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Title: Psychological Services for food allergy: the unmet need for patients and families in the UK

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Abstract

Research over the past twenty years has demonstrated the significant impact food allergy can have on quality of life and mental health of patients and their families, yet there is a paucity of psychological services to support families in coping with this condition. This paper provides a short overview of the psychological impact of food allergy, followed by a discussion of the use of paediatric psychological services for long-term conditions. To our knowledge few paediatric allergy clinics in the UK have funding for dedicated clinical psychology services. Two such services are based at Southampton General Hospital and the Evelina London Children's Hospital. This paper includes descriptions of these services and how they are currently being used by patients and families. This is followed by an allergy clinician's perspective on the use of psychological services. Recommendations are made for allergy services to work with hospital psychology services to develop, integrate and deliver psychological services for all patients with allergy and their families who are in need. Future research also needs to focus on the efficacy of psychological therapies and group interventions in food allergy.

Introduction

Management of food allergy involves constant vigilance to avoid coming into contact with allergens. Research over the last twenty years has demonstrated that this burden, along with the unpredictable nature of allergic reactions, has an impact on quality of life and mental health, including stress, worry, anxiety and depression. Food allergy particularly affects social life, such as eating out or staying over with friends; school life, including school trips and risk of bullying; relationships with parents; and can cause anxiety surrounding administering an adrenaline auto-injector, having skin prick tests, blood tests or food challenges (1-4). Emerging findings also suggest an association with post-traumatic stress symptoms (5). The impact on quality of life has been reported to be significantly worse if a child has comorbidites such as asthma or atopic dermatitis (6). Food allergy also affects quality of life in parents (1), particularly mothers who often carry the burden of managing food allergy and report high levels of stress and anxiety (2).

Qualitative research has explored in more detail the reasons why children, adolescents and parents display such high levels of anxiety. As children grow older and more independent they take on more responsibility for their allergy management. Developmentally, this means that teenagers have to make their own risk assessments of what is safe to eat, which can increase their anxiety (3). Older children and adolescents also express a need to be more like their friends and not be labelled by their allergy (3) and a lack of knowledge in how to use adrenaline auto-injectors and fear of needles is a great cause of anxiety (4). Parents have also reported high levels of worry about their child having an anaphylactic reaction and uncertainty around what to do if their child does go into anaphylactic shock (7). Mandell et al. interviewed parents of 17 children with peanut allergy who had a history of anaphylaxis. They found that a lack of information at diagnosis increased both anxiety and uncertainty in managing the risk of accidental ingestion of the allergen (7).

Very little research has been published on interventions to reduce anxiety and improve quality of life in those affected by food allergy, but those based on cognitive behavioural therapy (CBT) have shown initial promise. In the first case series study to assess CBT in a UK food allergy context, Knibb showed that a 12-week course of face-to-face CBT run by a health psychologist in a non-clinical setting can reduce anxiety, stress and depression and improve quality of life in mothers of children

with food allergy who self-referred for CBT (8). Brief CBT interventions may also be useful for anxious parents. In a randomised control trial, Boyle et al (9) provided mothers of children with food allergy with one CBT-based risk communication session in allergy clinic by clinicians with training in CBT, followed by reinforcement at 2 weeks and 6 weeks. Whilst overall, no significant difference was found between the intervention and control group in the short-term following such a brief intervention, a sub-group of mothers who had moderate to high anxiety in clinic exhibited statistically significantly reduced state anxiety at 6 weeks following the CBT intervention compared to controls. It is unclear if this is a clinically significant change and further research is needed on allergy specific parental psychological interventions.

There is no published research on similar interventions for children or adolescents with food allergy, but findings from research in children with other long-term conditions provides support for the use of psychological therapy. Paediatric psychology has an established intervention evidence base which promotes psychological well-being in children with chronic illness (10-12). Psychological assessment, formulation and treatment can address a wide range of presentations including: adjustment to diagnosis, anxiety, depression, post-traumatic stress, feeding problems, behavioural difficulties, pain management and improving adherence. The Paediatric Psychology Network (PPN-UK) evidence-based guidelines for the management of invasive and or distressing procedures provides good examples of how psychological knowledge and skills could be applied by allergy nurses, play specialists and clinical or health psychologists for the benefit of children undergoing skin prick testing or learning how to use an adrenaline auto-injector (13). Whilst some paediatric psychology guidance can be generalized, research is needed in order to establish evidence based effective psychological interventions specific to paediatric allergy, such as treatments for complex presentations of allergy anxiety. Nevertheless, there is a solid foundation from a fifty-year international history of paediatric psychology service provision upon which to build psychology services for the benefit of allergic children, their families and clinical teams.

