

**A feasibility, Randomised Controlled Trial evaluating a brief, online, group
Cognitive Behavioural Therapy intervention to improve psychological
outcomes for parents of children with food allergy**

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Abstract

Background: Food allergy has been documented to have a profound impact on parents of children with food allergy, with caregivers reporting a significant impact on quality of life (QoL) and psychological distress. Parents have reported increased stress, anxiety, worry and low mood in relation to their child's food allergy, and therefore interventions aimed at mitigating this impact are of prime importance. There has been emerging evidence to suggest that interventions involving Cognitive Behavioural Therapy (CBT) have the potential to improve these outcomes.

Method: This study used a feasibility, Randomised Controlled Trial design to compare a brief, online, group CBT intervention with a control group who did not take part in the intervention. Measures of food-allergy related QoL, worry, depression, anxiety, stress, and food-allergy self-efficacy were completed at baseline and one and three-month follow ups by 33 parents of children with food allergy. Participants in the intervention group also completed a feedback survey in order to comment on the acceptability of the intervention.

Results: This study showed that the RCT was, as a whole, feasible. A preliminary signal of efficacy was found for reducing worry, stress, anxiety, and the burden of food allergy on QoL. Food-allergy self-efficacy scores also improved. For parents who completed the intervention, the study was deemed acceptable. However, a higher drop-out rate in the intervention group in comparison to the control group indicated limitations to the feasibility of this study.

Conclusion: Promising initial findings indicate that a larger scale, adequately powered RCT is warranted. Changes to the protocol in order to improve participant engagement in the intervention group may be warranted in future studies.

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Part One – First Empirical Paper

A feasibility, Randomised Controlled Trial evaluating a brief, online, group Cognitive Behavioural Therapy intervention to improve psychological outcomes for parents of children with food allergy

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Introduction

Food allergy is the adverse reaction of the body's immune system to the ingestion of food protein. When a food allergen is ingested, the immune system detects the food protein as a threat and releases a number of chemicals which cause the symptoms of an allergic reaction. These symptoms can include watery eyes, a running nose, itching, rashes, swelling, gastrointestinal problems, and may vary in their severity. Reactions can progress to anaphylaxis, which is a serious allergic reaction that is rapid in onset; symptoms can include a range of respiratory, gastrointestinal, and cardiovascular symptoms (see Boyce et al., 2011 for a comprehensive list) which may result in death if not treated promptly and effectively with adrenaline (Sicherer & Sampson, 2010).

In the UK, food allergy is a prevalent problem, with an estimated 2 million people living with a diagnosed food allergy (The Natasha Allergy Research Foundation, n.d.). Prevalence rates are higher in children than in adults, with an estimated 5-8% of children affected compared to 1-2% of adults, with this prevalence thought to be increasing (Food Standards Agency, 2013; Sicherer & Sampson, 2018; Turner et al., 2015). Currently, treatment involves avoidance of food allergens and the administration of treatment for accidentally ingested foods. The current management of food allergy involves the burden of constant vigilance, planning and preparation, with this responsibility often falling on parents of young children (Knibb et al., 2019). Furthermore, those with food allergy and their caregivers have to manage the unpredictable nature of food allergy and live continually with the risk and fear of accidental food ingestion which can negatively impact the quality of life (QoL) of those diagnosed with food allergy and their immediate family (Cummings et al., 2010a).

Research in this field has started to examine the psychological impact food allergy can have not only on the allergic child but also their parents. Previous studies have suggested

that parents of children with food allergy experience higher stress and anxiety levels compared to the general population (Cortes et al., 2013; King et al., 2009) and parents of children without food allergy (Birdi et al., 2016; Lau et al., 2014). Reasons as to why food allergy can cause such distress in parents include: the constant vigilance needed to check safety of foods, anxiety caused by severe and potentially fatal consequences of accidental ingestion of the food allergen, anxiety caused by handing over control of allergy management to the child (for example reading their own food labels), risk from the environment, worry about the future of their child, and dietary restrictions leading to social restrictions and potentially isolation (Akeson et al., 2007; Gillespie et al., 2007; King et al., 2009; Valentine & Knibb., 2011; Knibb, 2015). Given the impact looking after a child with food allergy can have on psychological wellbeing and QoL in parents, the need for interventions to improve psychological outcomes is of high importance.

To date, there has been a paucity of research on interventions to improve psychological outcomes for parents of children with food allergy (see Sugunasingha et al., 2020 for a systematic review). However, there is emerging evidence to suggest that Cognitive Behavioural Therapy (CBT) may be a promising intervention for parents experiencing poor psychological outcomes and QoL. CBT is based on the rationale that our emotions, thoughts, behaviour, and physiological sensations interact with one another; what we think and do affects the way we feel and vice versa. Treatment involves identifying patterns of interactions that contribute to distress and learning ways to change these patterns to improve psychological wellbeing. CBT has a strong evidence base for a range of mental health issues including anxiety and depression (e.g., Bandelow et al., 2015; López-López et al., 2019; van Dis, 2019). Furthermore, there is supportive evidence that CBT interventions may be an effective intervention for improving psychological outcomes for long-term health conditions (Li et al., 2017; Pateraki & Morris., 2017; Panchal et al., 2020) and therefore may be

appropriate for parents experiencing poor mental wellbeing in relation to a child's food allergy.

Knibb (2015) designed the first study which reported on the effectiveness of CBT for mothers of children with food allergy. In this case series report, five mothers received 12 weeks of individual face-to-face CBT, with six mothers acting as controls. All participants completed measures of anxiety, depression, worry, stress, general mental health, generic and food allergy specific QoL at baseline and at 12 weeks. Results showed that anxiety, depression and worry in the CBT group significantly reduced and overall mental health and QoL significantly improved from baseline to 12 weeks for mothers in the CBT group. A larger randomised control trial conducted by Boyle et al. (2017) supported these promising initial findings. Two hundred mothers of children with food allergy were randomised to receive either a single-session individual CBT intervention or standard care, with anxiety and risk perception assessed at 6 weeks and 1 year. Results found significantly reduced risk perception in the intervention group in comparison to the control group, and reduced state anxiety at six weeks in the subgroup of mothers with moderate to high anxiety at enrolment. The study also found evidence of a reduction in physiological stress response in the intervention group, as measured by a salivary cortisol response to a simulated anaphylaxis scenario at one year. More recently, a feasibility study of a two-session online intervention for parents of children with food allergy aimed at empowering parents to raise confident children, showed a signal of efficacy for the reduction of anxiety and an increase in parental food allergy self-efficacy (Vreeken-Ross et al., 2021). The results of these studies indicate that a CBT intervention may be an appropriate intervention for parents of children with food allergy and further research is warranted.

Brief, group CBT interventions have the potential to offer a non-time consuming and cost-effective treatment option for parents of children with food allergy, an important factor

for high in demand allergy services (Knibb et al., 2019). Although a brief intervention may seem optimistic in being able to bring about change, previous research in the field of child anxiety has shown promising evidence for the use of brief interventions. Cartwright-Hatton et al., (2018) have shown that children whose parents attended a one-day group intervention were 16.5% less likely to have an anxiety disorder than children whose parents received treatment as usual, highlighting that an inexpensive, brief psycho-educational intervention may be useful in bringing about change. Furthermore, a systematic review of single session therapy for the treatment of anxiety disorders concluded that single session therapy was superior to no treatment in reducing anxiety symptoms both for adults and children (Bertuzzi et al., 2021).

There is already evidence that non-CBT-specific group interventions for parents with food allergic children can both be acceptable to parents and decrease parental burden (LeBovidge et al. 2008). Vreeken-Ross et al. (2021) have shown that a group, CBT intervention for parents is both feasible and acceptable, however, this study was aimed at minimising anxiety transmission from parent to child and raising confident children as opposed to improving psychological outcomes for parents in itself. Recommendations for the use of a control group and additional food allergy specific QoL measures were also made. The existing RCT of CBT for mothers of children with food allergy (Boyle et al., 2017) delivered CBT to individual parents and therefore did not examine the efficacy of a group intervention. The current study therefore builds on previous research and is the first to the researcher's knowledge to report on a brief, online, group CBT intervention for parents of children with food allergy using a randomised controlled design and allergy specific QoL measures. This study therefore is a contribution to the wider effort of providing evidence-based treatments for parents of children with food allergy impacted by the distressing psychosocial implications of caring for a food allergic child.

Method

Design

This study is a feasibility Randomised Controlled Trial (RCT), with a two-arm, parallel-group, 1:1 allocation. This study compared a brief, online, group CBT intervention aimed at improving psychological outcomes for parents of children with food allergy, with a control group who did not take part in the group intervention. It was not possible to blind the researcher or participants to group allocation.

As per the aims of a feasibility design (e.g., as reported by Thabane et al., 2010) this study reports on the feasibility of the key processes of the study, including recruitment and retention, and the acceptability of the protocol. It also reports whether a signal of efficacy was found.

The Consolidated Standards of Reporting Trials (CONSORT) extension for randomised pilot and feasibility trials (Eldridge et al., 2016) was used to aid in the transparency and quality of the reporting of this RCT.

Participants

Participants were recruited from social media posts advertised by both the lead researcher (GS) and Anaphylaxis Campaign, including posts in social media hosted support groups (such as “UK Infants with Allergies” and “Anaphylaxis Support UK”; see Appendix A for the recruitment poster). The study was also advertised via ‘Trialwell’ free of charge; ‘Trialwell’ is a digital platform that helps to raise awareness of research and clinical trials for the general public, while also helping researchers to recruit participants. Parents were eligible to take part in the study if they were a parent (aged 18 or above) of at least one child (0-17 years) with a diagnosed food allergy and self-reported that their child’s food allergy negatively affected their psychological wellbeing. Parents were excluded from the study if they: were under the current care of a mental health care team or were receiving any form of

psychological intervention, taking part in another research study involving psychological interventions, did not have the capacity to provide informed consent, did not understand written and spoken English, or if they were unable to access the online study.

Recommended sample sizes for feasibility studies can vary depending on the main objective of the study (Lewis et al., 2021). The main objective of the current study was to report on the feasibility of recruitment and the protocol generally, and to report on a signal of efficacy only (rather than to prove superiority of the intervention) therefore, a formal power calculation to determine sample size was not used. Whitehead et al. (2015) have highlighted “rules of thumb” (p.1062) approaches as one of the simplest methods to estimate sample sizes; examples of this approach include Julious (2005), who suggests a minimum sample size of 12 participants per arm and Browne (1995), who suggests a minimum sample size of 30 participants for feasibility studies. In line with these suggestions, this study aimed to recruit 30-40 participants. This sample size was also chosen to keep the study realistic in terms of timeframe (Hertzhog, 2008).

Procedure

Following study advertisement, individuals who were interested in finding out more about the study were asked to express their interest by emailing the lead researcher. For those who expressed interest via ‘Trialwell’ their details were passed onto the lead researcher (with their consent). The lead researcher then sent a participant information sheet (Appendix B) and arranged a screening call in order to determine eligibility for the study and answer any questions or queries. Individuals were asked if they were a parent of a child (0-17 years) with a diagnosed food allergy. Parents were not asked to provide evidence of diagnosis (e.g., a doctor’s letter), however, it should be noted that all parents reported that their child/children were prescribed an adrenaline auto-injector, indicating that a food allergy had been medically reviewed (see demographic results). Parents were also asked if they felt their child’s food

allergy negatively affected their psychological or emotional wellbeing. Self-report of this impact was deemed sufficient for entry into the study; parents were not administered psychological wellbeing measures at this point and did not have to meet clinical cut off scores to be considered eligible to take part. Parents were also asked if they were: under the current care of a mental health care team or were receiving any form of psychological intervention, taking part in another research study involving psychological interventions and, if they would be able to access the online materials. For those not eligible to take part in the study, the reasons for this were explained and appropriate signposting for further support was given, if necessary. Once a screening call had been completed and eligibility criteria had been met, the individual was emailed a link to complete an online consent form (Appendix C).

Once the online consent form had been completed, the participant was emailed another link to complete a series of baseline questionnaires. Upon completion of the baseline questionnaires, participants were randomly allocated to either the intervention or control arm using the Sealed Envelope online service (<https://www.sealedenvelope.com>). Participants randomised to the intervention group were invited to attend an online, group CBT workshop which consisted of two, three-hour sessions and were given the dates and times of the sessions in advance. Online workshops were run due to restrictions on social gatherings brought about by the COVID-19 pandemic and were hosted via the videoconferencing platform Zoom. Two sets of online workshops were run (one set ran at the weekend and one set ran on a weekday evening), allowing participants a choice of dates. Participants in the control group were informed of their allocation and were not invited to take part in the CBT workshop. Participants in both the intervention and control groups were asked to complete outcome measures at one month and three- month follow-up dates. For those in the intervention group, participants were invited to complete follow-up measures, regardless of

whether they had attended the complete intervention. Those in the control group received a CBT self-help workbook used in the intervention upon completion of the study.

Measures

All online consent forms and questionnaires were administered through the online survey platform Qualtrics at baseline, and at one month and three months following the CBT intervention (or the equivalent time point for participants in the parallel control group). The lead researcher used reminder emails and phone calls to encourage completion of the measures, up to a maximum of three reminder contacts.

Demographic and Food Allergy Questionnaire (Appendix D)

A demographic and food allergy questionnaire was developed by the researcher based on demographic and food allergy information presented in previous studies (e.g., Cummings et al., 2010b; Knibb, 2015). Information collected included the number of children living at home with food allergy, the age of the child/children with food allergy, type of food allergy and history of anaphylaxis.

Food Allergy Quality of Life – Parental Burden Scale (FAQ-PB; Appendix E)

The FAQ-PB scale (Cohen et al., 2004) is a 17-item questionnaire which uses a 7-point Likert scale ranging from 1 (not troubled) to 7 (extremely troubled) in order to assess the burden of food allergy felt by the parent, with higher scores representing more impaired quality of life. The FAQ-PB scale has been reported to have excellent internal consistency (Cronbach's $\alpha = 0.95$) and good convergent and construct validity in a U.K sample (Knibb & Stalker, 2013). Within the current sample, Cronbach's $\alpha = 0.90$, indicating good reliability.

Depression, Anxiety and Stress Scales, short form version (DASS -21; Appendix F)

The DASS-21 (Lovibond & Lovibond, 1995) is a 21-item self-report scale that is made up of three 7-item self-report scales that measure depression, anxiety, and stress. Responses are

given on a 4-point Likert scale ranging from 0 (did not apply to me at all) to 3 (applied to me very much, or most of the time). Higher scores represent higher levels of depression, anxiety, and stress. Henry and Crawford (2005) reported the internal consistency in a UK general population sample as being good ($\alpha = .88$ for the depression subscale; $\alpha = .82$ for the anxiety subscale, $\alpha = .90$ for the stress subscale, and $\alpha = .94$ for the total scale). Within a UK parental food allergy population this measure was shown to have good internal consistency (Cronbach's $\alpha = 0.89$; Roberts et al., 2021). Within the current sample this measure demonstrated good reliability for the depression and stress subscales ($\alpha = 0.85$ and $\alpha = 0.84$ respectively), acceptable reliability for the anxiety subscale ($\alpha = 0.79$), and excellent reliability for the total scale ($\alpha = 0.91$).

Penn State Worry Questionnaire (PSWQ; Appendix G)

The PSWQ (Meyer et al., 1990) is a 16-item questionnaire which uses a 5-point Likert scale ranging from 1 (not at all typical of me) to 5 (very typical of me) to measure worry. Higher scores indicate greater worry. This scale has been reported to have acceptable internal consistency (Cronbach's $\alpha > 0.7$), good test re-test reliability and good validity (Meyer et al., 1990). Within a UK parental food allergy population this measure was shown to have excellent internal consistency (Cronbach's $\alpha = 0.92$; Roberts et al., 2021). Within the current sample, Cronbach's $\alpha = 0.95$, indicating excellent reliability.

Food Allergy Self-Efficacy Scale for Parents (FASE-P; Appendix H)

The FASE-P (Knibb et al., 2015) is a 21-item scale designed to measure parental self-efficacy (perceived confidence) in managing a child's food allergy. Each item is rated from 0 (cannot do at all) to 100 (highly certain can do), with higher scores indicating greater self-efficacy for food allergy management. The scale has been demonstrated to have good construct validity and good internal consistency (Cronbach's $\alpha = 0.88$) in a UK sample of parents of food

allergic children (Knibb et al., 2015). Within the current sample, Cronbach's $\alpha = 0.89$, indicating good reliability.

Goal-based outcome measure (Appendix I)

A goal-based outcome measure was used to evaluate progress towards participant goals which were set as part of the CBT intervention. This measure was developed by the researcher and informed by Law and Jacob's (2015) work on goal-based outcomes.

Participants were asked to rate their self-reported progress towards their goal using a scale of 0 (no progress towards my goal) to 10 (reached goal fully).

Feedback Questionnaire (Appendix J)

A researcher-developed feedback questionnaire was administered to participants in the intervention group to explore their experiences of the CBT intervention and wider research study, and its associated acceptability. Some questions in the feedback questionnaire were based on The Client Change Interview (Elliott, 1999) in order to explore any perceived changes parents had noticed and if they attributed these changes to the CBT intervention.

Participants were asked to complete a number of Likert scale responses (e.g., "Please indicate how strongly you agree or disagree with the following statement: In general, I found taking part in the overall study...to be convenient") and free-text open questions (e.g., "What improvements do you think could be made to the group CBT workshop?").

Intervention

The intervention consisted of two, three-hour, online, group CBT workshops which were held on consecutive weeks. The workshops were facilitated by the lead researcher and another researcher studying the psychological impact of food allergy. Both facilitators were trainee clinical psychologists trained in CBT. A self-help workbook was also developed to be used alongside the CBT workshop in order to maximise engagement with the content of the

workshops and encourage the practice of key skills. This booklet was also sent to the control group following the completion of the study.

As discussed, a child's food allergy has been found to have an impact on a range of psychological outcomes, therefore, the CBT intervention was based on a transdiagnostic approach (Dalglish et al., 2020; McManus et al., 2010) and sought to target the underlying processes maintaining a range of psychological difficulties such as avoidance, behaviour congruent with the psychological difficulty, hypervigilance to threat and maladaptive cognitive appraisals (Barlow et al., 2004; Craske, 2012; Harvey et al., 2004; Moses & Barlow, 2006).

The CBT workshops and accompanying workbook were developed under the supervision of a Clinical Psychologist accredited by the British Association for Behavioural and Cognitive Psychotherapies (BABCP) and a Reader in Clinical Health Psychology with expertise in food allergy. The workshop content is summarised in Table 1.

