. M., & Barlow, D. H. (1992). Psychometric properties of the Penn State Worry Questionnaire in a clinical anxiety disorders sample. *Behaviour Research* and Therapy, 30(1), 33–7.
- Carleton, R.N., Norton, M.A., & Asmundson, G.J.G. (2007). Fearing the unknown: A short version of the intolerance of uncertainty scale. *Journal of Anxiety Disorders*, 21, 105-117. https://doi.org/10.1016/j.janxdis.2006.03.014

- Chelminski, I., & Zimmerman, M. (2003). Pathological worry in depressed and anxious patients. *Journal of Anxiety Disorders*, *17*(5), 533–46.
- Clark, D. A., & Beck, A. T. (2010). *Cognitive therapy of anxiety disorders: Science and practice*. New York: Guilford Press.
- Creamer, M., Bell, R., & Failla, S. (2003). Psychometric properties of the Impact of Event Scale—Revised. *Behaviour Research and Therapy*, 41(12), 1489–1496. https://doi.org/10.1016/j.brat.2003.07.010
- Cummings, A.J., Knibb, R.C., Erlewyn-Lajeunesse, M., King, R.M., Roberts, G., & Lucas, J.S.A. (2010). Management of nut allergy influences quality of life and anxiety in children and their mothers. *Pediatric Allergy & Immunology, 21,* 586-594. https://doi.org/10.1111/j.1399-3038.2009.00975.x
- Cummings, A. J., Knibb, R. C., King, R. M., & Lucas, J. S. (2010). The psychosocial impact of food allergy and food hypersensitivity in children, adolescents and their families: A review. *Allergy*, 65(8), 933–945. https://doi.org/10.1111/j.1398-9995.2010.02342.x
- Dugas, M. J., Gosselin, P., & Ladouceur, R. (2001). Intolerance of uncertainty and worry: Investigating specificity in a nonclinical sample. *Cognitive Therapy and Research*, 25(5), 551–558. https://doi.org/10.1023/A:1005553414688
- Dugas, M. J., & Ladouceur, R. (2000). Treatment of GAD: Targeting intolerance of uncertainty in two types of worry. *Behavior Modification*, 24(5), 635–657. https://doi.org/10.1177/0145445500245002
- Henry, J. D., & Crawford, J. R. (2005). The short-form version of the Depression anxiety stress scales (DASS-21): Construct validity and normative data in a large non-clinical sample. *British Journal of Clinical Psychology*, 44(2), 227–239. https://doi.org/10.1348/014466505X29657

Holm, S. (1979). A simple sequentially rejective multiple test procedure. Scandinavian Journal

of Statistics, 6, 65-70.

- Horsch, A., Mcmanus, F., & Edge, J. (2007). Anxiety, depressive, and posttraumatic stress symptoms in mothers of children with Type 1 diabetes. *Journal of Traumatic Stress*, 20(5), 881–891. https://doi.org/10.1002/jts.20247
- Kean, E. M., Kelsay, K., Wamboldt, F., & Wamboldt, M. Z. (2006). Posttraumatic stress in adolescents with asthma and their parents. *Journal of the American Academy of Child* and Adolescent Psychiatry, 45(1), 78–86. https://doi.org/10.1097/01.chi.0000186400.67346.02
- Kelsay, K. (2003). Psychological aspects of food allergy. *Current Allergy and Asthma Reports*, 3(1), 41–46. https://doi.org/10.1007/s11882-003-0011-z
- Khawaja, N. G., & Yu, L., N. H. (2010). A comparison of the 27-item and 12-item intolerance of uncertainty scales. *Clinical Psychologist*, 14, 97-106. https://doi.org/10.1080/13284207.2010.502542
- Knibb, R. C. (2015). Effectiveness of Cognitive Behaviour Therapy for Mothers of Children with Food Allergy: A Case Series. *Healthcare*, 3(4), 1194–1211. https://doi.org/10.3390/healthcare3041194
- Knibb, R.C., Barnes, C., & Stalker, C. (2015). Parental confidence in managing food allergy: development and validation of the food allergy self-efficacy scale for parents (FASE-P). *Clinical & Experimental Allergy*, 45, 1681-1689. https://doi.org/10.1111/cea.12599
- Lau, G. Y., Patel, N., Umasunthar, T., Gore, C., Warner, J. O., Hanna, H., Phillips, K., Zaki, A.M., Hodes, M., & Boyle, R. J. (2014). Anxiety and stress in mothers of food-allergic children. *Pediatric Allergy and Immunology*, 25(3). https://doi.org/10.1111/pai.12233
- Lovibond, S.H., & Lovibond, P.H. (1995). *Manual for the Depression Anxiety Stress Scales* (2nd ed.). Sydney: Psychology Foundation.