Nurse specialists, dieticians and doctors provide excellent services, with core psychological competencies and counselling skills underpinning their routine work, for example, on the use of AAIs or completing food challenges (14). However, when complex issues arise, such as non-adherence or

fears of food, the meta-psychological competencies a psychologist brings can be of benefit both to families and the team. In 2015, the British Psychological Society published 'What good looks like in psychological services for children, young people and their families', with a paper focusing on children with physical health needs (15). This paper highlighted that when psychologists are embedded in paediatric multi-disciplinary teams, families really benefit from the holistic approach to adjustment, management and coping with their child's chronic health condition. However, whilst most tertiary paediatric centres in the UK have long established psychological services, for example in diabetes clinics, this provision does not apply to all medical conditions, resulting in an inequality of access to psychological support (15,16). An allergy survey in one UK region illustrated that despite allergy professionals recognising the psychological needs of families; access to psychological services for families in paediatric allergy was limited (17). Where allergy is affecting mental health, it is possible that some children with food allergy may meet Child and Adolescent Mental Health Service criteria.

Psychological service provision for food allergy

Whilst some hospitals have general paediatric psychology services which children with severe food allergy may be referred to, few specialist services exist in the UK. Two allergy clinics in the UK who have funding for dedicated clinical psychology services are based at Southampton General Hospital and the Evelina London Children's Hospital. The Southampton paediatric allergy service has had provision of a clinical psychologist one day a week since 2014. Families are seen for an initial assessment and then either placed on a waiting list for psychological therapy, given recommendations and discharged or referred to community child and adolescent mental health services if the primary difficulty is that of a mental health problem. The psychologist also provides consultation and support to the multi-disciplinary team within team meetings, joint clinic appointments and liaison as required.

Over the first 14 months of this service, 40 referrals were made to clinical psychology from consultants, registrars, dietitians and specialist nurses. Seventy eight percent of referrals were seen for individual psychology therapy which included cognitive behavioural therapy, acceptance and commitment therapy and a systemic approach, with children and parents, according to individual need. The range of presenting difficulties can be seen in Table 1. Outcomes are assessed using

goal-based outcome measures which are individualised according to the understanding of each child's difficulties (Table 1).

The children's allergy service at the Evelina London Children's Hospital has had a clinical psychologist since 2016. The charity Action Against Allergy provided a financial gift enabling the creation of a specialist clinical psychology post for 2 days a week, which was funded fixed term for one year. In 2017 following a successful business case to the NHS and the support of continued funding from Action Against Allergy a highly specialist clinical psychologist was appointed, the time was increased to 4 days a week and an assistant psychologist started for 3 days a week. The service has continued to grow and now has the support of a trainee clinical psychologist 1 day a week and a student psychologist for 2 days a week. A review of the service after the first 6 months was carried out for the purpose of business planning to show the level of need identified by the Allergy team. In the first 6 months 71 new referrals were made to the psychology service and 43 patients had been seen for treatment. In total since the start of the service until present (January 2016-August 2018) 303 children and their families have been referred to the service and offered an intervention.

Due to demand for the service it has adopted a 'stepped care' system of delivering and monitoring treatments, with the aim of delivering the most cost-effective intervention to patients first; only 'stepping up' to intensive/specialist treatments as clinically required. In this way, all referrals are offered an intervention at triage. Providing early intervention, particularly for young children and their parents is important and assessment at an early stage can help prevent an increase in stress, worry and feeding/eating problems.

Step one focuses on prevention and promotion; the service delivers psychology workshops, based on cognitive behavioural therapy and narrative therapy techniques, to help children understand the role of feelings and worries in relation to allergies and develop good coping skills and strategies to manage difficult emotions. The psychology service also runs monthly parent workshops and parallel parent sessions in conjunction with the children's groups and these are based on the common themes and challenges identified by parents such as 'Improving communication with schools', 'How to manage feeding difficulties', 'Preparing for skin spick tests and food challenges' and 'Managing anxiety and parenting strategies'. Step two involves a telephone assessment, workshops and self-

help or a brief intervention of 1 to 3 sessions. Step three is face-to-face assessment and interventions (e.g. group workshops, short term psychological interventions). Step four involves specialist psychological interventions for patients and families with complex needs. Further detail on this approach can be found in the online supplement. The most common reasons for referral and outcomes for the service can be seen in Table 2. The uptake of these dedicated services in Southampton and London clearly demonstrates the need of such services for patients with allergy and their families.