Table 1*Content of the CBT workshop delivered to the intervention group***Workshop Session 1**

<i>Workshop topic</i>	<i>Content</i>
Introduction	<ul style="list-style-type: none"> • Welcome to the group and introductions • Outline of the workshop
Part One: ‘Understanding’: Psychoeducation on anxiety, worry and low mood in the context of a child’s food allergy (based on Beck et al., 1979; Borkovec et al., 1983; Westbrook et al., 2007)	<ul style="list-style-type: none"> • Normalisation of anxiety, worry and low mood in the context of a child’s food allergy • Discussion about the continuum of these emotions and when they might be adaptive or maladaptive • What is anxiety? • What is worry? • What is low mood and depression? • Discussion of the possible thoughts, emotions, physical symptoms, and behaviours in anxiety, worry and low mood in a food allergy context
Part One: ‘Understanding’: Psychoeducation on the CBT model (based on Greenberger & Padesky, 2016).	<ul style="list-style-type: none"> • What is CBT? • Introduction to the ‘Five Areas Model’ • Practise in completing a ‘Five Areas Model’ together as a group and separately
Part Two: ‘Working with thoughts’: Working with worried thoughts (based on Beck, 2011; Borkovec et al., 1983; Dugas & Robichaud., 2007; Wilkinson et al., 2011)	<ul style="list-style-type: none"> • Practical vs hypothetical worries • The worry decision tree • Dealing with practical worries: <ul style="list-style-type: none"> ○ Problem solving • How to let worry go including: <ul style="list-style-type: none"> ○ Challenging beliefs about the value of worry ○ Worry Time ○ Distraction ○ Mindfulness and visualisation
Part Two: ‘Working with thoughts’: Challenging negative thoughts (based on Beck, 2011; Beck et al., 1979; Greenberger & Padesky, 2016)	<ul style="list-style-type: none"> • Psychoeducation on thinking biases and how these relate to different types of emotional difficulties • Thought challenging and creating a balanced alternative thought • Using a thought record to monitor and challenge biased thoughts

Workshop Session 2

<i>Workshop topic</i>	<i>Content</i>
Welcome back	<ul style="list-style-type: none">• Check in and reflections from the past week• Recap of the CBT model
Part Three: ‘Working with behaviour’: Activity Scheduling for a healthy life balance (based on Kanter et al., 2009; Vivyan, 2015).	<ul style="list-style-type: none">• Psychoeducation on ACE activities and how an unbalance of these activities can lead to emotional difficulties• Steps to achieving a balance:<ul style="list-style-type: none">○ Keeping an activity diary○ Activity scheduling
Part Three: ‘Working with behaviour’: Facing fears: approaching instead of avoiding (based on Abramowitz et al., 2011; Papworth, 2020)	<ul style="list-style-type: none">• Psychoeducation on avoidance and safety behaviours• Challenging avoidance using graded exposure• Group creation of a ‘fear ladder’ using two vignettes of parents of children with food allergy
Part Four: Relaxation and managing physical sensations (based on Westbrook et al., 2007)	<ul style="list-style-type: none">• Psychoeducation on different kinds of breathing (i.e., normal breathing, exercise breathing and anxious breathing)• Breathing exercises• Progressive muscle relaxation• Grounding techniques
Part Five: Putting it all together (based on Beck, 2011)	<ul style="list-style-type: none">• Recap of the workshop so far• Goal setting:<ul style="list-style-type: none">○ SMART goal setting○ Participants invited to choose a goal to work towards following the workshops• Reviewing goals including:<ul style="list-style-type: none">○ Identifying potential obstacles and solutions○ Identifying what is going well
Ending	<ul style="list-style-type: none">• Time for questions or general thoughts/discussion about workshop material• Explaining the next steps of the research study• Sources of mental health support• Thanking participants for taking part

Ethical considerations

This research study gained favourable ethical opinion from the University of Surrey Ethics Committee (Ref: FHMS 20_21 005 EGA; Appendix K). In accordance with the British Psychological Society's Code of Human Research Ethics (Oates et al., 2021), all participants were provided with a participant information sheet and were given time to read and consider this information, as well as the opportunity to ask any further questions, before being asked to sign an online consent form. Participants were reminded about the voluntary nature of their participation and the right to withdraw from the research without having to give a reason. All data was managed in compliance with General Data Protection Regulations (2018) and University of Surrey policy.

Participants recruited to the research study self-identified as experiencing a negative impact on their psychological wellbeing in relation to their child's food allergy. All participants received a screening call before entry into the study and signposting to further sources of support was given, if necessary. All participants had the name and e-mail address of the lead researcher should they have wished to discuss any concerns whilst taking part in the study.

Participants in the intervention group were reminded at the start of the CBT workshops that the facilitators were not medically trained, and therefore could not provide information or advice pertaining to the medical management of food allergy. They were advised to contact a qualified health professional for any medical health concerns. Participants were also reminded that the group CBT intervention and self-help workbook (given to both groups) were not a replacement or substitute for mental health treatment provided by a qualified mental health professional and were encouraged to seek further support should they feel this was appropriate. Sources of mental health support were provided at the end of the of workshop and in the self-help workbook. The lead researcher had access

to supervision from a Clinical Psychologist and Reader in Clinical Health Psychology should any concerns regarding participant safety have arisen that required further discussion.

Patient and public involvement

Prior to designing the CBT workshop materials, the lead researcher attended an Anaphylaxis Campaign support group where they had the opportunity to hear about the impact of food allergy in order to inform the workshop protocol and the accompanying self-help booklet. Feedback on this protocol and the self-help booklet was sought from a parental member of an Anaphylaxis Campaign support group and a registered Clinical Psychologist who was also a parent of a child with food allergy.

Data Analysis

Study feasibility

In line with the CONSORT extension for randomised feasibility trials (Eldridge et al., 2016) descriptive statistics were used to present data pertaining to recruitment, retention, and workshop attendance. Baseline demographic and food allergy related characteristics are presented.

Preliminary efficacy

Mean scores on the outcome measures are presented for baseline, one month, and three-month follow-up data for those in control and intervention groups. As the preliminary effect of the CBT intervention was evaluated on the basis of outcome measure scores, similarity of baseline scores in each group was desirable (Corbett et al., 2014). The assessment of baseline differences can indicate whether randomisation achieved comparability between groups (Corbett et al., 2014). There was a statistically significant difference for anxiety baseline scores between those in the control group and intervention group ($t(31) = 2.16, p = 0.038$). Baseline imbalance could indicate that randomisation was not successfully achieved, however, the risk of selection bias was deemed to be low as random sequence generation

carried out by the online Sealed Envelope service using blocks of 4 and 2 was used. A decision was made to adjust analysis to protect for the difference in baseline variables that may influence outcome (in this case anxiety), which is common but not without debate (see de Boer et al., 2015 and Roberts & Torgerson., 1999 for further discussion). Therefore, mean change scores over time (i.e., from baseline to one month follow up and from baseline to three month follow up) were calculated. The differences in mean change scores between the intervention and control group were then compared, and Hedges' *g* was calculated to determine the effect size. Hedges' *g* was used as a measure of effect size due to the small (<20) and unequal sample sizes of the groups. Interpretation of effect size was based on Cohen's (1977) suggestion that 0.2 constitutes a small effect, 0.5 constitutes a medium effect and values of 0.8 or more constitute a large effect.

Acceptability of the CBT workshops and wider study as assessed by the intervention group

Descriptive statistics were used to present quantitative data from the participant feedback questionnaire. Content analysis was used on free-text responses included in the feedback questionnaire in order to examine the acceptability of the intervention. This analysis was based on a guide by Erlingsson and Brysiewicz (2017) and involved coding the verbatim free text responses into condensed units of meaning, grouping together codes that were related into categories and then developing overarching themes. Category frequencies are presented in order to reflect the most pertinent issues that were raised across the data set (Weber, 1990).

Results

Participants

Recruitment took place from the beginning of February 2021 and ran until the end of June 2021; 67 parents of children with food allergy expressed an interest in taking part in the study and were all sent a participant information sheet. 16 parents did not respond after further information had been sent. A further 7 parents were excluded at this point as 5 did not meet

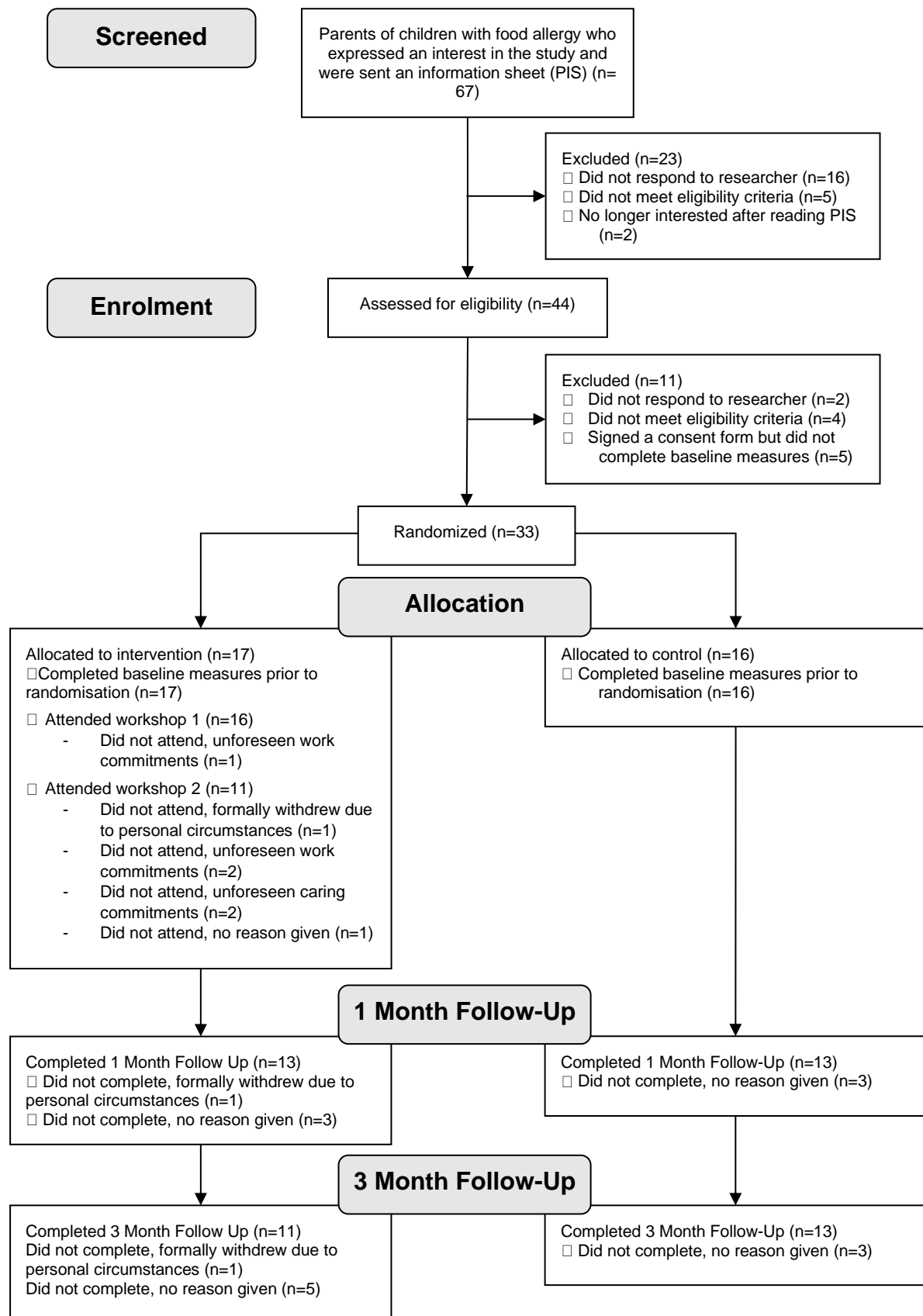
the eligibility criteria and 2 disclosed that the study was not what they had initially thought and were no longer interested. 44 parents received a screening call with the lead researcher; 6 were excluded at this point as 4 did not meet the eligibility criteria and 2 did not respond after this call or sign the consent form. 38 parents signed consent forms to take part in the study. Out of the 38 participants who consented to take part in the study, 33 completed baseline measures; out of the 5 participants who did not complete baseline measures no contact could be made to find out the reasons for this non-completion. Out of the 33 participants who completed baseline measures, 16 participants were randomly assigned to the control group and 17 participants were randomly assigned to the intervention group.

Within the intervention group, 16 (94%) participants attended the first CBT workshop, and 11 (65%) participants attended the second workshop. Following the first workshop, 1 participant formally withdrew from the study due to personal circumstances. Out of the remaining participants who did not attend both workshops, 2 participants cited unforeseen caring responsibilities for not being able to attend, 2 cited unforeseen work commitments and 1 participant did not give a reason. In terms of measure completion, 17 (100%) participants had completed a baseline measure before randomisation, 13 (76%) participants completed one month follow-up measures and 11 (65%) participants completed three-month follow-up measures.

Within the control group, 16 (100%) participants had completed a baseline measure before randomisation, 13 (81%) participants completed one month follow-up measures and 13 (81%) participants completed three-month follow-up measures. For the study as a whole, there was a completion rate of 79% at the one-month follow-up and 73% at the three-month follow-up. The flow of participants throughout the study is presented in a CONSORT diagram (Figure 1).

Figure 1

CONSORT diagram of participant flow through the study



Demographic data

Demographic data for participants is presented in Table 2. The majority of participants in the entire sample were female (94%) and all participants randomly allocated to the intervention group were female. The average age of participants was 38.06 (SD = 4.91). The majority of participants had one child living at home with food allergy (70%) with an average of 4.33 (SD = 2.18) allergies. The average age of the child (or children if parents reported having more than one child with food allergy) was 5.81 years old (SD = 3.98). The majority of children had a history of anaphylaxis (76%) and all children of parents in the study were prescribed an adrenaline auto injector.

Table 2.

Participant demographics

	Whole sample (n = 33)	Control group (n=16)	Intervention group (n=17)
Gender, n(%)			
Female	31 (94)	14 (88)	17 (100)
Male	2 (6)	2 (12)	0 (0)
Age, M (SD) years			
	38.06 (4.91)	37.81 (5.50)	38.31 (4.41)
Ethnicity, n(%)			
White British	26 (79)	12 (75)	14 (82)
White Irish	2 (6)	0 (0)	2 (12)
Other White background	3 (9)	2 (13)	1 (6)
Indian	1 (3)	1 (6)	0 (0)
Any other mixed/multiple ethnic background	1 (3)	1 (6)	0 (0)
Marital status, n(%)			
Married/Civil partnered/Living with partner	32 (97)	15 (94)	17 (100)
Separated/Divorced	1 (3)	1 (6)	0 (0)
Employment status, n(%)			
Working full time	12 (36)	6 (38)	6 (35)
Working part time	18 (55)	9 (56)	9 (53)
Not working	2 (6)	1 (6)	1 (6)
Other	1 (3)	0 (0)	1 (6)

Number of children living at home with food allergy, <i>n</i>(%)			
1	23 (70)	10 (63)	13 (76)
2	9 (27)	5 (31)	4 (24)
3	1 (3)	1 (6)	0 (0)
<hr/>			
Age of child/children with food allergy M(<i>SD</i>) in years	5.81 (3.98)	5.17 (3.46)	6.55 (4.49)
<hr/>			
Number of food allergies, M(<i>SD</i>)	4.33 (2.18)	4.48 (2.48)	4.25 (1.92)
<hr/>			
Foods child/children allergic to, %*			
Peanuts	67	69	65
Tree nuts	76	81	71
Egg	67	75	59
Milk	58	69	47
Fish	24	36	12
Shellfish	9	6	12
Soy	6	13	0
Other	79	69	88
<hr/>			
Time since most recent diagnosis given, <i>n</i>(%)			
Less than one year	5 (15)	4 (25)	1 (6)
One year	8 (24)	2 (12)	6 (35)
Two years	4 (12)	2 (12)	2 (12)
Three years	0 (0)	0 (0)	0 (0)
Four years	3 (9)	1 (6)	2 (12)
Five years	7 (21)	4 (25)	3 (18)
More than five years	6 (18)	3 (19)	3 (18)
<hr/>			
History of anaphylaxis, <i>n</i> (%)			
Yes	25 (76)	14 (88)	11 (65)
No	8 (24)	2 (12)	6 (35)
<hr/>			
Hospitalised due to an allergic reaction, <i>n</i>(%)			
Yes	25 (76)	12 (75)	13 (76)
No	8 (24)	4 (25)	4 (24)
<hr/>			
Prescribed an adrenaline auto injector, <i>n</i>(%)			
Yes	33 (100)	16 (100)	17 (100)
No	0 (0)	0 (0)	0 (0)
<hr/>			
Presence of atopic conditions, <i>n</i>(%)			
Yes	31 (94)	15 (94)	16 (94)
No	2 (6)	1 (6)	1 (6)

* Represents percentage of children with a reported allergy to the specific food group. Totals more than 100% due to children having more than one food allergy.

Outcome measures

Mean scores and change in mean scores from baseline to one and three month follow ups are presented in Table 3. A large effect of the intervention was found at one month ($g = 0.93$, 95% CI [0.14-1.72]) and at three months ($g = 1.43$, 95% CI [0.54-2.30]) for FAQL-PB scores; impairment in food allergy quality of life was reduced at one and three months for those in the intervention group in comparison to the control group. The intervention demonstrated a large effect on reduction of anxiety compared to the control group at one month ($g = 1.02$, 95% CI [0.22-1.81]), but this was not sustained at the three month follow up. The intervention also demonstrated a large effect on the reduction of worry ($g = 1.52$, 95% CI [0.61-2.40]) and stress ($g = 0.87$, 95% CI [0.05, 1.68]), and an improvement in food allergy self-efficacy ($g = -1.37$, 95% CI [-2.25, -0.47]) at three months in comparison to the control group; this effect was not seen at the one month follow up. There was no effect of the intervention on levels of depression at one month or three months.

Goal based outcome measures

Examples of goals included: to be in a different room, not supervising, whilst a co-parent fed a child twice a week, to practice relaxation techniques for 20 minutes each day, and to eat out at a restaurant as a family within a timeframe of 3 months. Participants had a mean score of 1.91 (SD = 1.22) at baseline, at mean score of 5.45 (SD = 2.02) at one-month follow-up and a mean score of 6.82 (SD = 1.99) at three-month follow-up, indicating participant progress towards goals of their choice. Further information relating to perceived participant change was collected as part of the feedback questionnaires and is presented subsequently.

Table 3. Mean scores, mean change from baseline scores at one and three month follow ups, mean change difference between the intervention and control groups and the effect size of this difference

Measure at timepoint	Intervention (CBT)			Control			Mean change difference	Hedges g effect size (95% CI)
	n	M (SD)	Mean change from baseline (SD)	n	M (SD)	Mean change from baseline (SD)		
FAQL-PB								
Baseline	17	5.79 (0.71)		16	5.29 (0.87)			
1 month	13	4.76 (1.02)	0.91 (0.80)	13	5.23 (1.00)	0.10 (0.87)	0.81	0.93 (0.14, 1.72)**
3 months	11	4.64 (0.78)	1.11 (0.81)	13	5.63 (1.29)	-0.40 (1.16)	1.51	1.43 (0.54, 2.30)**
PSWQ								
Baseline	17	60.59 (13.61)		16	55.00 (18.21)			
1 month	13	57.15 (12.54)	2.92 (6.56)	13	53.62 (15.78)	-1.85 (8.32)	4.77	0.62 (-0.15, 1.38)
3 months	11	50.91 (14.92)	9.18 (7.11)	13	53.62 (16.52)	-2.08 (7.19)	11.26	1.52 (0.61, 2.40)**
DASS-21 – Depression subscale								
Baseline	17	9.65 (5.88)		16	7.63 (7.70)			
1 month	13	6.46 (6.28)	2.92(6.30)	13	5.54 (7.75)	1.38 (4.86)	1.54	0.27 (-0.49, 1.01)
3 months	11	6.36 (6.44)	2.36 (4.72)	13	6.92 (7.51)	0.15 (5.63)	2.21	0.41 (-0.39, 1.19)
DASS-21 – Anxiety subscale								
Baseline	17	10.59 (7.06)		16	5.38 (6.76)			
1 month	13	4.62 (4.96)	4.92 (6.71)	13	5.85 (6.14)	-1.69 (5.76)	6.62	1.02 (0.22, 1.81)**
3 months	11	5.45 (5.07)	3.09 (6.28)	13	5.23 (5.20)	-1.23 (6.35)	4.32	0.66 (-0.15, 1.45)
DASS-21- Stress subscale								
Baseline	17	17.41 (6.16)		16	14.13 (8.96)			
1 month	13	12.31 (7.87)	5.08 (6.25)	13	14.46 (9.10)	-0.92 (9.33)	6.00	0.73 (-0.05, 1.50)
3 months	11	12.55 (7.22)	3.82 (8.12)	13	14.77 (8.74)	-2.92 (6.86)	6.74	0.87 (0.05, 1.68)**
FASE-P Total								
Baseline	16*	67.23 (13.71)		16	74.48 (12.33)			
1 month	13	73.10 (11.91)	-5.89 (4.89)	12*	68.23 (25.35)	7.07 (22.39)	-12.95	-0.79 (-1.57, 0.01)
3 months	11	74.50 (11.47)	-8.66 (8.04)	12*	71.09 (16.00)	5.00 (10.80)	-13.66	-1.37 (-2.25, -0.47)**

* Number of completers for the FASE-P is lower than for the whole sample, due to unregistered responses/missing data

** 95% confidence intervals do not cross zero for the effect size, indicating that zero is not a value for the true difference in mean change scores between the two groups.