Luyt, D., Ball, H., Kirk, K., & Stiefel, G. (2016). Diagnosis and management of food allergy in

children. *Paediatrics and Child Health*, 26, 287-291. https://doi.org/10.1016/j.jaci.2010.10.007

- Manikandan, S. (2010). Data transformation. *Journal of Pharmacology* & *Pharmacotherapeutics*, *1*(2), 126-127. https://doi.org/10.4103/0976-500X.72373
- Marklund, B., Ahlstedt, S., & Nordström, G. (2006). Health-related quality of life in food hypersensitive schoolchildren and their families: parents' perceptions. *Health and Quality of Life Outcomes*, 4(1), 48. https://doi.org/10.1186/1477-7525-4-48
- Meyer, T. J., Miller, M. L., Metzger, R. L., & Borkovec, T. D. (1990). Development and validation of the Penn State Worry Questionnaire. *Behaviour Research and Therapy*, 28(6), 487–95. https://doi.org/10.1016/0005-7967(90)90135-6
- Ogg, J., Wong, J., Wan, M. W., Davis, N., & Arkwright, P. D. (2017). Factors that determine parents' perception of their child's risk of life-threatening food-induced anaphylaxis. *Allergy and Asthma Proceedings*, 38(1), 44–53.

https://doi.org/10.2500/aap.2017.38.4002

- Oglesby, M. E., Boffa, J. W., Short, N. A., Raines, A. M., & Schmidt, N. B. (2016). Intolerance of uncertainty as a predictor of post-traumatic stress symptoms following a traumatic event. *Journal of Anxiety Disorders, 41,* 82-87. https://doi.org/10.1016/j.janxdis.2016.01.005
- Pinquart, M. (2019). Posttraumatic stress symptoms and disorder in parents of children and adolescents with chronic physical illnesses: A meta-analysis. *Journal of Traumatic Stress*, 32(1), 88-96). https://doi.org/10.1002/jts.22354
- Price, J., Kassam-adams, N., Alderfer, M. A., Christofferson, J., & Kazak, A. E. (2016).
 Systematic review: A reevaluation and update of the integrative (trajectory) model of pediatric medical traumatic stress. *Journal of Pediatric Psychology*, *41*, 86–97. https://doi.org/10.1093/jpepsy/jsv074

- Quach, L. L., & John, R. M. (2018). Psychosocial impact of growing up with food allergies. *Journal for Nurse Practitioners*, 14(6), 477–483. https://doi.org/10.1016/j.nurpra.2018.03.017
- Roth, P.L., Switzer, F.S., & Switzer, D.M. (1999). Missing data in multiple item scales: AMonte Carlo analysis of missing data. *Organizational Research Methods*, 2, 211-232.
- Rouf, K., White, L., & Evans, K. (2012). A qualitative investigation into the maternal experience of having a young child with severe food allergy. *Clinical Child Psychology* and Psychiatry, 17(1), 49–64. https://doi.org/10.1177/1359104511415636
- Sanagavarapu, P., Wainstein, B., Children, S., & Katelaris, C. (2016). Transition to school anxiety for mothers of children with food allergy: Implications for educators. *Australasian Journal of Early Childhood, 41*(4), 115-122.
- Shapiro, M. O., Short, N. A., Morabito, D., Schmidt, N. B. (2020). Prospective associations between intolerance of uncertainty and psychopathology. *Personality and Individual Differences*, *166*(1), 110210. https://doi.org/10.1016/j.paid.2020.110210
- Szulczewski, L., Mullins, L. L., Bidwell, S. L., Eddington, A. R., & Pai, A. L. H. (2017). Metaanalysis: Caregiver and youth uncertainty in pediatric chronic illness. *Journal of Pediatric Psychology*, 42(4), 395-421. https://doi.org/10.1093/jpepsy/jsw097
- Weiss, D.S., & Marmar, C.R. (1997). The Impact of Event Scale-Revised. In J.P. Wilson & T.M. Keane (Eds.), *Assessing Psychological Trauma and PTSD* (pp.399-411). New York: Guilford.
- Weiss, D., & Marsac, M. L. (2016). Coping and posttraumatic stress symptoms in children with food allergies. *Annals of Allergy, Asthma & Immunology, 17*(5), 561-562. https://doi.org/10.1016/j.anai.2016.08.022
- Williams, N. A., Parra, G. R., & Elkin, T. D. (2009). Subjective distress and emotional resources in parents of children with food allergy. *Children's Health Care*, 38(3), 213–

227. https://doi.org/10.1080/02739610903038792

World Health Organization. (2019). *International statistical classification of diseases and related health problems* (11th ed.). <u>https://icd.who.int/</u>

Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica*, 67(6), 361–70. https://doi.org/10.1111/j.1600-0447.1983.tb09716.x.