Psychological support – the allergist's perspective

The increased prevalence and increasingly complex nature of allergic disease has necessitated the development of multi-disciplinary allergy teams. The addition of psychologists with skills in the management of allergic disease to such a team is a relatively recent development. Living with allergic disease is complex as allergic children typically suffer with more than just a single allergic condition and children with food allergy are frequently allergic to more than one food. Whilst some food allergens are well recognised and more easily avoided e.g. peanut, patients with allergy to more ubiquitous foods such as wheat, egg and milk may find it more difficult to avoid such allergens. As a consequence, allergic patients and their families are at risk of reduced quality of life and adverse emotional responses and even if the skill set exists among staff, there is little time in a typical consultation for an Allergist or Allergy Nurse to identify and address such issues. Therefore, in clinical practice having access to a psychologist is invaluable and a critical part of a holistic allergy care package we strive to offer our patients.

A common reason we refer a patient and/or their family is extreme anxiety; this may manifest as reluctance to socialise, eat out, sleepover or travel. The underlying stimulus for anxiety may be complex, but often includes fear of accidental allergen exposure and subsequent anaphylaxis. An additional cause of anxiety concerns the need to undergo allergy procedures such as skin prick testing or oral food challenge tests. We also refer patients who are anxious to undergo allergy therapies such as biologic or immunotherapy injections or oral immunotherapy to foods.

Reassuringly, we see patients and their families rapidly respond to psychological interventions, sometimes even after a single consultation. Psychologists are expert at identifying stressors and are quickly able to intervene. This can often be done at a group level, which provides a cost-effective strategy in clinic services. Psychological interventions should ideally be applied early-on in the 'allergy journey' with the hope that prompt recognition and treatment of food-related adverse psychological experiences will facilitate effective management practices. Given the high burden of allergic disease, and under provision of allergy psychologists, very few deserving patients will have access to such care. There is a great need therefore for all health care providers, family members and the wider public who take care of children with allergies, to learn from psychologists those skills needed for the prompt recognition of adverse psychological behaviours and early frontline interventions that could be applied.

Recommendations going forward

The Royal College of Paediatrics and Child Health Standards for children with ongoing health needs specify that "service planners ensure children have timely access to a range of mental health and psychosocial services that are integrated with children's health services and that all health care staff have the competencies to support the psychological needs of children" (18). The challenge now is for allergy services to work with hospital paediatric psychology services to develop, integrate and deliver psychological services for all children with allergy and their families who are in need. Beyond this is consideration of psychological need in primary care and the Department of Health steer on how to deliver care close to home. Existing psychological research in allergy demonstrates the needs of patients and families. Future research needs to focus on the efficacy of psychological therapies and group interventions in an allergy population, including adults, and the patient experience of accessing psychological therapies. Allergy typically emerges in childhood. Whilst we have focussed on the needs of children and families; the psychological needs of adults with allergy also require attention. Such research will inform our understanding, to further develop and evaluate allergy psychological interventions which show emerging promise.

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Table 1. Common reasons for referral to Clinical Psychology and outcomes of the service at Southampton General Hospital

Common reasons for referral	**Outcomes of the service**
Anxiety related to eating	Reduction in reported parent and child anxiety
Avoidance of eating at school or outside the home	Decreased avoidance of eating at school and restaurants
Anxiety related to food challenges	Completion of food challenges
Misinterpretation of anxiety symptoms as allergic symptoms	Ability to recognise anxiety symptoms as opposed to allergy symptoms
Low mood related to having multiple allergies	Increased mood reported by parent and child
Phobia of using the auto-injector; avoidance of use of adrenaline rescue medication	Feeling comfortable to use the auto-injector if needed
Poor social functioning	Decreased avoidance of social situations where food is involved

Table 2. Common reasons for referral to Clinical Psychology and outcomes of the service at Evelina London Children's Hospital

Common reasons for referral	**Outcomes of the service**
Child anxiety	Reduction in child reported anxiety
Parental anxiety/overprotection	Reduction in parent reported anxiety
Parental distress/trauma following anaphylaxis	Reduction in parent reported anxiety
Difficulties adjusting to the diagnosis of allergies	Coping with allergy and improvement in quality of life
Challenging behaviours (such as anger/frustration and 'feelings of 'difference),	Reduction in challenging behaviours
Feeding difficulties	Improvement of diet, decreasing food aversion
Problems with adherence to treatment	Improved adherence
Needle phobia such as the skin prick test and using the AAI	Support with skin prick tests
Anxiety about food challenge	Supporting children with food challenges
Sleep difficulties	Sleep improvement
Depression/low self-esteem	Improvement in depression/self-esteem
Teasing/bullying	Coping with bullying