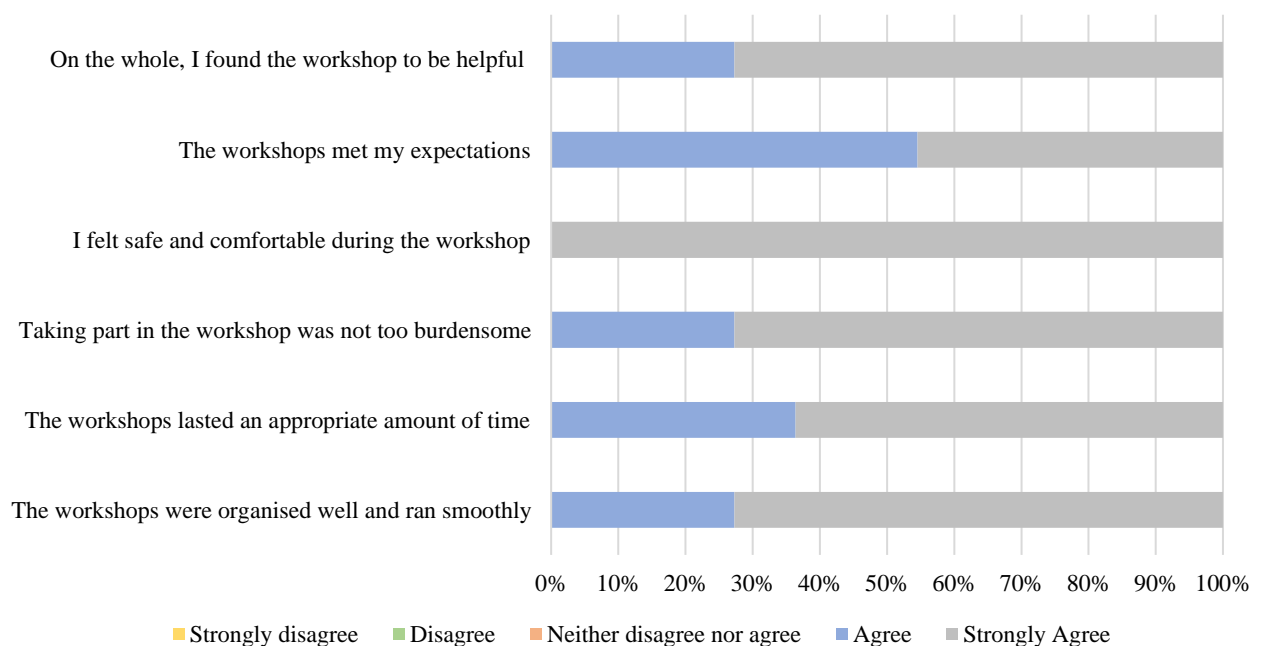
Acceptability of the CBT workshops and wider study as assessed by the intervention group

Eleven participants in the intervention condition completed feedback questionnaires; all participants had completed both parts of the CBT workshop.

Participants were asked to rate how strongly they agreed or disagreed with a number of statements in order to understand the acceptability of the CBT group workshop; 27% agreed and 73% strongly agreed that the workshop was organised well and ran smoothly, 36% agreed and 64% strongly agreed that the workshops lasted an appropriate amount of time, 27% agreed and 73% strongly agreed that taking part in the workshop was not too burdensome, 100% strongly agreed that they felt safe and comfortable during the workshop, 54.5% agreed and 45.5% strongly agreed that the workshop met their expectations and, 27% agreed and 73% strongly agreed that on the whole, they had found the group session to be helpful (Figure 2).

Figure 2.

Participant responses to feedback statements regarding the CBT workshop

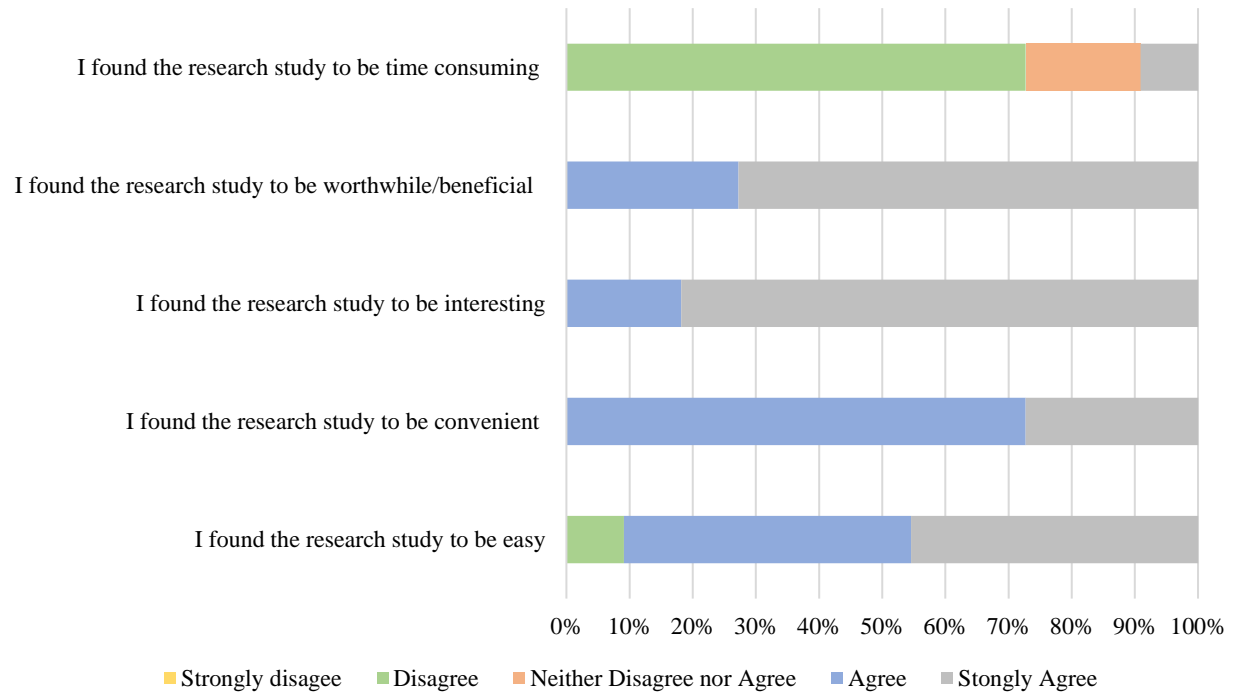


In relation to perceived changes noticed by the participants (details of which can be found in Table 4), the majority of participants felt they were very unlikely or somewhat unlikely to have been experienced if they had not attended the workshop (36% and 46% respectively). 18% felt that it was neither likely nor unlikely that these changes would have taken place if they had not taken part in the workshop. All participants said they would be likely to recommend group CBT to other parents of children with food allergy; 91% said they would be very likely to recommend it and 9% said they would be somewhat likely to recommend it.

In terms of exploring the acceptability of the entire study (including the consent process, completing outcome measures, attending the CBT workshop, and giving feedback), participants were asked how strongly they agreed or disagreed with a number of statements. 45.5% agreed, 45.5% strongly agreed and 9% disagreed that the study was easy, 73% agreed and 27% strongly agreed that the study was convenient, 18% agreed and 82% strongly agreed that the study was interesting, 73% disagreed, 18% neither agreed nor disagreed and 9% strongly agreed that the study was time consuming, and 27% agreed and 73% strongly agreed that the study was worthwhile and beneficial (Figure 3).

Figure 3.

Participant responses to feedback statements regarding the entire research study (consent process, completing outcome measures, completing the CBT workshops, and giving feedback)



Content analysis of free-text responses revealed the most helpful aspect of the workshop was meeting other parents of children with food allergy (Table 4). Parents also appreciated being given tangible tools and techniques to help them manage the psychological impact of food allergy. Incidentally, the most frequently reported change was using the tools and techniques taught as part of the workshop. Parents also commented on being more aware of their thoughts, feelings and behaviours and implementing strategies to help with these. In terms of improvements to the CBT workshop, the most common response was that parents wished for there to be more group discussion and interaction. A few participants mentioned that they could not think of any improvements to be made, but other suggestions for improvement included face-to-face sessions, follow-up sessions, the involvement of an allergist or nutritionist, and using less complicated outcome measures.

Table 4. Content analysis of open-text responses to feedback questionnaire

Themes	Sub-categories with examples	Frequency
Helpful aspects of the workshops	Meeting other parents of children with food allergy	8
	<i>“Meeting other mums who felt the same as me; knowing I wasn’t alone in my anxiety”</i>	
	<i>“Seeing the faces of other mums in the same position as me ,made me feel less isolated”</i>	
	Delivery of CBT tools and techniques	4
	<i>“All of the tangible methods of dealing with anxiety and approaching difficult situations”</i>	
	<i>“Breathing has been a really good strategy for me”</i>	
	Reassurance, validation, and normalising of emotions	3
	<i>“Feeling validated in our anxieties but given hope that they are manageable”</i>	
	<i>“Reassurance about what is normal throughout”</i>	
	Supportive facilitation	3
	<i>“It was delivered in a very sensitive way”</i>	
	Specific food allergy content	1
	<i>“Being allergy focussed and not a generalised CBT was the best thing”</i>	
Suggestions for improvements	More group discussion and interaction	4
	<i>“I think encouraging participants to contribute more about their own fears/experiences would help, if they felt comfortable to”</i>	
	<i>“Some opportunities for further group discussion may have helped me focus my thoughts at times”</i>	
	No suggestions made	3
	<i>“I think it worked really well and doesn’t need improvements”</i>	

	Face to face sessions	2
	<i>“In person, rather than online”</i>	
	Follow-up sessions	2
	<i>“Follow-up sessions would be good to make sure we are on track/for refreshers”</i>	
	Participation of a medical health professional	1
	<i>“Participation of an allergist or nutritionist”</i>	
	Less complicated outcome measures	1
	<i>“Found some of the questionnaire questions a bit confusing/difficult to answer”</i>	
Changes noticed since the workshop	Putting in place coping strategies and utilising tools	7
	<i>“I have begun to use the coping strategies when I do feel anxious”</i>	
	<i>“I have better awareness of how to stop my thoughts spiralling and weighing up risks and benefits to give a rounded view of the situation”</i>	
	Able to identify thoughts, feelings, and behaviours	3
	<i>“Better able to identify why I am feeling anxious”</i>	
	<i>“Much more aware of checking in with myself and identifying thoughts/feelings”</i>	
	Different relationship with difficult emotions	2
	<i>“Less embarrassed about my anxieties”</i>	
	Trying new experiences	1
	<i>“Allow husband to try some new food experiences with my son”</i>	
	None	1
	<i>“Nothing noticeable”</i>	

Discussion

This study showed that a RCT of a brief, online, group CBT intervention for improving psychological outcomes in parents of children with food allergy was, as a whole, feasible. A preliminary signal of efficacy was found for reducing worry, stress, anxiety, and the burden of food allergy on QoL. There was also a preliminary signal of efficacy found for increasing food-allergy self-efficacy scores. For those who completed the CBT intervention and subsequent feedback forms, the study was deemed acceptable. However, there were some limitations to the feasibility of the study for the intervention group which will be discussed further.

Study outcomes

In terms of attendance at the CBT workshops, an encouraging 94% of participants in the intervention group attended the first half of the workshop, with 65% of participants attending the second workshop. Reasons given for workshop non-attendance included withdrawal due to personal circumstances, unforeseen caring responsibilities, unforeseen work commitments, and one participant did not give a reason. Participant workshop attendance was similar to rates found in Cartwright-Hatton et al. (2018), where 59% of parents allocated to the intervention group attended a workshop targeting parental anxiety. This uptake rate was explained by having one or two workshops offered, thereby limiting the accessibility of the intervention (Cartwright-Hatton et al., 2018). In the current study participants were offered the choice of two workshop options (a weekend option or a weekday evening option) and it could have been possible that offering more of a choice in workshop days and times would have given those who could not attend due to unforeseen circumstances the opportunity to attend an alternative workshop session. As there was higher participant engagement for the first part of the workshop, it could be possible that a one-day workshop is more feasible for parents than trying to attend a workshop spread over two weeks, however, high retention

rates for interventions involving two sessions have been reported elsewhere (Vreeken-Ross et al., 2021).

In terms of measure completion, in the intervention group, 76% of participants completed one month follow-up measures and 65% of participants completed three-month follow-up measures. Again, this is similar to rates of completion found in the Cartwright-Hatton et al. (2018) study, where 55% of parents in the intervention group completed three-month follow-up measures. This response rate was improved at a 12-month follow up due to adjustments in the follow-up process, which included completing a follow-up assessment by telephone (Cartwright-Hatton et al., 2018), suggesting that adjustments may be needed to the current study protocol to increase response rates. Attrition in the intervention group may have also occurred due to parents not finding the CBT intervention acceptable or helpful, decreasingly the likelihood of measure completion. Parents may not have felt comfortable to share this information at follow up with the researcher as the researcher had also devised and facilitated the CBT workshop.

In the control group, 81% of participants completed one- and three-month follow-up measures. The differences in completion rates between the control and intervention groups could be explained by overall time-burden on research participants; it could be possible that those in the control group felt less burdened by filling in outcome measures as they had not had to participate in the workshops. It could be hypothesised that the higher attrition rate in the intervention group could have been affected by ‘online fatigue’ where filling in online questionnaires and participating in an online workshop felt too burdensome. Overall levels of ‘online fatigue’ are likely to have been heightened due to the increase in online communication and working as a result of the COVID-19 pandemic. It could also be hypothesised that participant motivation may have had an impact on completion rates, with

those in the control group motivated to complete outcome measures in order to receive the CBT self-help booklet.

Overall completion rates for the study (79% at one-month follow-up and 73% at three-month follow-up) were in line with other internet-based randomised controlled trials, where higher rates of loss to follow up are not unusual (Carvalho et al., 2021; Mathieu et al., 2013). However, lower workshop attendance rates for the second part of the intervention and lower response rates for follow-up measures may indicate the study was less feasible for those in the intervention group, and some changes to the current study protocol may be warranted. Changes could include offering a greater range of times/dates for CBT workshops and greater efforts to follow participants up, including ascertaining reasons for drop out if possible. In the current study, participants were contacted up to a maximum of three times in order to encourage engagement; future studies could include reporting of these rates in order to ascertain how many follow ups parents, who often have to balance a range of demands, may require. Future studies could also include a short, online, anonymous feedback survey to ascertain reasons for non-attendance and measure completion. An anonymous feedback survey may be particularly important to capture information that participants do not feel comfortable sharing with a researcher in person. A future full trial would also benefit from having separate researchers to recruit participants, facilitate the workshop and, collect follow up measures and feedback.

As this was a feasibility study, the aims are not to detect statistically significant differences between groups, however, a signal of efficacy for some outcome measures was found. At the one-month follow-up, the intervention demonstrated a large effect of the intervention in reducing the impact of food allergy on QoL and anxiety in comparison to control groups. At the three-month follow-up, the effect of the intervention on food allergy QoL was sustained, and it also demonstrated a large effect on the reduction of worry and

stress. Food allergy self-efficacy also improved at the three-month follow-up in comparison to the control group, with the intervention demonstrating a large effect. These results are in line with previous studies which have shown CBT interventions to reduce parental anxiety (Boyle et al., 2017; Knibb 2015 and Vreeken-Ross et al., 2021), worry (Knibb, 2015) and the negative impact of food allergy on QoL (Knibb, 2015). However, it should be noted that in this study, a reduction in parental anxiety was not sustained, and at three months there was no effect of the intervention on levels of anxiety in comparison to the control group, although levels of anxiety did not return to those captured at pre-intervention baseline. It could be argued that a “booster” session may be helpful to recap some of the key anxiety tools and techniques as presented in the workshop, as suggested by two members of the intervention group in the feedback questionnaire. Research that followed participants up over a longer-time frame may also be warranted to see if a brief CBT intervention could sustain improvements in long term psychological outcomes.

This study was the first RCT of a CBT intervention to report on both measures of food allergy related QoL and food allergy self-efficacy. Average scores on both measures improved over the course of follow-up, and there was a large effect of the intervention in comparison to controls on food allergy QoL at one and three months, and food allergy self-efficacy at three months. Lower levels of food-allergy self-efficacy, as defined as confidence in one’s own capabilities to manage food allergy (Knibb et al., 2015), have been associated with poorer psychological outcomes and poorer allergy related QoL (Knibb et al., 2015; Roberts et al., 2021). In Knibb et al.’s (2015) study, parental self-efficacy was the best predictor of QoL as measured by the FAQL-PB scale, therefore a positive change in self-efficacy may represent a mechanism through which CBT works to improve allergy-related QoL. This is a tentative suggestion, as the current research cannot determine causation and previous studies have only used correlational designs to measure the relationships between

self-efficacy and psychological outcomes (e.g., Knibb et al., 2015; Gallagher et al., 2013).

Therefore, further research is needed to understand the relationship between CBT, self-efficacy, and improvements in psychological outcomes.

For those who completed both parts of the CBT workshop and subsequently completed feedback measures, the CBT intervention and wider study were deemed highly acceptable, although it should be noted that the attrition in the intervention group may indicate that the study is not acceptable for some parents. Parents reported that the most helpful aspect of the CBT workshop was meeting other parents of children with food allergy. This may not be surprising considering how isolation has been reported in the wider allergy literature as one of the main negative psychosocial impacts of food allergy (Mandell et al., 2005; Quach & John, 2018; Rouf et al., 2011). Therefore, the group aspect of intervention may be of particular therapeutic importance. Indeed, in relation to suggested improvements for the workshops, participants asked for further group discussion and involvement, again highlighting the beneficial nature of group interactions.

In terms of the perceived changes noticed by participants, it was reported by some that they felt more able to recognise their thoughts, feelings and behaviours and put in place techniques to help them cope with the negative consequences of these. There were also positive increases in steps towards completing self-selected goals. The majority of participants attributed changes to the intervention, with only one participant indicating that they had no way of knowing if changes were likely to have occurred as a result of the intervention. All participants reported that they would recommend group CBT as an intervention for parents who were experiencing wellbeing difficulties as a result of their child's food allergy.

Limitations

The results of this study may not be generalisable to the wider population of parents of children with food allergy. Firstly, the majority of participants in this study were female, with all of the participants in the intervention group being mothers, despite all parents being invited to take part in the study. The lack of male participants self-referring to the study may indicate that they are less likely to seek psychological intervention or that they may experience the psychosocial impact of parenting a child with food allergy differently to mothers. Further studies exploring the psychological impact of a child's food allergy and appropriate interventions for fathers are needed. Secondly, the majority of participants in this study were white British; further studies would benefit from a more culturally and ethnically diverse sample of participants due to potentially different social and cultural expectations relating to family roles and the preparation/sharing of food. This is also an important consideration as previous research has shown that risk perception can differ amongst ethnicities (Widge et al., 2018).

There are also limitations to the study design in relation to establishing a treatment effect. Participants in the intervention group were given a CBT self-help booklet at the end of the first CBT session in order to encourage the practise of key skills, however, due to this it is not possible to ascertain if any changes captured were due to participation in the CBT workshop or due to engagement with the self-help materials. It is important to consider the influence of the study design on three month follow up results; it could be hypothesised that the effects of the intervention that were seen at three months but not one month were due to engagement with self-help materials in the months following the intervention. Conversely, the effect of the intervention on anxiety was not sustained at three months, perhaps indicating that the effect of the CBT workshop was short-term and engagement with self-help materials was not enough to sustain this effect. At this stage, it is not possible to determine which

element of the intervention was efficacious at which time point. A three-armed intervention comparing a CBT workshop, a CBT self-help booklet and a control group would be useful in a full trial in order to understand the treatment effect of each element of the intervention.