Table 1

Differences in Worry, Anxiety, and Post-Traumatic Stress Symptoms in Parents Whose Children do and do not Have Indicators of More

Severe Food Allergies

| | | | | PS | SWQ | | | | | DAS | SS-21 | Anxiet | у | | | Π | ES-R | | |
|-------------------------------|-------------|---------|---------|---------|---------|------------------|-----------|----------|---------|--------|---------|-----------|-----------|---------|--------|---------|-----------|------------------|------|
| Severity indicator: | : | Y | ES | N | 0 | | | YI | ES | N | 10 | | | Y | ES | N | 0 | | |
| | n/N | Μ | SD | М | SD | p^{a} | d | М | SD | Μ | SD | p^{b} | d | М | SD | М | SD | p^{b} | d |
| AAI Prescribed | 78/104 | 57.9 | 11.3 | 53.4 | 16.0 | 0.191 | 0.36 | 9.4 | 9.6 | 9.9 | 9.5 | 0.751 | -0.05 | 23.5 | 21.1 | 19.2 | 18.2 | 0.545 | 0.21 |
| AAI Given | 21/105 | 61.8 | 11.9 | 55.5 | 12.6 | .042* | 0.50 | 11.7 | 10.0 | 8.9 | 9.4 | 0.134 | 0.29 | 36.3 | 19.2 | 18.7 | 19.2 | <.001* | 0.92 |
| Anaphylaxis | | | | | | | | | | | | | | | | | | | |
| History | 60/105 | 57.5 | 11.7 | 55.7 | 13.8 | 0.467 | 0.14 | 10.5 | 10.3 | 8.1 | 8.2 | 0.315 | 0.25 | 24.0 | 20.9 | 20.1 | 19.6 | 0.476 | 0.19 |
| A&E Attended | 57/104 | 57.0 | 12.5 | 56.7 | 13.0 | 0.923 | 0.02 | 10.8 | 10.1 | 8.1 | 8.7 | 0.189 | 0.29 | 27.3 | 21.7 | 16.8 | 17.1 | .022* | 0.54 |
| Anaphylaxis | | | | | | | | | | | | | | | | | | | |
| Symptoms | 45/105 | 59.8 | 11.4 | 54.5 | 13.1 | .031* | 0.43 | 12.3 | 10.9 | 7.4 | 7.8 | .020* | 0.53 | 29.4 | 23.4 | 17.1 | 16.1 | .016* | 0.63 |
| $\overline{Note. PSWQ} = Pen$ | n State W | orry Q | uestio | nnaire | ; DAS | S-21 = 2 | Depress | sion Ar | xiety | Stres | s Sca | les 21; I | ES-R = 1 | Impact | of Eve | ents So | cale Re | vised; | |
| AAI prescribed = A | At least on | e child | with | an adre | enaline | e auto-ir | ijector j | prescrit | bed for | food | l allei | rgy; AA | [Given | = AAI | admin | istered | l at leas | st once | |
| during an allergic r | eaction; A | naphy | laxis I | History | = At | least on | e previo | ous par | ent-rep | oortee | d ana | phylactic | c reactio | n to fo | od; Að | kE atte | ended = | Acciden | t |

PARENTAL ANXIETY & PTSS IN PEDIATRIC FOOD ALLERGY

and Emergency attended at least once due to food allergy; Anaphylaxis Symptoms = Parent reports having at least one child who has experienced at least three symptoms indicative of anaphylaxis during allergic reactions.

^aindependent samples t-test ^bMann-Whitney U test

*p<.05 **p<.01

Table 2

Correlations Between Intolerance of Uncertainty, Food Allergy Self-Efficacy, Worry,

| | 1 | 2 | 3 | 4 | 5 |
|-------------------------------|-------------------|------------------|-------|-------|---|
| 1. Intolerance of Uncertainty | - | | | | |
| (IUS-S) | | | | | |
| 2. Food Allergy Self-Efficacy | 42** ^a | - | | | |
| (FASE-P) | | | | | |
| 3. Worry (PSWQ) | .66**a | 22* ^a | - | | |
| 4. Anxiety (DASS-21) | .45** | 24* | .51** | - | |
| 5. PTSS (IES-R) | .47** | 33** | .37** | .58** | - |