The results of this study may also show bias due to the lower attendance rate for the second part of the CBT workshop and lower rate of completion for outcome measures in the intervention group. Responses at three months were collected from parents who had attended both workshop sessions and therefore may have found the study to be more feasible than those who did not take part in the entire workshop or complete outcome measures. Reasons for outcome measure non-completion were not captured due to no response after the maximum number of contacts, therefore the experiences and opinions of those who dropped out of the study are not captured. This may have been due to participants not feeling able to give what may be perceived as ‘negative’ feedback to the researcher who also recruited participants to the study and ran the CBT workshops. Feedback survey responses from those in the intervention group may have also been biased due to contact with the lead researcher, who built rapport with participants during screening calls and CBT workshops.

Despite limitations, this study adds to the growing body of literature on psychological interventions to manage the psychosocial impact of parenting a child with food allergy; this research is greatly needed given the rising rates of food allergy in the UK and the high demand for specialist psychology services (Knibb et al., 2019). A strength of this study is that it used a randomised controlled design to control for confounding factors, such as the impact of the COVID-19 pandemic on parental outcomes. This study also used a range of psychological outcome measures that were shown to have good psychometric properties in samples of parents with food allergic children.

Clinical implications

The results of the current study indicate that a brief, online, group CBT intervention may be an acceptable intervention to help manage the psychosocial impact of parenting a child with food allergy. CBT delivered on an individual basis can be a time-intensive therapy, for which there may be a long waiting list. As the intervention was brief, it could be seen as a promising intervention for use in time-stretched services. The group format of the intervention means that a number of parents could receive an intervention at the same time, with peer support from the group also adding to the therapeutic benefit. This particular intervention was delivered by a trainee clinical psychologist, however, due to the nature of the intervention being low-intensity, the content of the workshops could be manualised and delivered by other health professionals in an allergy clinic setting. Vickers et al. (2019) have demonstrated that health professionals not previously trained in CBT can reach competence levels quickly in delivering this type of intervention, indicating an appropriate intervention that could be implemented in existing allergy services, rather than relying on speciality psychology services which may be sparse (Herbert et al., 2019; Knibb et al., 2019).

Conclusion

The aim of this study was to evaluate the feasibility, acceptability, and preliminary efficacy of a brief, online, group CBT intervention to improve psychological outcomes in parents of children of food allergy. The results presented a mixed picture in terms of feasibility; the study as a whole retained participants to a level found in other online RCTs, however, higher drop-out rates in the intervention compared to the control group may indicate higher participant burden and lower feasibility for those allocated to the intervention group. Therefore, changes to the protocol in order to improve participant engagement in the intervention group may be warranted in future studies. In line with previous studies evaluating CBT, there was a promising signal of efficacy found for improving psychological

outcomes. The intervention appeared to lower levels of anxiety, stress, worry and mitigate the negative impact of food allergy on food allergy specific QoL. The intervention also appeared to increase food allergy self-efficacy, in relation to the control group. The intervention was also deemed highly acceptable, with all participants stating that they found the intervention helpful and that they would recommend the group CBT workshops to other parents of children with food allergy. These results indicate that a larger scale, adequately powered RCT is warranted, to see if the promising results of smaller studies, including the current study, can be extrapolated to a wider parental population.

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List of Appendices for Part One

Appendix A: Recruitment poster

Appendix B: Participant information sheet

Appendix C: Participant consent form (online version)

Appendix D: Demographics and Food Allergy Questionnaire

Appendix E: Food Allergy Quality of Life Parental Burden Scale

Appendix F: Depression, Anxiety and Stress Scales (short form version)

Appendix G: Penn State Worry Questionnaire

Appendix H: Food Allergy Self-Efficacy Scale for Parents

Appendix I: Goal based outcome measure

Appendix J: Feedback questionnaire

Appendix K: Ethical approval from the University of Surrey Ethics Committee

Research Project:

The feasibility of a group CBT intervention for improving psychological outcomes in parents of children with food allergy.

We are running a research project in order to understand more about appropriate psychological interventions for parents whose quality of life and wellbeing may be affected by a child's food allergy.

Cognitive Behavioural Therapy (CBT) is a talking therapy which aims to help people manage their problems by changing the way they think and behave. We would like to find out if a one-day, group CBT workshop is beneficial, feasible and acceptable to parents experiencing problems with their wellbeing related to a child's food allergy. We would also like to talk to parents to find out more about their experiences of accessing psychological therapy in relation to concerns over their child's food allergy.



If you are a parent (aged 18 or above), who has a child/children (aged 0-17 years of age) with a food allergy, please contact us if you are interested in finding out more about this project:

Gina Sherlock (Trainee Clinical Psychologist)



This research project has received ethical approval from the University Ethics Committee at the University of Surrey.

Appendix B: Participant information sheet

PARTICIPANT INFORMATION SHEET

Title of Study: The feasibility of a group CBT intervention for improving psychological outcomes in parents of children with food allergy.

University of Surrey Ref: FHMS 20-21 005 EGA

PLEASE KEEP A COPY OF THIS INFORMATION SHEET FOR YOUR RECORDS

Section: Taking Part

Introduction

Thank you for your interest in this study looking at group Cognitive Behavioural Therapy (CBT) for parents of children with food allergy.

We would like to understand if a brief, group CBT session for parents of children with food allergy is a suitable way to improve the quality of life and wellbeing of caregivers. Therefore we would like to invite you, as a parent of a food-allergic child, to participate in this research project.

The purpose of this information sheet is to provide you with details about the study, so that you can understand why the research is being done and what your participation would involve. Please read this information carefully and discuss it with others if you wish. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Participation is completely voluntary, and you are able to withdraw from the study at any point, without having to give a reason.

This study is being undertaken by Gina Sherlock (Trainee Clinical Psychologist) as part of the Doctorate in Clinical Psychology and will be supervised by Dr Christina Jones (Senior Lecturer, School of Psychology, Faculty of Health and Medical Sciences).

If you have any questions, you can contact us using the contact details at the end of this information sheet.

What is the purpose of the study?

Food allergy has been found to have a negative impact on the quality of life and wellbeing of parents with food-allergic children. Parents report higher levels of stress, anxiety, worry and depression than parents of non-food-allergic children. This highlights the need for appropriate and effective psychological interventions, aimed at improving the quality of life and wellbeing of parents affected by their child's food allergy.

Research has suggested that interventions involving Cognitive Behavioural Therapy (CBT) have the potential to improve the lives of those impacted by a food allergy, however, more research is needed in order to explore this. This research is interested in whether a one day, group CBT workshop to improve wellbeing and QoL in parents of food-allergic children is *feasible*; this is, is this particular form of CBT useful for parents who experience poor wellbeing as a result of care-giving for a child/children with food allergy?

We hope that by collecting data from you, we can gain an insight into:

- 1) Whether people are happy to be recruited into this type of study, and if they are happy to take part in all parts of the study
- 2) Whether people taking part can complete the questionnaires we plan to use, without difficulty
- 3) Whether people taking part find this type of study acceptable, practical, and appropriate
- 4) How helpful parents of children with a food allergy find the CBT workshop
- 5) How the study could be improved/adapted in any way to improve acceptability to participants
- 6) If the intervention shows promise of improving wellbeing and quality of life in parents of children with food allergy.

We would also like to find out about parents' experiences of accessing psychological support. Research has told us that the ways in which a child's allergy can impact the parent varies, with some parents experiencing higher levels of distress than others. We would like to understand a bit more about why some parents may be seeking psychological support, their experiences of accessing allergy-specific support, and the ways in which they think a psychological intervention may help with their problems. This information would help us to understand which parents psychological support may be most helpful for, and what this should consist of.

Who is responsible for this study?

This study is the responsibility of Gina Sherlock (Trainee Clinical Psychologist) and Dr Christina Jones (Senior Lecturer) at the University of Surrey.

Why have I been invited to take part?

You are invited to participate in this study because you are the parent of a food-allergic child/children, who currently feels that this impacts on their wellbeing. You have expressed an interest in taking part in this study.

To be eligible to take part in this study, you must be over 18 years of age and be a parent of a child/children who is/are aged between 0 and 17 years of age with a food allergy.

Do I have to take part?

No, participation is voluntary, and you do not have to take part. Once you have been given this information sheet, you will have time to consider the research study. You will have seven days to read this information, after which a researcher will be in contact with you to see if you would like to take part or not. Please contact us if there is anything that is not clear, if you have any questions, or if you would like more information.

What will happen to me if I decide to take part?

If you decide to take part, you will be given this information sheet to keep and will be asked to sign a consent form to confirm your agreement to participate. You will be given a copy of this consent form.

Once you have given written consent to take part in the study, you will be asked to complete a series of questionnaires. These questionnaires will ask you about your wellbeing and quality of life.

You will then be randomly allocated to **one** of two groups where you will receive **either**:

- a) The usual care and access to services you are currently receiving (control group)
- OR**
- b) The usual care and access to services you are currently receiving **plus** a group CBT workshop for parents of children with food allergy (intervention group).

Parents who are allocated to the intervention group will be invited to attend a one-day CBT workshop at the University of Surrey. Unfortunately, we cannot reimburse you for travel to the group. An online CBT workshop will be available in light of Covid-19 restrictions; this will either be a one- day workshop or two half-day workshops depending on participant preference and availability. You will be asked to complete the same questionnaire as you did at the start of the study at one month and three months after the workshop. Those parents who are asked to take part in a CBT workshop will also be asked to complete a feedback survey as part of the three-month follow up questionnaire, so that we are able to evaluate the study.

Participants who are allocated to the control group will not be invited to attend a CBT workshop. You will be asked to complete the same questionnaire as you did at the start of the study at one month and three-month follow ups. You will be given a CBT-informed self-help booklet at the end of the study, after you have completed the three-month follow up questionnaires.

Additionally, if you are a parent who has been allocated to take part in a CBT workshop, you will be asked if you would like to take part in an optional interview. This interview will ask you about your reasons for accessing psychological support in relation to your child's food allergy, your experiences of accessing allergy-specific support and how you think a psychological intervention may help you. This interview will be held on a one-to-one basis by telephone/Skype/Zoom and will arranged at a time that is convenient for you, before you attend a workshop. The interview will be recorded to ensure that all important information from the interview is captured.

Overall, your involvement in the study will last approximately 4 months.

All of the information recorded and collected during this study will be kept confidential and stored securely. The only people who will be allowed to see this are those who are part of the research team. Your name will be removed from all of the documents used in the study, and you will be assigned a 'participant ID number'. Participants who decide to take part in the interviews will be recorded by Dictaphone or using the recording function on a videoconferencing platform (e.g., Zoom). This recording will be transcribed (written up), and all identifiable information will be removed. The research team may use direct quotes from the interviews in a report of the study results, but these will all be completely anonymised.

What happens if I do not want to take part or if I change my mind?

Participation in this study is completely optional. You are free to withdraw from the study at any time, without giving a reason. To withdraw from the study please contact Gina Sherlock, Trainee Clinical Psychologist. Contact details are at the end of this information sheet.

Anonymised data collected up until the point you withdraw will be used in analysis, but no further data will be collected.

What are the possible benefits in taking part?

Those who take part may benefit from psychological management techniques delivered in the workshop or in the self-help materials.

The results from the study may not be directly useful to you however, it is hoped that results will aid our understanding of psychological interventions for parents of children with food allergy and will be used to improve allergy-specific services.

Are there any potential risks involved?

When taking part in a psychological study there is always the chance that difficult feelings may arise. If for any reason you do become distressed during the research study and need support, please contact a member of the research team. You can also see your GP if you experience any difficult feelings as a consequence of the research study.

How is the project being funded?

This research is a student project as part of the Doctorate in Clinical Psychology at the University of Surrey.

Will my participation be kept confidential?

We are responsible for making sure your participation is kept confidential and any data is kept secure and used only in the way described in this information sheet. When processing and storing information, we will comply with the Data Protection Act 2018 and the General Data Protection Regulations (GDPR, 2018) to protect your confidentiality. During the study, your information will be labelled with a participant number, not your name. All data will be stored securely. Only a small number of researchers will have access to your personal information (e.g. name, telephone number) to be used for contact purposes only (e.g. to send questionnaires or arrange interviews). All personal information will be stored separately to results in a secure location.

We will use anonymous direct quotations in reports. You will not be identified in any reports/publications resulting from this research study and those reading the study will not know who has contributed to the research study.

Your information may be subject to review for monitoring and audit purposes, by individuals from the University of Surrey and/or regulators who will treat your data in confidence.

In certain exceptional circumstances where information arising from your participation indicates that you or others may be at significant risk of harm, the researcher may need to report this to an appropriate authority, in accordance with regulations set out in the GDPR, 2018. This would usually be discussed with you first.

Examples of those exceptional circumstances when confidential information may have to be disclosed are:

- The researcher believes you are at serious risk of harm, either from yourself or others
- The researcher suspects a child may be at risk of harm

- You pose a serious risk of harm to, or threaten or abuse others
- As a statutory requirement e.g. reporting certain infectious diseases
- Under a court order requiring the University of Surrey to divulge information
- We are passed information relating to an act of terrorism

Will my data be shared or used in future research studies?

No data will be shared outside of the University of Surrey or used for future research studies.

Information may be subject to review by responsible individuals from the University of Surrey and/or regulators for monitoring and audit purposes.

What will happen to the results of the study?

When we have collected all the results for this study, we will analyse them and then publish and present the results. A final report summarising the main findings will be produced and submitted as part of a university-assessed assignment for the Doctorate in Clinical Psychology. The results will also be written up for publication in academic journals and may be presented at relevant conferences and events.

Any published findings or quotations will use pseudonyms and will maintain your confidentiality and anonymity. You will not be identified in any reports, publications, or presentations.

You will be able to request a summary of the findings by contacting a researcher.

Who has reviewed this study?

This research has been reviewed by an independent group of people, called an Ethics Committee. This study was reviewed and given a favourable ethical opinion by the University of Surrey Ethics Committee.

Section: Your personal data

What is personal data?

'Personal Data' means any information that identifies you as an individual. We will be collecting and using some of your personal data that is relevant to completing the study and this section describes what that means.

The information that we will collect will include your name, contact details, age, ID number and potentially your audio-recording, which is regarded as 'personal data'. We will also be collecting information about your ethnic origin, gender and details about your psychological health, which is regarded as a 'special category personal data'. We will use this information as explained in the 'What is the purpose of the study' section above.

All of the information recorded and collected during this study will be kept confidential and stored securely. The only people who will be allowed to see this are those who are part of the research team.

Who is handling my personal data?

The University of Surrey, who has the legal responsibility for managing the personal data in this study, will act as the 'Data Controller' for this study. The research team will process your personal data on behalf of the controller and are responsible for looking after your information and using it properly.

What will happen to my personal data?

As a publicly-funded organisation, we have to ensure that when we use **identifiable personal** information from people who have agreed to take part in research, that this data is processed fairly and lawfully. The University of Surrey processes personal data for the purposes of carrying out research in the **public interest** and special category data is processed on an additional condition necessary for **research purposes**. This means that when you agree to take part in this research study, we will use and look after your data in the ways needed to achieve the outcomes of the study.

Your personal data will be held and processed in the strictest confidence, and in accordance with current data protection regulations. When acting as the data controller, the University will keep identifiable information about you for 10 years after the study has finished after which time any identifiers will be removed from the aggregated research data.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you decide to withdraw from the study, we may not be able to withdraw your data. We will keep and use the minimum amount of personally-identifiable information about you that we have already obtained in order to complete the study.

If you wish to make a complaint about how we have handled your personal data, you can contact our Data Protection Officer Suzie Mereweather who will investigate the matter (dataprotection@surrey.ac.uk). If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful, you can complain to the Information Commissioner's Office (ICO) (<https://ico.org.uk/>).

You can find out more about how we use your information <https://www.surrey.ac.uk/information-management/data-protection> and/or by contacting dataprotection@surrey.ac.uk.

Section: Further information

What if you have a query or something goes wrong?

If you are unsure about something you can contact the research team for further advice using the contact details at the bottom of this information sheet.

However, if your query has not been handled to your satisfaction, or if you are unhappy and wish to make a formal complaint to someone independent of the research team, then please contact:

Research Integrity and Governance Office (RIGO)
Research and Innovation Services
University of Surrey
Senate House, Guildford, Surrey, GU2 7XH
Phone: +44 (0)1483 689110

Email: rigo@surrey.ac.uk

The University has in place the relevant insurance policies which apply to this study. If you wish to complain or have any concerns about any aspect of the way you have been treated during the course of this study, then you should follow the instructions given above.

Who should I contact for further information?

If you have any questions or require more information about this study, please contact the research team using the following contact details:

Trainee Clinical Psychologist: Gina Sherlock



Thank you for reading this information sheet and for considering taking part in this research.

Appendix C: Participant consent form (online version)

Consent Form

INFORMED CONSENT FORM.

Thank you for considering taking part in this research.

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Study: The feasibility of a group CBT intervention for improving psychological outcomes in parents of children with food allergy.

University of Surrey Ref: FHMS 20-21 005 EGA

The person asking for your consent must explain the project to you before you agree to take part. If you have any questions about the Information Sheet or their explanation, please ask the researcher before you make your decision. You will be given a copy of this Consent Form and the Information Sheet to keep and refer to at any time.

By clicking on each box, you are consenting to this part of the study. Any un-ticked boxes will mean that you DO NOT agree to that part of the study, and this may mean you are ineligible for the study.

Q1

I confirm that I have read and understood the information sheet dated 15/03/2021 for the above study. I have had the opportunity to consider the information and asked questions which have been answered satisfactorily.

☐ Yes

Q2

I understand that my participation is voluntary and that I am free to withdraw at any time during the study without giving any reason. Furthermore, I understand that data already collected up until the point of withdrawal will be used in analysis, but no further data will be collected.

☐ Yes

Q3

I understand that information I provide may be subject to review by responsible individuals from the University of Surrey and/or regulators for monitoring and audit purposes.

☐ Yes

Q4

I agree to take part in this study.

☐ Yes

Q5

I understand that information I provide will be used in various anonymised outputs including reports, publications, and presentations.

☐ Yes

Q6

I understand that my personal data, including this consent form, which link me to the

research data, will be kept securely in accordance with data protection guidelines, and only be accessible to the immediate research team or responsible persons at the University.

☐ Yes

Q7

I understand any personal contact details collected about me, such as my phone number and address, will not be shared beyond the study team.

☐ Yes

Q8

I understand that my participation in this research study involves being randomly allocated to either a control group or an intervention group.

☐ Yes

Q9

I understand that if I am allocated to the intervention group, my anonymity cannot be guaranteed in the group CBT workshops, but participants will be asked to keep the discussions confidential and the research team will keep any information collected confidential

☐ Yes

Q10

If I am allocated to the intervention group, I agree to keep the discussions in the group CBT workshops confidential.

☐ Yes

Q11

If allocated to the intervention group, I agree for the researchers to contact me if I do not attend the group CBT workshop.

☐ Yes

Q12

I consent to the processing of my special category data [ethnic origin, gender & psychological health] for the purposes stated in the information sheet

☐ Yes

Q13

OPTIONAL. I consent for my interview to be recorded, and for this recording to be used for the purposes stated in the information sheet.

☐ Yes

☐ No

Q18 Please print name

Q19 Please sign below:

Q19 Please enter date

Appendix D: Demographics and Food Allergy Questionnaire

Age:

How do you identify your gender?:

Male	
Female	
Non-binary	
If the above do not apply to you, please enter how you identify your gender	

How do you identify your ethnicity?:

White	
White British	
White Irish	
Irish Traveller or Gypsy	
Any other White background (please describe)	
Asian/Asian British	
Indian	
Pakistani	
Bangladeshi	
Chinese	
Any other Asian background (please describe)	
Black/African/Caribbean/Black British	
African	
Caribbean	
Any other Black/African/Caribbean background (please describe)	
Mixed/Multiple Ethnic Groups	
White and Black Caribbean	
White and Black African	
White and Asian	
Any other Mixed/Multiple ethnic background (please describe)	
Another ethnic group	
If the above do not apply to you, please enter how you identify your ethnicity	

Marital status:

Married/Civil partnered/Living with partner	
Separated/divorced	
Single	
Widowed	



Employment status:

Working full-time	
Working part-time	
Full-time education	
Not working	
Other (please describe)	

☐

Number of children living at home with a food allergy:

Age of child/children with food allergy (If you have more than one child with a food allergy, please state age for *each* child):

Number of food allergies (if you have more than one child with a food allergy, please indicate number of food allergies for *each* child):

Foods child/children allergic to (if you have more than one child with a food allergy, please indicate foods allergic to for *each* child):

Peanut	
Treenuts	
Egg	
Milk	
Fish	
Shellfish	
Soy	
Other (please state)	

Time since child/children were diagnosed (if more than one child has been diagnosed with a food allergy, please state time since *each* child was diagnosed):

Less than one year	
One year	
Two years	

Three years	
Four years	
Five years	
Other (please state)	

Does your child/any of your children with a food allergy have a history of anaphylaxis*?
(Please select answer which applies)

* For the purposes of this research study, anaphylaxis is defined as a severe allergic reaction requiring an immediate emergency response.

YES

NO

Has your child/any of your children with a food allergy been hospitalised due to an allergic reaction? (Please select answer which applies)

YES

NO

Is your child/any of your children with a food allergy prescribed an adrenaline auto injector? (Please select answer which applies)

YES

NO

Are any of the following atopic conditions present in your child/any of your children with a food allergy? (Please select all that apply)

Asthma	
Hay fever	
Eczema	
Other (please state)	

Appendix E: Food Allergy Quality of Life – Parental Burden Scale (Cohen et al., 2004)

[Questionnaire redacted]

Appendix F: Depression, Anxiety and Stress Scales – Short form version (Lovibond & Lovibond, 1995)

[Questionnaire redacted]

Appendix G: Penn State Worry Questionnaire (Meyer et al., 1990)

[Questionnaire redacted]

Appendix H: Food Allergy Self-Efficacy Scale for Parents (Knibb, 2015)

[Questionnaire redacted]

Appendix I: Goal-based outcome measure (based on Law & Jacob, 2015).

We would like to ask you about your progress towards the goal you set during the Group CBT session.

Please rate the progress you feel you have made towards your goal below. A score of 0 means that no progress had been made towards your goal and a score of 10 means that you have reached your goal fully. A score of 5 would mean you are exactly half-way to meeting your goal.

0	1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	---	----

Appendix J: Feedback questionnaire

Participants' feedback survey

Thank you for taking part in our research study on CBT interventions for parents of children with food allergy. We would very much appreciate your feedback so that we are able to understand your experience of taking part. There are two sections to this questionnaire; the first section asks for feedback on the CBT group workshop and the second section asks for feedback on the research study as a whole.

Understanding your experience of the Group CBT Workshop for parents of children with food allergy

1. Please assess the following statements based on your experiences of taking part in the Group CBT Session for parents of children with food allergy:

	Strongly Disagree	Disagree	Neither Disagree nor Agree	Agree	Strongly Agree
The group session was organised well and ran smoothly					
The group session lasted an appropriate amount of time					
Taking part in the group session was not too burdensome for me					
I felt safe and comfortable during the session					
The group session met my expectations					
On the whole, I found the group session to be helpful					

2. What do you think were the best aspects of the Group CBT workshop?

3. What improvements do you think could be made to the Group CBT workshop?

4. What changes, if any, have you noticed in yourself since taking part in the Group CBT workshop?

5. How likely do you think these changes would have been if you had not taken part in the Group CBT workshop?

1. Very likely without the CBT workshop
2. Somewhat likely without the CBT workshop
3. Neither likely nor unlikely (no way of telling)
4. Somewhat unlikely without the CBT workshop
5. Very unlikely without the CBT workshop

6. Is there anything you wanted to change that hasn't changed since taking part in the Group CBT workshop?

7. How likely would you be to recommend Group CBT to other parents of children with food allergies?

1. Very Likely
2. Somewhat Likely
3. Neither Likely nor Unlikely
4. Somewhat Unlikely
5. Very Unlikely

Understanding your experience of the research study as a whole

8. Please state your reason for taking part in this research study:

Please select as many answers that apply to you

I thought this study offered the best treatment available ☐

I believed that results from this study could benefit other parents in the future ☐

I wanted to contribute to scientific research ☐

I thought I would receive better care as part of this study ☐

My family/friends thought I should participate ☐

Other (please give details below)

9. Please indicate how strongly you agree or disagree with each of the following statements:
“In general, I found taking part in the overall study (consenting to take part in the study, filling out questionnaires, attending the Group CBT session and giving feedback) to be”:

	Strongly Disagree	Disagree	Neither Disagree nor Agree	Agree	Strongly Agree
Easy					
Convenient					
Interesting					
Worthwhile/beneficial					
Time consuming					

10. Are there any changes to the research study that you would make so that it can be more helpful for parents of children with food allergies?

Appendix K: Ethical approval from the University of Surrey Ethics Committee

RESEARCH & INNOVATION SERVICES
SURREY.AC.UK/RIS



Research Integrity & Governance
Office (RIGO)
4th floor Senate House
Guildford
Surrey GU2 7XH UK
T: +44 (0)1483 68 9103/2051
ethics@surrey.ac.uk
www.surrey.ac.uk

Gina Sherlock
School of Psychology
FHMS

16 October 2020

Dear Gina,

EGA ref: FHMS 20_21 005 EGA

Study Title: The feasibility of a group CBT intervention for improving psychological outcomes in parents of children with food allergy

On behalf of the Ethics Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the submitted protocol and final supporting documentation listed in the table below.

Date of confirmation of ethical opinion: **16th October 2020**

This opinion is given on the understanding that you will comply with the relevant University policies, ethical and professional standards and any applicable regulatory requirements, and have completed all mandatory training provided by the University of Surrey.

If the project includes distribution of a survey or questionnaire to members of the University community, researchers are asked to include a statement advising that the project has been reviewed by the University's Ethics Committee.

Given the exceptional nature of the situation arising as a result of the Novel Coronavirus (COVID-19) pandemic, the University Ethics Committee (UEC) requires all ongoing research to make changes to how participant interactions are conducted. Researchers must consider if their strategy for recruitment, consent and data collection can be changed to remote interaction.

Research which cannot be conducted remotely, and which requires face-to-face interaction will be able to re-start in a managed way, subject to conditions to ensure the health and safety of everyone concerned being met.

Please follow guidelines below and note that all research activity must comply with current University guidance regarding the Covid19 pandemic:

<https://www.surrey.ac.uk/coronavirus/researchers/research-university-ethics-committee-approval>



If you have not already moved your consent, PIS and face-to-face activities to an on-line format, you will now need to inform us via email how you plan to proceed with this study. You may proceed either by pausing the project, or by adapting human participation aspects to remote/online activity, or by re-starting in a managed way in accordance to the guidelines in the link above. Please familiarise yourself with the above link and advise us on your plan.

You will need to inform us how you plan to proceed within 7 days of the date of this letter via email to ethics@surrey.ac.uk

If you wish to make any changes to the Protocol for this project, now or later, other than those permitted in the guidance provided in the above link, you must submit a Notification of Amendment form before any changes can be implemented. Please refer to the Guidance on Amendments which can be found on the Research Integrity and Governance Office webpages. Please note that the governance approval of this project is valid until the study end date provided.

Please be aware that the Committee will need to be notified of any incidents, deviations from protocol or adverse events that may potentially impact the research participants or your data integrity, and if the study is terminated earlier than expected with reasons. You should do this by contacting ethics@surrey.ac.uk. Please be advised that the Ethics Committee and/or RIGO can audit research projects to ensure that researchers are abiding by the University requirements and guidelines.

This favourable ethical opinion is valid for the duration of the project. If you require an extension to the study end date, you must submit a notification of amendment. Please note that if the study is not completed within five years of the above date, you will be required to submit a new application to the Ethics Committee.

Please notify RIGO (ethics@surrey.ac.uk) when the research has been completed.

The final list of documents reviewed by the Committee is as follows:

Document	Version	Date
SAGE response pdf 514292-514283-64833543	-	21 st Sept 2020
EGA form	1.0	28 th Sept 2020
Protocol	1.0	24 th Sept 2020
Participant Information Sheet	1.0	27 th Sept 2020
Consent form	1.0	27 th Sept 2020
Data Management Plan	1.0	28 th Sept 2020
Recruitment materials	1.0	14 th Oct 2020
Team Summary	1.0	14 th Oct 2020
Consort diagram	1.0	14 th Oct 2020

Yours sincerely



Research Integrity and Governance Co-ordinator
Copy to Dr Christina Jones



Part Two – Second Empirical Paper

**A qualitative exploration of the psychological support needs of mothers of children with
food allergy**

Word count: 9,918

(Excluding Abstract, Tables/Figures, References and Appendices)

Abstract

Background: Allergy research has established that a child's food allergy seems to have a psychological impact on the lives of parents, therefore attention must now turn to developing effective interventions which mitigate this impact. In order to develop interventions that are acceptable for parents of children with food allergy, it is important to understand their perceived psychological needs. There is currently a lack of qualitative research which explores this; this research is important as it can offer unique insights into and provide a contextual understanding of food allergy associated distress. It has been suggested that current understandings of parental distress could benefit from a more nuanced perspective. Thus, this study sought to establish parents' psychological support needs from their own perspectives.

Method: Ten mothers of children with food allergy completed semi-structured interviews. Interview transcripts were analysed using reflexive thematic analysis.

Results: Four main themes were constructed: 1) Feeling equipped to manage anxiety 2) "Dealing with a world that doesn't necessarily get it" 3) Feeling the weight of judgement, and 4) "We do allergies, we don't do mental health" – gaps in the healthcare system. Mothers' experience of food allergy associated distress was experienced at an individual level but was often influenced by interactions within the wider system.

Conclusion: Parents may benefit from a range of psychological support which could intervene at the individual, interpersonal, and healthcare system level. Further clinical research is needed to explore the effectiveness and acceptability of a range of psychologically-informed interventions for parents.

Introduction

The psychological impact of managing a child's food allergy has been explored more closely in allergy research over the past twenty years. Quantitative studies have shown that parents of food-allergic children experience high levels of stress and anxiety (Cummings et al., 2010a; King et al., 2009; Lau et al., 2004), with clinically significant levels of worry and posttraumatic stress symptoms also reported (Roberts et al., 2021). Qualitative research has explored the experiences of parenting a child with food allergy, highlighting the unique factors pertinent to living with food allergy which may contribute to associated distress. Parents have reported: living with constant concern about accidental exposures (Abrams et al., 2020), strong emotions of fear after a reaction, leading to constant vigilance and the need to carefully plan and prepare (Gillespie et al., 2007; Mandell et al., 2002) in addition to social isolation (Abrams et al., 2020), including feeling misunderstood by others (Rouf et al., 2011). A qualitative meta-synthesis of parents' experiences of living with a child's food allergy based on 24 studies (Moen et al., 2019) highlighted that the emotional and social impact of parenting a child with food allergy was often characterised by living with fear; they concluded that support from healthcare professionals was essential in providing families with a way to manage. Thus, research has established that a child's food allergy seems to have a psychological impact on the lives of parents, and now attention must turn to developing effective interventions which mitigate this impact.

In order to develop interventions that are acceptable for parents of children with food allergy, it is crucial to understand their perceived psychological needs. Whilst previous qualitative research has sought to understand the general experience of parenting a child with food allergy, little research has explored what parents feel they need psychological support with in particular and their perceptions of what would be useful. This is important as previous research has highlighted that levels of parental distress can vary; whilst some parents may

require psychological support, some may not. Gillespie et al. (2007) highlighted how some mothers reported adapting to the risks of food allergy and incorporated this as part of their lives; however, some reported a much larger impact on their lifestyle. Results from quantitative studies have also shown this range of parental psychological distress (Knibb & Semper, 2013; Roy & Roberts, 2011), indicating that only a sub-group of parents of food allergic children may require psychological intervention. It is thought that mothers in particular may be at risk of the negative psychosocial impact of parenting a child with food allergy; a study by King et al. (2009) highlighted that mothers reported higher levels of stress and anxiety than fathers and reported that a child's food allergy had a greater impact on their quality of life than any other members of the family. This may be due to mothers taking the primary role in managing a child's food allergy, with fathers described as 'helping' rather than taking a central role (Mandell et al., 2002). It has also been suggested that those who tend to worry about other areas of their lives, have misperceptions about the risk of a severe reaction, or have a child with complex food allergies (or indeed a combination of these factors) may experience a high level of distress when managing a child's food allergy (Knibb, 2015).

Due to these individual differences in psychological distress, existing studies have highlighted the principle of an 'optimum' level of anxiety (Mandell et al., 2005), where it is thought that 'adaptive anxiety' involves parents displaying a high enough level of anxiety to engage in risk management and keep their child safe, but not so much anxiety that this leads to imposing too many restraints on the child's and/or family's life. Whilst this may be an important finding which acts as a starting point from which to view parental perceptions of risk, Rouf and Evans (2019), writing from their dual position of both clinical psychologists and parents of children with severe food allergies, argue that striking this 'balance' can be a hard task which is likely to be impacted by contextual factors. They therefore call for more

contextual understandings of parental distress, and state that “parental anxiety needs to be viewed in a wider context that pays attention to gender, culture and an awareness of wider society” (Rouf & Evans, 2019, p. 31). For example, they discussed how gender biases in caring for a child with food allergy can sometimes lead to negative stereotyping of mothers as ‘over-anxious’. Furthermore, they commented that public understandings of food allergy are still in their infancy, which can on some occasions mean ‘allergy’ is misunderstood as ‘intolerance’ or ‘preference’. The authors acknowledged that research has provided more understanding on the psychological impact of food allergy, but “responding helpfully to people affected by allergy involves the interplay of issues which are deeper than apparent in emerging research on allergy” (Rouf & Evans, 2019, p.32). Responding helpfully to parents affected by food allergy therefore involves trying to understand the nuance of their experiences so that support can be provided that is sensitive to perceived parental needs.

Of those who may require an intervention, a smaller number may be able to access this. A lack of psychological interventions for parents of children with food allergy, in comparison to parents of children with other chronic illnesses, has been noted (Rouf et al., 2011). UK funding for psychological support varies from region to region, and as such work to support parents can be provided by a range of professionals, in a variety of ways, under time limitations (Knibb, 2019). Although calls for access to psychological support for families have been made (e.g., Muraro et al., 2015) there remains little information about psychologically-informed interventions in National Institute for Health and Clinical Excellence guidelines for allergy (NICE, 2011). In the development of interventions aimed at mitigating the psychological impact of a child’s food allergy, parents have a key role to play in sharing their unique insights if healthcare provision is to be developed in partnership with clients, rather than “didactic service delivery” (Gallagher et al., 2009, p. 1117).

Current study

The psychological impact of a child's food allergy and the psychological support needs of parents are relatively new areas of research, and as such, more studies are needed to understand the often-complex interaction between food allergy, psychological distress, and appropriate intervention (Feng & Kim, 2018). Previous qualitative studies have explored and documented the psychosocial impact of living with a child's food allergy in general, however little research has examined the perceived support needs of parents seeking a psychological intervention. Such information is of vital importance when developing psychological interventions that are both acceptable and meaningful to parents.

Understanding the nuance of psychological distress of parents of children with food allergy is a key aspect of developing and providing appropriate support. A qualitative approach has the potential to offer rich and detailed information to gain a deeper insight into parental psychological support needs which focuses on understanding context (Gallagher et al., 2009; Lyons, 2011). The research therefore seeks to explore the psychological support needs of parents of children with food allergy. It is hoped that with a clearer understanding of these support needs, as informed by parents themselves, interventions can be shaped to best help those who may require psychological support. Therefore, the research question is as follows: What are the psychological support needs of parents of children with food allergy?

Method

Ontological and epistemological position

Willig (2013) highlights how qualitative research can be carried out from a range of ontological and epistemological positions, and it is fundamental for the researcher to explicitly acknowledge their own position in order to identify the assumptions which shape the research and knowledge generation. A critical realist approach was adopted "where an underlying reality might be recognised but seen as mediated through the multiple social

realities of participants and wider culture” (Terry & Hayfield, 2021, p.9). This position represents a realist ontological position (where an underlying reality is assumed to exist) combined with an epistemological position which acknowledges the constructivist nature of scientific knowledge (Elger, 2010). Therefore, participant accounts were understood as lived realities that are formed and exist within wider social and cultural contexts (Terry et al., 2017).

Participants

Participants were invited to take part in a wider study in which this qualitative study is nested. The details of this wider study and the recruitment methods used, including eligibility criteria, can be found in Part One of this thesis.

Convenience sampling was used and a subset of parents from the intervention group in the wider study expressed their interest in taking part in qualitative interviews to share their reasons for wanting to access psychological support, their experiences of accessing support, and what kind of support would be helpful for them. All participants were interviewed before taking part in the intervention as described in Part One of this thesis.

Ten mothers of children with food allergy were recruited for qualitative interviews. The decision to interview ten parents was a pragmatic one, considering parent preference to take part in an interview and the timescales of the study. At least six participants has been identified as a sufficient number of participants for studies involving thematic analysis (Braun & Clarke, 2013; Terry & Hayfield, 2021).

It should be noted that although both mothers and fathers were invited to participate in this study, the majority of participants in the wider study were mothers, which meant that the subset of participants expressing interest in interviews was made up only of mothers. Therefore, although not an aim of the study, only the experiences of mothers are captured.

Procedure

Semi-structured in-depth interviews were carried out between April and June 2021 with ten mothers of children with a diagnosed food allergy. Due to restrictions caused by the COVID-19 pandemic, all interviews were held remotely over Zoom.

A semi-structured topic guide was used in order to explore the aforementioned areas of interest, whilst allowing participants the freedom to discuss more flexibly the areas of importance to them (Appendix A). The topic guide began with a broad question around why mothers were seeking psychological support to understand the main areas mothers felt they needed support with. In order to ‘unpick’ and gain more in depth understanding of areas of identified support needs, more specific questions around the ‘problems’ identified were added to the topic guide (e.g., What makes these problems better? What makes them worse?). Prior to developing the topic guide, the lead researcher attended an Anaphylaxis Campaign support group where they had the opportunity to hear about the impact of food allergy. This highlighted how some mothers were proactively seeking support, so it was important to capture what support mothers had sought, if this had met any kind of psychological support need, and what psychological support needs remained. Finally, as literature has highlighted that allergy-specific psychological support can be sparse and delivered in a variety of ways (Knibb et al., 2019), a question was added to the interview schedule to explore mothers’ experiences of accessing psychological support in particular, as part of understanding what psychological support needs may be being met or unmet in the sample of parents interviewed.

Interviews were digitally recorded and transcribed verbatim. Once interviews had been transcribed, the digital recordings were erased.

Ethical considerations

This research study gained favourable ethical opinion from the University of Surrey Ethics Committee (Ref: FHMS 20_21 005 EGA; see Appendix K in Part One). All participants were

given an information sheet and the opportunity to ask questions before signing an electronic consent form (see Appendices B and C in Part One). In line with the British Psychological Society's Code of Human Research Ethics (Oates et al., 2021), confidentiality was ensured by removing all identifying details from the transcripts, such as names of people and places. All participants gave their consent for direct quotations to be used within reports resulting from the research. Pseudonyms were also allocated for each participant by the lead researcher.

Interviews involved the discussion of the psychological impact of parenting a child with a food allergy, which had the potential to elicit distressing emotions for mothers. Participants were reminded at the start of the interviews that they could take a break or stop the interview at any time. Signposting to further sources of support was provided during the interviews, if necessary. All participants who took part in the interviews later attended a CBT workshop for parents of children with food allergy as outlined in Part One of this thesis and were given an accompanying workbook where sources of mental health support were provided. All participants had the contact details of the lead researcher should they have wished to have discussed any concerns arising from the interviews. The lead researcher had access to supervision from a Clinical Psychologist and Reader in Clinical Health Psychology should any concerns regarding participant safety have arisen during interviews.