Anxiety, and Post-Traumatic Stress Symptoms

Note. IUS-S = Intolerance of Uncertainty Scale – Short Form; FASE-P = Food Allergy Self-Efficacy Scale for Parents; PSWQ = Penn State Worry Questionnaire; DASS-21 = Depression Anxiety Stress Scales 21; IES-R = Impact of Events Scale Revised. ^{*a*}Pearson's correlation coefficient, all other correlations using non-parametric Spearman's

rank correlation coefficient

*p < .05 **p < .01

Table 3

Logistic Regression Model of PTSS in Parents of Children with Food Allergies

| | 0 | CT 0 | | |
|-----------|------|------|--------|-----------------------|
| Predictor | β | SE B | p | OR (e^{p}) [95% |
| | | | | confidence intervals] |
| Step 1 | | | | |
| AAI given | 1.84 | .56 | .001** | 6.29 [2.09, 18.93] |
| Step 2 | | | | |
| AAI given | 2.00 | .61 | .001** | 7.41 [2.23, 24.70] |
| IUS-S | 0.07 | .03 | .006** | 1.07 [1.02, 1.13] |
| FASE-P | 03 | .02 | .089 | 0.97 [0.94, 1.00] |

Note. AAI Given = Adrenaline auto-injector administered at least once during an allergic reaction; IUS-S = Intolerance of Uncertainty Scale – Short Form; FASE-P = Food Allergy Self-Efficacy Scale for Parents.

*p<.05 **p<.01

Supplementary Material 1

Table S1

| Allergen | Ν |
|--|---|
| Peanut | 69 (56.1%) |
| Milk | 68 (55.3%) |
| Egg | 63 (51.2%) |
| Tree Nut | 53 (43.1%) |
| Soy | 28 (22.8%) |
| Sesame | 24 (19.5%) |
| Wheat | 21 (17.1%) |
| Shellfish | 8 (6.5%) |
| Fish | 6 (4.9%) |
| Other | 42 (34.2%) |
| | |
| Symptom | N |
| Symptom Runny or congested nose | N 77 (62.6%) |
| Symptom Runny or congested nose Bloated stomach | N 77 (62.6%) 48 (39.0%) |
| SymptomRunny or congested noseBloated stomachAbdominal pain | N 77 (62.6%) 48 (39.0%) 83 (67.5%) |
| SymptomRunny or congested noseBloated stomachAbdominal painDiarrhoea | <i>N</i> 77 (62.6%) 48 (39.0%) 83 (67.5%) 62 (50.4%) |
| SymptomRunny or congested noseBloated stomachAbdominal painDiarrhoeaVomitting | <i>N</i> 77 (62.6%) 48 (39.0%) 83 (67.5%) 62 (50.4%) 82 (66.7%) |
| SymptomRunny or congested noseBloated stomachAbdominal painDiarrhoeaVomittingHives or itchy skin rash | N 77 (62.6%) 48 (39.0%) 83 (67.5%) 62 (50.4%) 82 (66.7%) 107 (87.0%) |
| SymptomRunny or congested noseBloated stomachAbdominal painDiarrhoeaVomittingHives or itchy skin rashItchy/tingling mouth | N 77 (62.6%) 48 (39.0%) 83 (67.5%) 62 (50.4%) 82 (66.7%) 107 (87.0%) 78 (63.4%) |
| SymptomRunny or congested noseBloated stomachAbdominal painDiarrhoeaVomittingHives or itchy skin rashItchy/tingling mouthPersistent cough ^a | N 77 (62.6%) 48 (39.0%) 83 (67.5%) 62 (50.4%) 82 (66.7%) 107 (87.0%) 78 (63.4%) 52 (42.3%) |
| SymptomRunny or congested noseBloated stomachAbdominal painDiarrhoeaVomittingHives or itchy skin rashItchy/tingling mouthPersistent coughaSwollen lips, face, or | N 77 (62.6%) 48 (39.0%) 83 (67.5%) 62 (50.4%) 82 (66.7%) 107 (87.0%) 78 (63.4%) 52 (42.3%) 84 (68.3%) |

Child Food Allergy(s) and Symptoms Reported by Parents

| Swollen tongue ^a | 31 (25.2%) |
|-------------------------------------|------------|
| Difficulty swallowing ^a | 37(30.1%) |
| Breathing difficulties ^a | 51 (41.5%) |
| Dizziness ^a | 31 (25.2%) |
| Sudden tiredness ^a | 54 (43.9%) |
| Collapse ^a | 20 (16.3%) |
| Sudden change in | 56 (45.5%) |
| behaviour | |
| | |

^aincluded as anaphylaxis symptom