Data analysis

Braun and Clarke's approach to thematic analysis (TA) has been defined as a theoretically flexible method for identifying, analysing, and interpreting shared patterns of meaning across qualitative data (Braun et al., 2014). Due to this flexibility, it has been identified as an appropriate research method to answer a range of questions in clinical health psychology, including understanding individual lived experiences and perceptions of health conditions (Braun et al., 2014). It has also been highlighted as "the first qualitative method of analysis

that researchers should learn” (Braun & Clarke, 2006, p. 78) due to its clear outlining of key tools and skills. Therefore, TA was deemed to be an appropriate method of qualitative analysis to answer this particular research question, in line with the researcher’s underlying theoretical position and level of experience in qualitative analysis.

Reflexive TA was carried out according to the six-stage process developed by Clarke and Braun (2016). Firstly, the researcher gained familiarisation with the data by reading and re-reading interview transcripts and making unstructured notes about any areas of initial interest. Data was then coded into individual units of meaning using NVivo software. Mainly semantic (descriptive) coding was used, with some latent coding being used when interpretations by the researcher were made (see Appendix B for an example of coded data from the initial coding stage). The researcher then began to ‘search for themes’ by clustering together codes that appeared to relate to a particular pattern of meaning. Themes were then reviewed before being defined and named (see Appendix C for thematic maps). Finally, the results of the thematic analysis were written up.

As “themes cannot exist separately from the researcher...[and] are generated by the researcher through data engagement mediated by all that they bring to this process” (Braun & Clarke, 2020, p.39) a reflexive account has been written, taking into consideration how the author’s position shaped and impacted on the research process (Appendix D). Braun and Clarke’s (2021) tool for evaluating thematic analysis was used as a framework for considering the research quality.

Results

Participants

Demographic details and pseudonyms for the 10 mothers who took part in the interviews are presented in Table 1.

Table 1. *Participant demographics*

Demographic measure	Rachel	Laura	Louise	Ali	Lizzie	Roisin	Heather	Erin	Nicole	Amy
Gender	Female	Female	Female	Female	Female	Female	Female	Female	Female	Female
Age bracket (years)	35-39	30-34	35-39	40-44	35-39	35-39	40-44	45-49	35-39	35-39
Ethnicity	White British	White British	Other White	White British	White British	White Irish	White British	White British	White British	White British
Marital status	Married/Civil Partnered/Living with partner	Married/Civil Partnered/Living with partner	Married/Civil Partnered/Living with partner	Married/Civil Partnered/Living with partner	Married/Civil Partnered/Living with partner	Married/Civil Partnered/Living with partner	Married/Civil Partnered/Living with partner	Married/Civil Partnered/Living with partner	Married/Civil Partnered/Living with partner	Married/Civil Partnered/Living with partner
Number of children living at home with a food allergy	1	1	1	2	1	1	1	1	2	1
Age bracket of child/children with food allergy (years)	0-2	0-2	0-2	6-11	12-16	6-11	12-16	3-5	6-11	6-11
Number of food allergies*	5	5	4	4	6	1	6	4	5	8
History of anaphylaxis	No	Yes	No	Yes	Yes	Yes	No	Yes	Yes	No

* If participant had more than one child with food allergy, this denotes the highest number of food allergies any one child has

Thematic Analysis

Four overarching themes were constructed. The first theme '*Feeling equipped to manage anxiety*' highlights how parents felt they needed support with managing anxiety and were seeking tangible support to help them feel 'equipped' to manage. This theme was separated into two subthemes '*Everyday, chronic anxiety*' and '*Traumatic experiences and acute events*', highlighting that experiences of anxiety might take the form of lower level, but chronic, anxieties that have an impact over time and higher-level anxiety relating to acute events and even traumatic experiences. The second theme "*Dealing with a world that doesn't necessarily get it*" describes how parents reported the impact of a lack of understanding of food allergy; in many cases the understanding of others appeared to have moderating effect on the levels of anxiety that parents felt. A lack of understanding also had an impact on trust and family dynamics. The third theme '*Feeling the weight of judgement*' describes how parents had to contend with both feelings of judgement from others and self-judgement and self-criticism, leading to feelings of isolation and guilt. Finally, the fourth theme "*We do allergies, we don't do mental health*" – *gaps in the healthcare system*' describes how parents felt there were multiple gaps in the healthcare system which contributed to their psychological needs not being acknowledged or addressed. In some instances, the way allergy services were run had a direct impact on the level of psychological distress parents experienced. The reporting of themes will be contextualised with discussion referencing relevant literature (Braun & Clarke., 2013; Terry et al., 2017).

Theme 1: Feeling equipped to manage anxiety

Subtheme: Everyday, chronic anxieties

Mothers spoke about wanting psychological support to manage the everyday anxieties of living with a child's food allergy. As reflected by the wider literature, mothers spoke about anxiety as being related to the anticipation of a future allergic reaction and experiencing worry, fearfulness, and hyperarousal in relation to this potential threat (Polloni & Muraro, 2019; Westwell-Roper et al., 2021). They described a “*continual kind of...like thought process around “is this safe?” (Laura)* and a constant process of having to plan and prepare in order to reduce the risk of exposure to an allergen. Laura explained “*naturally, that over time will take it's kind of toll on you sort of emotionally*”. Heather described this process as “*like Groundhog Day, every day, you can't have a day off from it*”, indicating the chronicity of the impact of food allergy. The accumulation of daily strains and stresses, including experiencing a constant state of hypervigilance has been related to exhaustion, ongoing anxiety, and helplessness (Broome et al., 2014; Trollvik & Severinsson, 2004; Williams et al., 2009). It has also been suggested that the daily measures taken to avoid allergen exposure are more closely associated with poorer quality of life than the impact of actual exposure to an allergen (Bollinger et al., 2006; Marklund et al., 2007).

Mothers spoke about the ways they currently managed their anxieties around allergen exposure, which often involved “*being in control of everything*” (Louise) and attempts to reduce the risks of allergens which involved vigilance and avoidance. Ali explained how “*it's become apparent as the years have gone on that I hyper control everything, um, and plan plan plan all scenarios*”. Whilst some vigilance and avoidance are indeed necessary in the management of food allergy, some mothers explained that they were seeking psychological support to manage in different ways due to the perceived undesired impact of their current methods of coping. Nicole explained:

*“I’m quite mindful of how it affects certain aspects of our life if that makes sense?
And I don’t want...I don’t want to limit their life in ways that don’t need to be limited
due to my anxieties...when it comes to the other methods...avoidance, it doesn’t feel
very fair, people are missing out and [child] is missing out and there’s places he’d
like to go”.*

Furthermore, some mothers recognised that their current coping strategies reinforced the anxiety they experienced; *“I will probably be checking, and checking again, and even triple checking...and again that’s all kind of part of the anxiety as well, isn’t it?” (Roisin).*

Here, Roisin and Nicole describe how avoidance and checking behaviours help them to reduce the threat of allergen exposure in the short term, however, they lead to undesirable consequences which maintain anxiety in the longer term. Mothers also commented on how controlling the environment of a younger child was easier to do and how they had concerns for how they may cope with anxiety when control of allergy management was transferred to their child as they got older: *“Yeah, it’s much harder to control things [as the children get older], so yeah, it’s...and I guess the realisation that as I am less able to control things my coping is potentially not going to improve” (Ali).*

The use of control as a coping strategy has been reported in other qualitative studies (e.g., Gillespie et al., 2007; Lagercrantz et al., 2017; Mandell et al., 2002; Rouf et al., 2011; Stensgaard et al., 2017). Mother’s attempts to gain a sense of control over food allergy is perhaps not surprising due to its uncertain and unpredictable nature (Steiner et al., 2020); indeed Stensgaard et al. (2017) highlighted how adolescents with food allergy and their families have to live with uncertainty as “permanent companions” (p. 3371) in their lives. Steiner et al. (2020) have proposed that individual differences in caregivers’ comfort with uncertainty may help to explain why some caregivers report a larger impact of food allergy than others. Intolerance of uncertainty has been defined in its most simple terms as an

underlying “fear of the unknown” (Carleton, 2016, p.31). The Cognitive Behavioural Therapy (CBT) model of intolerance of uncertainty (Herbert & Dugas., 2019; Robichaud et al., 2019) posits that individuals who fear uncertainty are more likely to make threatening interpretations of uncertain situations and overestimate the likelihood of negative outcomes. These interpretations may underpin heightened levels of anxiety and fear, leading to worry and behaviours to control or reduce uncertainty (e.g., in this case avoidance or trying to plan for all scenarios). Intolerance of uncertainty has been associated with higher food allergy associated anxiety in the current literature (Roberts et al., 2021; Soller et al., 2020) and therefore may play a central role in its maintenance.

In terms of psychological support that mothers felt would be helpful for managing day-to-day anxiety, many named tangible ‘tools’ including “*a chance to break down the...er...a fixed way of thinking*” (Nicole), “*coping strategies and kind of how to talk myself down really and calm myself...probably like breathing things or visualisation things*” (Amy), ways to “*calm myself down a bit ...and try and listen to the voice of reason, rather than the voice of worry a bit more*” (Lizzie) and “*tools to help being ok with giving up control a little bit*” (Louise). Parents hoped that these ‘tools’ might help them to feel “*kind of that bit more steady in yourself for feeling better equipped to handle sort of everything that having a child with food allergies kind of brings really*” (Laura). As illustrated by the above quotes, mothers referred to desiring tools that helped with cognitions, behaviours, and the physiological effects of anxiety. Therefore, interventions based on CBT, which seek to understand how thoughts, behaviours, physical sensations, and emotions interact to keep anxiety going (Beck, 2011) may be an appropriate form of intervention. Treatment involves the use of the desired ‘tools’ and techniques in order to change behaviours, thoughts and the physical sensations associated with anxiety. Furthermore, CBT interventions aimed at addressing intolerance of uncertainty such as problem solving training and behavioural experiments to modify safety

seeking behaviours and avoidance might be helpful (Herbert & Dugas, 2019). Initial research on CBT interventions for parents of children with food allergy have shown promising findings for reducing parental anxiety (Boyle et al., 2017; Knibb, 2015; Vreeken-Ross et al., 2021), indicating that CBT-based approaches may be warranted.

Whilst CBT may be an appropriate recommendation for parents seeking tangible, practical tools to help reduce their day-to-day anxiety, it was clear from mothers' accounts that it was extremely important for any psychological intervention to be delivered by professionals with an understanding of food allergy. One mother described her experience of CBT in a general primary care service as being unhelpful, as she felt that the therapist delivering the CBT was "*was struggling to understand*" (Rachel) the very real risks to her son. She commented: "*something more allergy focused, where you can explain that type of thing in more detail with somebody who understands allergies – that might help me more than somebody who didn't have any experience of food allergies*" (Rachel).

Clinician experience with the specific issues pertinent to managing a child's chronic health condition has been deemed of prime importance for understanding the uniqueness of certain challenges and therefore tailoring treatments in a helpful way (Woolfe-King, 2018). This is thought to build trust between the practitioner and client (Shaker et al., 2020) and highlights the importance of a good "provider fit" (Broome et al., 2014, p.536).

Subtheme: Traumatic experiences and acute events

Aside from day-to-day anxieties that parents faced, many felt anxiety was heightened after a traumatic episode or an acute event such as an allergic reaction or other healthcare difficulty. An increase in anxiety after a reaction has been reported in a qualitative study by Mandell et al. (2002), with some parents reporting a high level of anxiety which subsided after a short period of heightened vigilance. This was a pattern reported by one mother:

“the sort of six weeks or so after [a reaction] you’re watching...you’re watching that bit closer. Your actual anxiety’s a little bit more heightened to what it was. So, the anxiety is already there and then it’s worse for a short while, and then you know it goes back to normal” (Lizzie).

In contrast, some mothers reported that a high level of anxiety after an acute reaction remained. They reported distressing memories of the reaction and one mother reported ‘reliving’ her experience of her child’s allergic reaction:

“I had to make him sick, which was sticking my fingers down his throat, and he knew what I was doing, and it was just horrible...when I think about that I just go back to sitting on that couch thinking...you know, and all those thoughts, you know” (Erin)

Erin went on to describe extreme apprehension about having to manage another reaction and described uncomfortable physiological symptoms when thinking about this: *“there’s a lot of apprehension about having to deal with the next one...you feel the butterflies first and then the heart racing...I recognise that as being different from how I used to be”*. Allergic reactions, including the progression to potential anaphylaxis, constitutes a threat to life and can be fatal if not treated quickly (Muraro et al., 2007). This threat to life can therefore be considered a traumatic experience which may give rise to acute stress reactions which include symptoms of distressing memories of the event, dissociative reactions (e.g., flashbacks), efforts to avoid external reminders, thoughts or feelings about the event and, hypervigilance (Polloni et al., 2020; Schiaffini et al., 2019). In a study by Roberts et al. (2021) 42% of parents of children with food allergy scored above the clinical cut off for post-traumatic stress symptoms (PTSS), with 34% scoring over the clinical cut off for post-traumatic stress disorder (PTSD). Parents reported stressful events including witnessing both anaphylactic and non-anaphylactic reactions in their child and other events including finding out their child had been exposed to an allergen. These rates of acute stress reactions were similar to

another study that reported 32% of caretakers scored above a significant threshold score on a questionnaire designed to evaluate PTSS (Annunziato et al., 2012). It is therefore important for clinicians to be aware allergic reactions may pose a risk for acute stress reactions, with some parents requiring support for *“a lot of trauma seated just below the surface”* (Nicole). Nicole explained that having support with *“being able to kind of process that and make sense of it [the reaction]”* would be helpful: *“Being supported after an incident...having that debrief almost at the allergy clinic, that is so important...to have that reassurance from them that I did the right thing...that I can ask those questions about what happened”*. Such a “debrief” session could offer clinicians the opportunity to assess parents after a traumatic event for symptoms of an acute stress reaction. Referrals could then be made for a complete assessment of symptoms and appropriate psychological support if needed (Polloni et al., 2020). Without such interventions, parents who experience PTSS may be at risk from developing PTSD over time (Rechenberg et al., 2017).

Theme 2: “Dealing with a world that doesn’t necessarily get it”

Mothers described how they felt there were varying levels of understanding when it came to food allergy. Mostly, parents described how they felt they were *“dealing with a world that doesn’t necessarily get it”* (Nicole) and there was a sense that *“it’s seen as quite a minor, erm, trivial thing by a lot of people”* (Amy). Examples of poor awareness of risk were given:

“People think “Okay you’re allergic to peanuts” and that’s fine, but they don’t think of if it’s a chocolate bar, for example, to look at the...at the packaging and...to ensure they can’t...they can have it or they can’t have it, you know?” (Roisin).

This poor awareness in others appeared to act as a moderator of parental anxiety; the less understanding the more anxiety parents felt: *“That is part of where the anxiety stems from as well, because you, you know that you’re... you’re putting a lot of trust in people who aren’t as informed, as you are”* (Nicole). Here, Nicole raises the important issue of trust. In order to

trust others, they must show that they understand the seriousness of the food allergy and are competent in being able to manage risk. Roisin tells the following story:

“Erm, in saying that all her reactions have been in like extended family member homes which then also leads to my anxiety in that, you know, she would be looked after by my mother sometimes and the reactions have happened there and my brother’s house, and even though I know they’re very aware of everything it’s just changing their outlook and ensuring that everything is... doesn’t contain the allergy”

Here is it understandable that Roisin feels reluctant to trust others to take care of her child.

This could also be considered an example of how it is important to consider context when thinking about maternal anxiety; in this scenario Roisin’s anxieties may be seen as an understandable consequence of other peoples’ misunderstanding. Ali also described situations when her anxiety was worse as being related to how seriously other people would take her child’s food allergy: *“heading back to school...it [the anxiety] was worse than ever...what would their teacher be like? Will they get it? Will they...will they take it seriously? (Ali).* In contrast to this, when others do understand the importance of safe allergy management, this may lower levels of parental anxiety and help build trust to transfer care to others: *“My mum’s always been great...she’s got...had the milks he has...you know...he could go to her house, and he’s got everything set up there” (Heather).*

The mothers’ quotes may be understood in relation to Rouf and Evans’s (2019) ‘Anxiety Seesaw’. They propose that anxiety may fluctuate depending on daily micro-interactions with others; low allergy awareness in others may lead to high anxiety in a parent, whilst high allergy awareness may lead to lower anxiety. They described shared responsibility for allergy management as creating ‘good psychological safety’ (Rouf & Evans, 2019, p. 32). Lack of awareness of food allergy has repeatedly been cited in the available literature as a major source of frustration for parents and one of the most difficult

parts of managing a child's food allergy (Broome et al., 2014; Cummings et al., 2010b; Gillespie et al., 2007; Mandell et al., 2002; Rouf et al., 2011). The lack of social support to help manage a child's food allergy can also be considered a stressor in itself, with mothers feeling an overwhelming sense of sole responsibility in caring for their child (Mandell et al., 2005; Rouf et al., 2011).

Some mothers also commented on how a lack of understanding could relate to interpersonal difficulties and tension within the family, highlighting a further area of psychosocial support need. Mothers described a lack of understanding amongst family members surrounding how the management of the food allergy should take place, causing tension within the family unit:

“Family dynamics as well that's quite important, erm, so where you would have thought maybe your parents, who I have a lovely relationship with... but it's just a generational thing possibly... so that that's kind of caused tension in the family at points at different... different times, erm, not that they would wish him any harm or anything but it's just lack of understanding. Erm, but yeah just, erm, tension I have with extended family...with your spouse as well, who's not...my husband's not so, erm, anxious about it all the time, you know?” (Amy)

Strain on interpersonal relationships has been acknowledged in other studies as a stressor impacting psychological wellbeing (e.g., Chooniedas et al., 2020). In a survey of 2900 parents, 25% reported that managing a child's food allergy caused a strain on their marriage (Gupta et al., 2010). Tension within the family unit may lead to breakdown in support systems; such support is important as it can help the parent to adjust and cope with managing a child's food allergy (LeBovidge et al., 2006). Therefore, interventions which use a family approach may be helpful for managing difficult interpersonal relationships which have an

impact on parental wellbeing (King et al., 2009; Pinsof & Wynne, 1995; Wright & Leahey, 2012).

When considering their psychosocial support needs, mothers explained that they sometimes only felt truly understood by others in a similar position: *“I don’t think there’s a great understanding unless you’re in it yourself” (Erin)*. Mothers explained that they felt support from peers was helpful in reducing feelings of isolation and normalised their experiences:

“There will be a number of times someone might write something about an experience, and I think I literally could have written that myself because that’s how...that’s what we’ve experienced... although scenarios are very different and yeah, I think sometimes there’s reassurance and thinking ‘I’m not just going bonkers, that is quite a common feeling for people’” (Laura)

This highlights the importance of peer support and may indicate that group interventions, which allow parents to connect with each other may be powerful for those feeling the isolation that “dealing with a world that doesn’t necessarily get it” may bring (LeBovidge et al., 2008; Stewart et al., 2011).

Theme 3: Feeling the weight of judgement

Mothers spoke about judgement, from both others and themselves, as affecting their psychological wellbeing. Firstly, parents described feeling worried about other people’s perceptions of the way they managed their child’s food allergy: *“I think it’s that worry or that anxiety around what other people perceive of what you’re doing and whether you’re being overbearing or controlling or whatever” (Laura)*. Here, Laura describes being acutely aware of other people’s perceptions, which she comments as feeding directly into worry and anxiety. This perception of being judged was also found in a qualitative study by Rouf et al. (2011), where parents described a consciousness of judgement which the authors described as

the “the social discomfort of allergy” (p. 58), again highlighting the importance of social context when understanding parental anxiety. Mothers described how this social judgement could lead to a sense of isolation:

“I feel, and that I’ve picked up from other parents is that sense of erm being quite different from others parents...that you stand apart a bit, for instance decisions about parties... school trips...the...when you’re...you’re still taking your child and staying at a party with your child long after everyone else has left... you’re hovering by them with food...you’re, erm, what it...you know, that sense that erm, and...and certainly from some people that sense...that judgement that you’re being too pro...overprotective” (Nicole)

Here, Nicole explains how she feels fundamentally different from others and “standing apart from others”. There was a sense that due to this, parents felt they had to explain to others their behaviours, which weighed heavily upon them and was tiring:

“And it’s having to justify a lot why I do certain things. Erm, I’m very black and white, and it don’t take any risks, like he doesn’t eat ‘may contain’, for example...and it’s that whole you know, “Why do you need to do this? Why do you need to do that?” It...it...you know...it’s multifaceted... you know it’s just dealing with all those different layers and pressures and opinions” (Heather)

Heather describes a process of having to explain to others why she makes certain decisions surrounding her child’s allergy management. Some mothers referred to their parenting style being perceived as a “helicopter parent”, with “this perception that you are just completely over the top with them” (Heather). A sense of frustration has been reported in the wider literature when parents feel that their anxiety and therefore associated risk management is labelled as inappropriate or detrimental (Mandell et al., 2002), again highlighting the need to feel understood.

Alongside feeling the weight of judgement from others, there was also a theme of feeling the weight of self-judgement, which was often critical in nature. Parents often evaluated and judged their own decisions and their own actions, often in a negative light. Parents appeared to blame themselves for certain outcomes or situations, concentrating highly on their own role:

*“I feel like he lacked in the social aspects quite a lot, erm, because of me, because of him not going to nursery and because of my fear of taking him to different places”
(Rachel)*

“I think it stems right back to that first reaction...I can still re...we didn’t know he had milk and soya allergies and I can still remember walking to the shop, buying a box of baby porridge, taking it home, making it up, feeding it to him, and then, ‘wumph’ he reacted. And that knowledge of all those decisions that I, and I alone made. Even though everyone will be like “Yeah but you didn’t know” ... but they still were a series of actions I took that led to that reaction...and that... you know how that feels... you know how that feels... you know, yeah” (Nicole)

In these examples, both Nicole and Rachel appeared to focus heavily on their own role, without taking into consideration other factors that may have been relevant to decisions or actions that were made. This resulted in parents blaming themselves and feeling “*super guilty*” (Louise). Beliefs surrounding being a bad mother for restricting a child’s social life have been reported elsewhere (Knibb, 2015), and parents of young children have reported feeling guilty due to mistakes made during the initial learning process of managing a child’s chronic illness (Sullivan-Bolyai et al., 2003). Such feelings of guilt may arise due to cultural and social meanings of what being a “mother” entails; it is generally thought that being a mother means keeping a child safe and fostering intellectual, social, and emotional development (Broome et al., 2014; Ruddick, 1995). When a mother’s

competency of carrying out this role is challenged (e.g., by having to restrict social activities or manage an allergic reaction) it could possibly lead to questions over parental abilities, resulting in guilt if mothers do not feel they have “met” the requirements of their role. Amy describes how she sees her role as a mother and the associated expectations of this role: *“you do feel such a lioness as a mum, you just want to protect all the time and ultimately...the buck stops with me”*.

The feelings of judgement, self-criticism and guilt touched upon by the mothers in this study may suggest that compassion-based approaches may be an appropriate intervention. One example of a compassion-based approach is Compassion Focused Therapy (CFT; Gilbert, 2014), which was developed in order to address self-criticism by cultivating “inner compassion” (Gilbert, 2014, p.6). Although there is currently a dearth of literature on the effectiveness of compassion focused approaches with parents of children with food allergy, CFT has been shown to be an acceptable intervention for individuals with chronic illness (Carvalho et al., 2021) and may be appropriate for mothers who notice a large amount of self-judgement and guilt, or do not receive compassion from others, in relation to managing their child’s food allergy.

Theme 4: “We do allergies, we don’t do mental health” – gaps in the healthcare system

Mothers described that they felt there were many gaps in the healthcare system, and the way that allergy was managed in some instances perpetuated the anxiety they felt. Mothers felt that once an allergy was diagnosed, they waited a long time for any kind of regular allergy follow up, Louise commented *“a year after your initial diagnosis, that’s a long time not to hear from anybody or have any support from anybody”*. Long gaps between appointments also meant that parents had many questions that went unanswered, which had a direct impact on their mental wellbeing. Louise explained that after her child was diagnosed there was a

period of adjustment where many questions came to mind, but there was nobody to ask these questions to:

“Cause they did ask if I had questions at an initial appointment, right after his diagnosis. But it’s not really until after, like months after, that I realised I had, you know, hundreds of questions and I just wanted to sit down and talk to somebody about what this means for him [son] ...and I think it also contributed to us, just you know, completely freezing in fear and doing nothing...and so we just did nothing and lived in fear, every day, which is terrible”

Here, Louise’s experience of being left with unanswered questions contributed to anxiety and fear, but also to ‘freezing’ which elicited feelings of guilt. It was felt that more periodic check ins would be helpful, including a follow-up appointment once parents had had a chance to adapt to their child’s diagnosis. Regular allergy follow ups are relatively uncommon due to resource limitations (Abrams et al., 2020; Diwakar et al., 2017) however, ongoing communication and continuity of care have been reported to lessen anxiety relating to a child’s treatment for long term conditions (Woolf-King et al., 2018).

Parents also mentioned that when they did have questions, or indeed felt they needed support, there was gaps in where they might seek this from: *“There was no in between...there’s the person who knows the most in the country, probably, about this and then the mums on your street and there’s no one in between” (Erin)*. Here, Erin discussed the gaps that exist within healthcare, and being faced with either having to ask a consultant *“who would never have the time, you know” (Erin)* or ask for support from other parents. Parents discussed how due to a lack of formal support in healthcare services, they tried to be resourceful and fill these gaps with other means. Whilst some of this informal support seeking was helpful, parents felt in other ways this sometimes perpetuated their anxieties:

“Erm, I think with the social media you... you've got to be careful not to take on other people's worries and... and sort of take everything with a bit of a pinch of salt, erm, some of its helpful but I think some parents worry more than I do, erm, and some things they...they worry about I don't worry about...It...it...it's...you know, nobody that I've met on there so far has got a child with the exact same allergies, so you know, everyone's alerted to different things, so you... you've...you've always got to have your own things in mind erm, when reading things haven't you? (Lizzie)”

Rachel spoke about having to ‘snooze’ social media groups or *“leave the group or something because that can actually kind of trigger like an anxiety or a negative thought” (Rachel).*

This highlights that although informal support, such as social media, may be a helpful in some circumstances, it may also be a source of anxiety (Chooniedas, 2020). Akeson et al. (2007) found that psychosocial and information needs were largely met by informal support and allergy charities rather than healthcare services. Furthermore, a review of freely available online support for food allergy-related emotional wellbeing highlighted a need for resources to be more readable and accessible, as well as empirically researched (Vreeken-Ross et al., 2021). Limitations to informal support highlight the need for accurate, evidence-informed information and interventions provided by healthcare services.

The mothers' accounts also communicated there was the feeling that the medical management of the food allergy was prioritised, and there was a need for allergy care to be more psychologically informed. Parents commented that they felt appointments are set up in such a way that they felt unable to bring up their psychological needs.

“We've...even at our last allergy appointment we had...we typed up questions like ‘Can you give us resources for support groups that are local to us?’ ‘Can you talk to us about you know...this...that?’ and they just...there's not time in those appointments...their priority during those appointments is to do the testing” (Louise)

Mothers also explained that even if they had wanted to ask for support at an allergy appointment this was extremely difficult to do due to the presence of their child at the appointment: *“what’s one thing I would say is it’s very difficult even to use that consultant consultation to reach out and get some support because your child’s sitting there” (Amy)* Mothers did not want to communicate their anxieties in front of their children, which led to constraints in what they might broach in the appointments:

“Erm, in terms of what’s unhelpful I guess it’s that sense that you don’t...where you’re only talking to the allergy nurses for instance, in front of the children actually I’m pretty wary of showing how maybe broken off I am...and...and how scared I am because you don’t... I’m conscious of not creating that feeling in the children who are watching me so. So...so...you’re caging those questions quite carefully perhaps” (Nicole)

This suggests that if parents are not followed up routinely in separate spaces or if their mental health needs are not explicitly considered as part of an assessment, their needs may go unnoticed and concerns unaddressed. Previous research has shown that allergists have reported not having time to assess the psychosocial aspects of food allergy and have found using screening measures intrusive and ineffective at identifying above-threshold anxiety during routine allergy appointments (Memaury et al., 2022; Rubes et al., 2014). Feng and Kim (2020) and Herbert et al. (2016) have concluded that it remains key for allergists to consider the wellbeing of patients and families and have made suggestions for specific questions to ask to identify areas requiring further support. Feng and Kim (2020) have also suggested that a separate appointment dedicated to discussing the psychological aspects of managing food allergy should be considered. Mothers in this study felt that when assessing parental needs, an appointment where they can discuss their concerns separately from their

child might be necessary. Thorough assessment of need is important as it can lead to targeted intervention development (Herbert & Dunn Galvin, 2021).

Linked to the prioritisation of medical management, parents felt that there was very little acknowledgement of the psychological impact of food allergy: *“I feel like when you’re prescribed an EPI pen whether you take it at the time or not there should be something psychological...what I expect goes along with being prescribed that...”* (Erin). Erin’s quote echoes findings from other qualitative studies which have shown that parents feel that healthcare professionals often focus on the medical aspects of care, are ‘scientific’ in their approach and ignore the emotional elements of food allergy (Broome et al., 2014; McBride et al., 2010). Parents have also reported that even when they are given relevant allergy information, this focused on allergen avoidance, with information on emotional wellbeing being absent (Chooniedas et al., 2020). Furthermore, it was felt that there was little awareness around psychological support that could be recommended, with parents feeling unsure how best to get the support they needed:

“It just boggles my mind that it’s just not...it must be out there, but when we are asking the medical...when we’re asking our contacts in the medical professional they’re just like “Dunno”, it’s...you know... “we do allergies, we don’t do mental health” how are they not overlapping? It’s just crazy (Ali)

The majority of mothers reported that they had not accessed psychological support even though they felt this would be beneficial. Mothers described this as not being offered. This shows how pathways for parents to access psychological support could be made clearer, with healthcare professionals offering clear signposting or an integration of psychological support into routine allergy practice. Studies have shown that integrated health services, which includes embedding psychological care within teams, have benefitted families by offering a

holistic approach that focuses on more than just diagnosis and medical management (Mercer et al., 2015; Satherley et al., 2021).

Discussion

This research sought to explore the psychological support needs of mothers of children with food allergy; this understanding is essential to support the development of acceptable interventions aimed at mitigating the negative psychosocial impact of parenting a child with food allergy. An in-depth qualitative approach was used to explore mothers' own experiences, needs and preferences for support. Four main themes were constructed: 1) Feeling equipped to manage anxiety 2) "Dealing with a world that doesn't necessarily get it" 3) Feeling the weight of judgement and 4) "We do allergies, we don't do mental health" – gaps in the healthcare system.

It has been reported that the most commonly described form of psychological distress in parents of children with food allergy is anxiety (Westwell-Roper, 2021). Therefore, it may not be surprising that mothers in the study primarily wanted support for food-allergy specific anxiety, which included both the experience of chronic, everyday anxiety and anxiety relating to traumatic events. The findings in this current research suggested that parents wanted tangible tools to help them manage this anxiety; as Westwell-Roper (2021) argues, attributes of food-allergy anxiety, such as intolerance of uncertainty, fit within a CBT framework and therefore may be responsive to individual CBT. However, they also conclude that multiple contextual factors are likely to affect the overall distress associated with food allergy, which may require other distinct forms of support and intervention. The data in this study supports this argument, as mothers spoke about wider contextual issues which directly contributed to their distress. Wider contextual issues included: feeling misunderstood by professionals, family members and wider society, poor risk awareness from others leading to issues with trust, feeling labelled and judged, and the lack of a psychologically informed healthcare

system for food allergy. These factors appeared to moderate the level of anxiety mothers felt and highlight that it is only by viewing maternal anxiety within this wider context and paying attention to the complex interplay of issues mothers face that helpfully responding to mothers can take place.

Clinical implications

Implications for practice were produced from this research; in paying attention to wider contextual issues, support must focus on intervening at individual, interpersonal and healthcare service levels. At an individual level, psychological interventions aimed at managing both chronic, every-day anxiety and anxiety related to traumatic experiences could be offered to parents. CBT may be an appropriate intervention which gives parents tangible tools to manage the interplay of distressing thoughts, emotions, behaviours, and physical sensations and currently has the most evidence base in the literature. Other psychological interventions, such as trauma-focused approaches for managing acute stress reactions or compassion-focused approaches for parents experiencing self-criticism and guilt may be appropriate and warranted, however, clinical research is needed to establish their effectiveness with a food-allergy parent population. Individual psychological support must be adapted to be food-allergy specific, and where possible, should be provided by a professional with a food-allergy background or a background in child health concerns (Herbert et al., 2016). It is important that healthcare professionals understand the nuances of living with a child's food allergy and help parents, who can sometimes feel the huge impact of being misunderstood, to feel heard.

At an interpersonal level, family approaches aimed at managing strained relationships may be useful, as well as approaches that facilitate discussions of shared allergy responsibility, constituting a further area for future research. As Abrams et al. (2020) concluded, “mobilizing towards collective adherence, through engagement of all parties, is

essential” (p.597). Healthcare professionals trained in allergy may also have a role to play in increasing community awareness of food allergy, such as taking part in outreach events or delivering training to schools. Group interventions which involve a level of peer support may be useful in fostering interpersonal connectedness and a non-judgemental space for parents. It has been proposed by Herbert and Dunn Galvin (2020) that a combination of interventions may be appropriate, and approaches should be tailored for each client in the context of their family and wider community experiences.

At a healthcare service level, more holistic care of food allergy appears to be needed. Parents may require an assessment of psychological need, which may involve questions asked by an allergist during a routine appointment, or separate appointments where parents can discuss the psychosocial impact of their food allergy without their child present. It has been proposed that the client perspective and psychosocial aspects of allergy should form a fundamental part of undergraduate curricula for physicians to improve psychologically-informed care and appropriate referrals for psychological support where available (Barker et al., 2021).

The provision of psychological support and appropriate interventions must be improved, with the integration of a multi-disciplinary team into services or better signposting to existing forms of psychological support which can be tailored to fit the needs of parents by training up staff without existing food-allergy knowledge. It has been proposed that both allergy and mental health communities should work together to create food-allergy educational training programmes to facilitate a growing number of professionals with food allergy expertise (Herbert et al., 2019).

An Integrated Care Pathway (ICP) can be defined as “an outline of planned care for a specific patient group” (Croucher, 2005, p.6). Outlines of planned care should be informed by guidelines, evidenced-based, and patient-centred. The Royal College of Paediatrics and Child

Health (RCPCH) were funded by the Department of Health to develop care pathways to address the gap in services identified. The Food Allergy Care Pathway for Children states that once a diagnosis has been confirmed, a full history should be taken, including any psychosocial issues. It also states that professionals should know how food allergy may impact on different aspects of daily life of both the patient and the family and be able to “provide details of resources including patient charities, websites and local support groups as well as psychosocial support if required” (RCPCH, 2011, p.7). Despite the clear recommendations set forward in the pathway, examples of successful implementation of ICPs are lacking (Daniels et al., 2021). The results of this study seem to confirm that recommendations do not appear to be implemented at the service level consistently. Therefore, more research is needed on the evaluation of implementing ICPs at a local level in order to identify the barriers and facilitators to implementing change. It is important that this research specifically captures information pertaining to the psychosocial impact of food allergy on caregivers. This is no easy task, and formal guidelines for implementation strategies have been called for (Daniels et al., 2021).

Strengths, limitations, and considerations

This study sought to explore the psychological support needs of parents of children with food allergy; understanding the nuance of psychological distress of parents is a key aspect of developing appropriate support. Previous qualitative studies have sought to understand the experiences of parenting a child with food allergy in general, however, relatively little research has been conducted in exploring perceived psychological support needs. Thus, the current study offers an important contribution to a wider effort to develop interventions that are both effective and acceptable to parents of children with food allergy by offering insights that could potentially inform future research and healthcare practices as guided by parents themselves. As Braun and Clarke (2019) have suggested, “good clinical practice...depends

on the sorts of knowledge generated through small, in-depth qualitative studies, as well as information generated through large scale clinical trials” (p. 720).

It is important to situate the findings from this study within the context in which the research was conducted (Yardley, 2000). This research took place during the COVID-19 pandemic, which was likely to have had a large impact on mothers’ experiences of anxiety and their subsequent reporting of their psychological needs that perhaps was not representative of their ‘usual’ experience. Many mothers commented on how the COVID-19 lockdown had ‘allowed’ them to avoid certain situations that might otherwise have caused them anxiety, such as going to social gatherings or out to restaurants. Many mothers commented on how their anxiety was heightened as the country moved out of lockdown, with the perception that risk was increasing as the world was opening up again. It is therefore likely that the most salient aspects of anxiety, and therefore what was most dominant in participant interviews, were influenced by the wider context of the COVID-19 pandemic.

This research sought to explore the perceived psychological support needs of parents of children with food allergy. Despite an attempt to recruit a mixed sample of mothers and fathers to the wider study reported in Part One, a lack of fathers recruited to the study meant that the subgroup of participants recruited for interviews consisted only of mothers. This is important to note as it could speak to wider suggestions in the literature that there could be gender differences in the experiences of parenting a child with food allergy, and therefore associated distress (Dunn Galvin et al., 2006; Hoehn et al., 2017). It may also speak to evidence which suggests males are less likely to seek support for mental health difficulties (Doherty & Kartalova-O’ Doherty, 2010; Sagar-Ouriaghli et al., 2019). Therefore, further research with fathers of children with food allergy is needed to better understand their own unique insights regarding psychological support needs.

With regards to recruitment methods, it is possible that the sampling method used in this research may have constrained or guided participant answers. All participants in this current study consisted of a subgroup of mothers allocated to the intervention group in the RCT outlined in Part One of this thesis. Although interviews took part before participation in the intervention, all participants were expecting to take part in a CBT workshop at a later date, and therefore may have been mothers with a preference for this type of psychological support, or at the very least, may have considered this type of support to be helpful. It is also possible that the lead researcher's interpretation of the data would have been shaped by their training in and familiarity with CBT approaches, however, it is acknowledged that analysis cannot take place in a "theoretical vacuum" and quality practice involves reflexive engagement with TA (Braun & Clarke, 2020, p. 331). Therefore, the aim is not to 'avoid' bias, but to acknowledge that researcher experience and context shapes the knowledge produced. The reflexive account offers further discussion of the ways in which knowledge was produced by the researcher (Appendix D).

Conclusion

There is a need for the development of interventions to mitigate the psychological impact of managing a child's food allergy to be informed through engagement with parents themselves. A qualitative approach can offer a nuanced understanding of parental distress; this study sought to establish mothers' psychological support needs from their own perspectives. Mothers' experience of food allergy associated distress was experienced at an individual level, with tangible support requested to manage the thoughts, behaviours, and physiological symptoms of anxiety, but was also often influenced by interactions within the wider system. Taking this into consideration, interventions at the individual level, interpersonal level and healthcare system level are recommended. Further clinical research is needed to investigate the effectiveness and acceptability of a range of psychologically-informed interventions for

parents. Furthermore, research is needed on how recommendations included in ICPs are implemented at a service level.

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List of Appendices for Part Two

Appendix A: Semi-structured topic guide

Appendix B: Example of coded data from the initial coding stage

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Appendix A: Semi-structured topic guide

Please can you tell me about why you would like to access psychological support in relation to your child's food allergy? (What problems do you face? What problems would you like help with? What areas do you feel you need support with?)

In your opinion, what keeps these problems going? (Why have they not got better on their own? What makes them better? What makes them worse? Are there any other factors that you think may influence your ability to manage your child's allergy?)

What do you do at the moment to manage the problem? (What strategies do you use to help you cope? What things help you cope? How effective are these things? What would you like to be different?)

What support (e.g., nurse specialist/doctor/dietician/support group/self-help) have you sought/been given in order to help with these problems? (What has been helpful about this support? What has been unhelpful?)

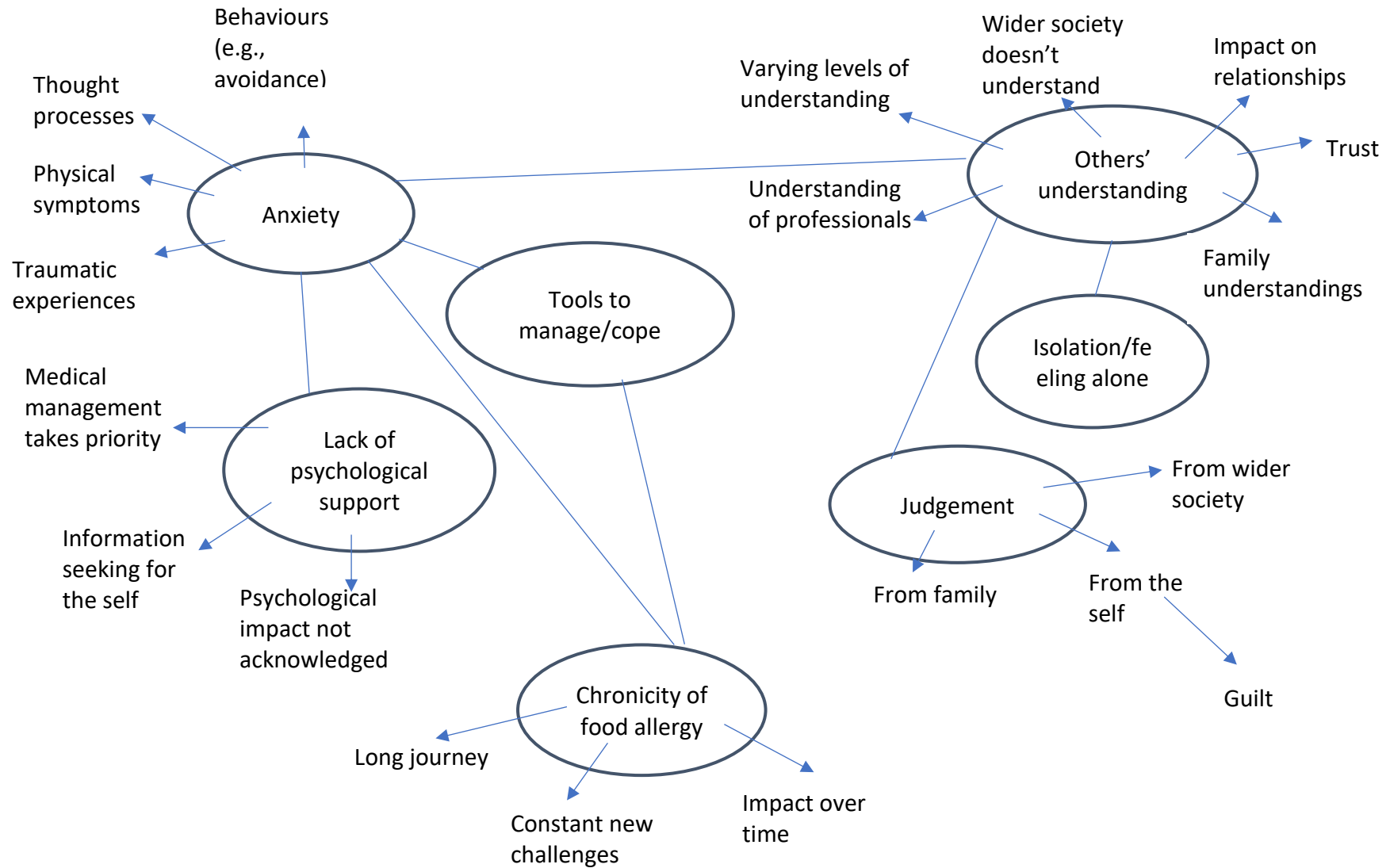
What are your experiences of accessing psychological support in particular, in relation to your child's food allergy?

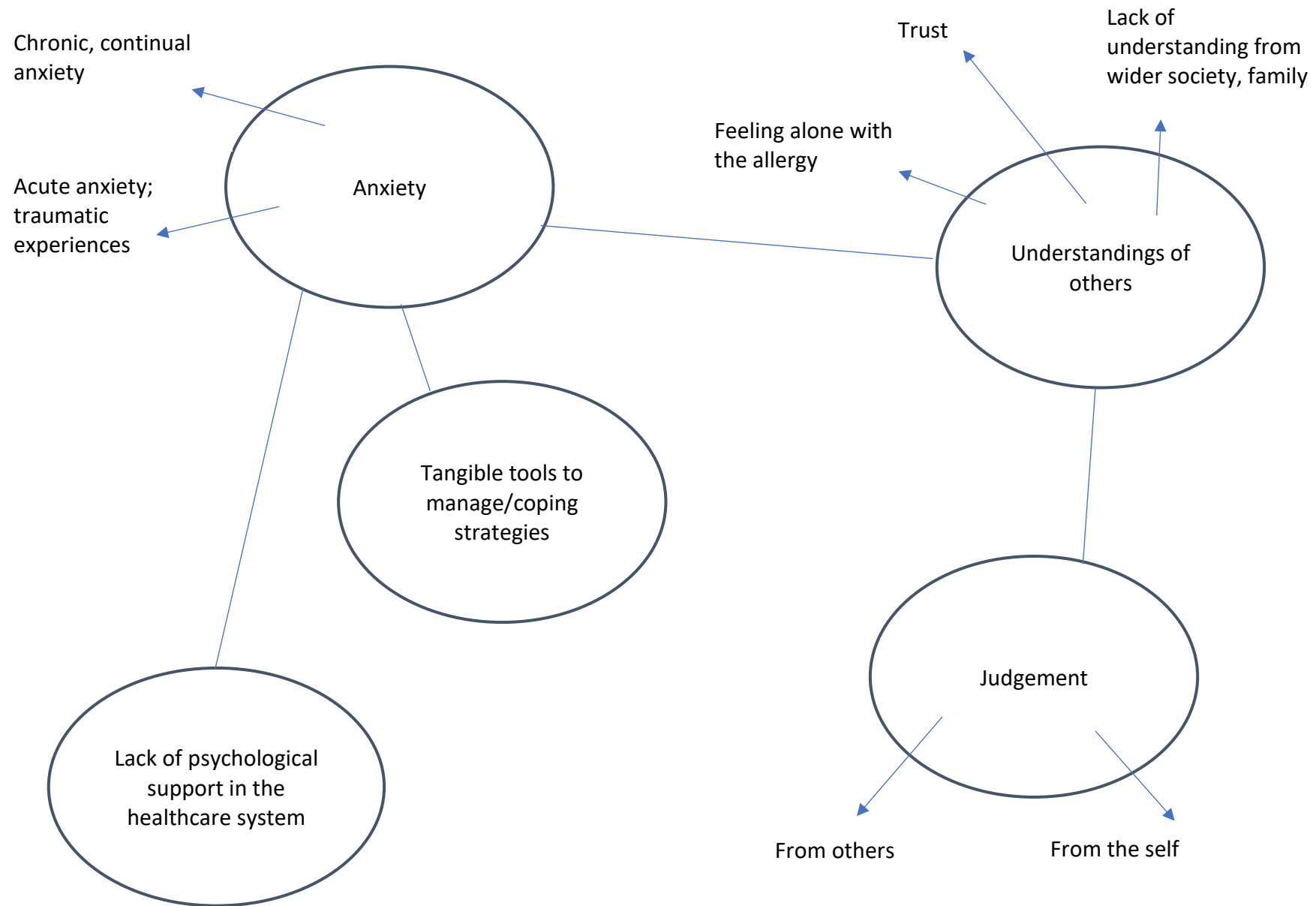
How do you think a psychological intervention may help you? (What do you think a psychological intervention could offer you to help with these things? What is needed from a psychological intervention in order for it to be useful to you?)

Appendix B: Example of coded data from the initial coding stage

Data	Codes
<p>Researcher: First of all, please can you tell me a bit about why you would like to access psychological support in relation to your child's food allergy?</p> <p>Laura: Erm, I guess it's probably, the... just the ongoing worry and um anxiety around kind of food allergy, and what it means for him, and for us as a family moving forward... um... and it's all very new...so my son's two and a half, erm, no allergies in the family previously, um and I think there's very varying levels of understanding within family, as well as kind of yeah society in general, and I think, maybe sometimes it's underestimated just that continual...erm...what's the word? Like, I'm trying to think of the word, but continual kind of like thought process around 'is this safe?' and the planning of going somewhere or where the hospital might be and and all of those things you have to put into place. It's not kind of as straightforward as just simply avoiding one food and naturally that over time will take it's kind of toll on you sort of emotionally, um and I think... yeah just the awareness that we have a very long journey ahead of us, um and so that's probably it in a nutshell.</p>	<p>Ongoing worry and anxiety</p> <p>Questioning the impact on the child and the wider family</p> <p>New diagnosis within the family</p> <p>Varying levels of understanding within the family</p> <p>Varying levels of understanding within society in general</p> <p>Impact of food allergy underestimated</p> <p>Continual thought process around safety</p> <p>Continual planning</p> <p>Not as straightforward as avoiding one food</p> <p>Emotional impact over time</p> <p>Acceptance of the emotional impact of food allergy</p> <p>Awareness of a long journey ahead</p> <p>Realities of a chronic and incurable diagnosis</p>

Appendix C: Thematic maps (including initial thematic map and subsequent development)





Every day, chronic
anxiety



Traumatic experiences
and acute events



Feeling equipped to
manage anxiety

Understandings of
others*

Lack of psychological
support in the healthcare
system**

Judgement***

*Later named “Dealing with a world that doesn’t get it”

** Later named “We do allergies, we don’t do mental health – gaps in the healthcare system”

***Later named “Feeling the weight of judgement”

Appendix D: Self-reflexive account

A reflexive account is written in the first person, in acknowledgement of how my own positionings, experiences and assumptions have shaped the research. Firstly, in my past employment I worked closely with family carers of individuals with a variety of long-term physical and mental health conditions. I have often been struck by the remarkable resilience of family members with caring roles and have noticed how they often provide a lot of emotional and practical support which is perhaps taken as a “given” from current healthcare services. The support needs of carers are something which I have noticed can sometimes go unassessed by busy services and therefore my initial interest in researching the psychological supports needs of parents was borne out of wish to understand the perspectives of those who take on a role that I conceived as being underacknowledged. Here, I was positioned from the outset to view parents of children with food allergy as not being ‘heard’, and therefore viewed this research as a way for these voices to be captured.

In addition to the above, I was also acutely aware of the literature I had read around how mothers experiencing anxiety in the context of food allergy can sometimes be conceptualised as being ‘overly-anxious mothers’. I was struck by themes of others not understanding food allergy and the subsequent isolation experienced. Therefore, I feel I placed a large importance on the mother’s experience of the interviews as I did not want to perpetuate feelings of not being understood. This could have constrained my questioning, such as not wanting to “unpick” perceptions of risk. I was also acutely aware of my own position as an individual without a severe food allergy and as an individual who is not a parent; as another person who yet again might not understand the nuance of living with food allergy. Due to this, I did not want my questions to perpetuate a sense of not feeling understood, leading perhaps to a more constrained line of exploration in which I stuck quite

closely to the interview schedule. I noticed that over time, I felt more able to deviate from the interview schedule and ask follow-up questions, perhaps indicating a gradual increase in confidence in how to broach difficult topics.

During the interviews I noticed I was often caught between this position of wanting the mothers involved in the research to feel heard and my position of a trainee clinical psychologist with knowledge of psychological theories. For example, I was most struck by this when listening to an account of a mother who said that she had not found discussions about “perceived risk” versus “actual risk” helpful during previous psychological therapy. The cognitive behavioural theory of anxiety (Beck et al., 1985), which states that anxiety can occur due to an overestimation of risk, came to mind and I began to formulate her reported difficulties as linked to an overestimation of the risk of her child dying from an allergic reaction. However, I acknowledged how easy it was for me, as someone who does not have to live with this risk and as someone without a child, to formulate in this way. I thought about how ‘logical’ explanations about risk which focus on the numbers of deaths caused by anaphylactic reactions compared to other every-day risks such as dying in a car accident, might not be helpful for everyone when considering the emotional impact of managing a child’s food allergy and may not take into consideration the wider context of food allergy anxiety. Therefore, my wish was to create a ‘balance’ between identifying cognitive processes which may maintain anxiety, and could therefore be helpful in developing useful interventions, and giving voice to the nuances of living with food allergy which often go unheard. My whole coding process, the creation of themes and subsequent write up was guided by these considerations. I do not know if I have achieved this, and some anxiety remains as to how mothers of children with food allergy might receive this paper. However, whilst participant views on interpretations are important, I also hold in mind Riessman’s (1993) rejection of “the idea that the analyst’s intellectual independence should be abdicated

or eroded by taking participants' opinions as an authoritative judgement of the veracity or value of the interpretation" (Riessman, 1993, as reported in Yardley, 2000, p.221).

I am also aware that my position as a trainee clinical psychologist has shaped the research in other ways. My interview schedule was informed by questions you might ask in a clinical interview, and therefore in some ways my interviews felt very much like an assessment session I might have with a client. I noticed myself occasionally slipping into this territory during interviews, such as trying to hypothesise about reported difficulties which was leading and may have changed the direction of the discussion. For example, during one participant's discussion about fear, I made a hypothesis about this being a fear of fear itself, which the client acknowledged she had not thought about before. Furthermore, during my training, I have most often studied and used CBT and systemic models in my own practice, which may have pulled me to conceptualise helpful interventions based on these theories.

Part Three: Clinical Experience

Year One

Core Adult Placement (12 months): Adult Community Mental Health Team and Adult Crisis Team

My first year of clinical training was primarily set within an adult community mental health team (CMHT), working with adults aged 18-65 experiencing severe and enduring mental health difficulties. I completed psychological assessments, formulations and 1:1 interventions informed by Cognitive Behavioural Therapy (CBT) models. I delivered training to staff in a residential care home setting on supporting residents with low mood and depression. I also spent four months placed within an adult crisis resolution team delivering short-term psychological support, integrating ideas from CBT and Compassion Focused Therapy (CFT) to individuals experiencing acute mental health difficulties. Both placements involved working closely with multidisciplinary team (MDT) members, offering consultation, and attending 'complex case' care meetings.

Year Two

Core Older Adult Placement (6 months): Older Adult Community Mental Health Team and Dementia Assessment Service

My older adult placement was split between a Dementia Assessment Service (DAS) and a CMHT for older adults. Across both services I provided psychological support to individuals experiencing a mental health difficulty and/or adjusting to a diagnosis of dementia. This work was a mixture of 1:1 and couples therapy and was based on CBT and systemic principles.

I also used a Positive Behaviour Support (PBS) framework within a care home setting to aid in the understanding and management of behaviour that challenged in the context of a client's dementia diagnosis. I contributed to 'complex case' formulation meetings, client review meetings, and reflective practice sessions for members of the wider MDT.

Core Child Placement (6 months): Child and Adolescent Mental Health Service and Child Development Centre

My child placement was split between a mental health service for children and adolescents and a child development centre, which assesses children for possible autism spectrum conditions (ASC). I contributed to ASC assessments by conducting school observations, teacher interviews and cognitive assessments (using the WISC V). I also delivered a presentation to the MDT about how to answer parental/caregiver questions around how to talk to their child about their ASC diagnosis. My work within the mental health team involved offering assessment, formulation and interventions to adolescents experiencing a range of mental health difficulties using CBT, narrative, and systemic approaches. I also provided monthly professional supervision to an Assistant Psychologist within the service.

Year Three**Specialist Placement (6 months): Neuropsychology placement within a Dementia Assessment Service and Adult Community Mental Health Team**

On my specialist placement I developed my skills in neuropsychological assessment, formulation, and intervention. Working in the DAS team, I developed skills in psychometric test administration (including the WAIS-IV, WMS-IV, D-KEFS, TOPF and GNT), interpretation and the use of these results to information recommendations in relation to a suspected dementia. Alongside my supervisor, I was also involved in offering diagnoses and post-diagnostic support. Within this service I also co-facilitated staff training on how to administer the Montreal Cognitive Assessment and supervised an audit of memory services carried out by two undergraduate psychology students. My work within the adult CMHT included offering neuropsychological formulation and intervention for clients with a mental health condition where there was an additional neurological concern. This included a full note review, formulation, and consultation to the wider MDT in relation to a client whose neurological condition was interplaying with their mental health presentation. This also

included an opportunity to work with my supervisor on a piece of cognitive rehabilitation work for a client experiencing cognitive difficulties in the context of a diagnosis of schizophrenia.

Core Learning Disabilities Placement (6 months): Community Team for People with Learning Disabilities

I worked in a community team supporting adults with learning disabilities and mental health needs/behaviours that challenge. I offered 1:1 therapeutic work drawing on principles of CBT, attachment theory, narrative and systemic therapy, adapting all interventions to support the communication needs of clients. I worked alongside a senior psychological therapist specialising in systemic practice as a reflecting team member whilst delivering a piece of family work. I had the opportunity to develop a PBS plan for a client transitioning from the family home to a residential care setting; I administered a Brief Behavioural Assessment Tool with the client's family, conducted a teacher interview and a school observation in order to develop a person-centred plan. I co-facilitated a Tree of Life group which included offering 1:1 pre-group assessments, co-facilitating an online group, and offering 1:1 feedback sessions and reviews. I attended weekly psychological therapies meetings and co-presented a presentation on compassionate leadership.

Part Four: Assessments

PSYCHD CLINICAL PROGRAMME

TABLE OF ASSESSMENTS COMPLETED DURING TRAINING

Year I Assessments

ASSESSMENT	TITLE
WAIS	WAIS Interpretation and Administration
Practice Report of Clinical Activity	Assessment and formulation of Aida*, a female in her late thirties experiencing anxiety linked to a fear of psychosis recurrence.
Report of Clinical Activity N=1	A report of assessment, formulation and intervention using CBT for low self-esteem with Peter*, a male in his mid-sixties experiencing symptoms of depression and anxiety
Major Research Project Proposal	The feasibility of a group CBT intervention for improving psychological outcomes in parents of children with food allergy
Service-Related Project	What percentage of referrals to Tier 3 CAMHS provide specified risk information, as detailed on the service referral form?

Year II Assessments

ASSESSMENT	TITLE
Report of Clinical Activity/Report of Clinical Activity – Formal Assessment	A neuropsychological assessment of Rumana*, a female aged 60, experiencing concerns about her memory and mood.
Presentation of Clinical Activity	A systemically informed assessment, formulation, and intervention with Jack*, a young person in his mid-teens, experiencing feelings of ‘stuckness’ following on from the onset of tics.

Year III Assessments

ASSESSMENT	TITLE
Major Research Project Paper 1	A feasibility, Randomised Controlled Trial evaluating a brief, online, group Cognitive Behavioural Therapy intervention to improve psychological outcomes for parents of children with food allergy.
Major Research Project Paper 2	A qualitative exploration of the psychological support needs of mothers of children with food allergy
Application of Systemic Ideas to a Clinical Scenario	A systemic formulation and intervention plan for working with Joel* and his family; an example of working with

	adolescent ‘depression’ within the context of a blended family
Report of Clinical Activity/Report of Clinical Activity – Formal Assessment	A neuropsychological assessment of Jim*, a male aged 80, experiencing worsening cognitive difficulties following a diagnosis of Mild Cognitive Impairment.

Note: * All names are fictional or pseudonyms used to protect client anonymity