Understanding the social and emotional impact of food allergy in children and their families

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Food Allergy

Food allergy is different to other chronic conditions as the sufferer is generally well and in good health, but is continually at risk of a severe or life-threatening allergic reaction.

Management of food allergy can therefore be a burden due to the constant vigilance required to avoid known allergens.

Cummings et al., (Allergy, 2010, 65, 933-945): Review of literature concluded that food allergy has a detrimental affect on quality of life and psychological distress such as anxiety and stress on the patient and family.
Causes of the impact

- **Unpredictability of food allergy**
  - Children are well the majority of the time
  - Time bomb waiting to go off

- **Social**
  - Eating out
  - Parties/school trips
  - Family holidays

- **Family dynamics**
  - Mothers affected more than fathers
  - Sibling rivalry/bullying

- **Economic issues**
  - Dietary cost
  - Food labelling
  - Not able to work
Food Allergy

Since 2010 a range of research on the psychological impact of food allergy has been published

– Quality of life in patients and parents compared to healthy populations
– Anxiety and depression, worry and stress
– Coping and food allergy management in patients and parents
– Self-efficacy and confidence in managing food allergy
– Self-concepts, illness beliefs and using psychological models to predict intentions and behaviour
– Interventions: group support, online support, CBT
Food Allergy and HRQoL

Are patients and parents different to a healthy population?


Health-Related Quality of Life in Children With Food Allergy and Their Parents: A Systematic Review of the Literature

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Food Allergy and HRQoL
Are patients and parents different to a healthy population?

• 15 studies have now looked at HRQoL of children compared to a healthy group
  – Poorer emotional health (parent proxy for child and child self-report)
  – Poorer social quality of life (children)
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  – More bodily pain (adolescents)
  – Poorer overall HRQoL (children and adolescents)
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  – More/Fewer limitations in schoolwork (children and adolescents)
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Food Allergy and HRQoL

Are patients and parents different to a healthy population?

- Reasons for differences:
  - Different study populations
  - Norm data vs control group
  - Different QoL scales used
  - Different countries and cultures
  - Impact of socio-economic group
  - Impact of food allergy characteristics such as type of food or severity of condition
  - Impact of other psychological factors such as self-efficacy, levels of anxiety or stress
Food Allergy and Psychological Distress

Research has looked at anxiety, depression and stress

32% of parents suffer from some level of anxiety and 17.5% suffer from some level of depression prior to attending allergy clinic for diagnosis in their child. Levels do not sig. drop after clinic attendance (*Knibb & Semper, PAI, 2013, 24, 798-803*)

Anxiety in mothers higher than norm levels but levels drop after prescription of AAI for child (*Cummings, PAI, 2010, 21, 586-94*)

Anxiety levels drop after food challenges (*Knibb et al., CEA, 2012, 42, 451-9; Zijlstra et al., PAI, 2010, 21, e439-e445*)

Anxiety levels higher when adolescents have more responsibility for their self care (*Annunziato et al, JHP, 2015, 20, 693-701*)
Food Allergy and Coping

Fenton et al., Risk Analysis, 2011, 31, 171-183

- Interviewed 10 children (8-12 years) and 10 teenagers (13-18 years) in Canada:
  - Younger children relied heavily on parents to manage risk
  - **Avoidance** of risky foods or places and educating others used as strategies to cope by children and teenagers
  - Adolescents described being **extremely vigilant**, being alert and on guard in order to overcome risk and risk related anxiety and fear
  - A few adolescents described giving in, **feeling helpless** and disempowered which was accompanied by overcompensating and obsessive behaviour such as hand washing
Food Allergy and Coping

Semper & Knibb (2015)

• 157 parents of food allergic children completed measures of depression, stress and coping:
  • Stress levels higher than a general population
  • Lower stress predicted by greater use of acceptance coping
  • More use of alcohol or smoking as a way of coping predicted greater levels of stress
  • Avoidance coping predicted greater levels of depression
Food Allergy and Self-Concepts

Sources of Self Concept

- Other’s Images
- Social Comparisons
- Self Concept
- Cultural Teachings
- Your Interpretations & Evaluations
Food Allergy and Self-Concepts

COMPONENTS OF SELF-CONCEPT

1. Self-esteem
2. Body Image
3. Personal Identity
4. Role performance

Sources of

Social
Comparisons

Current
Team
Role

Food Allergy, Self-concepts and responsibility for own health care.
Food Allergy and Self-Concepts

Multidimensional analysis of food-allergic children and adolescents’ self-concept: A comparison with a healthy matched sample

Laura Polloni¹, Ileana Baldi², Francesca Lazzarotto¹, Roberta Bonaguro¹, Alice Toniolo¹, Dario Gregori² and Antonella Muraro¹
Food Allergy and Self-Concepts

N=77 9-19 year olds with food allergy and 77 matched healthy controls

Patients had lower scores than controls (which decreased with increasing age) for:

- **Family**
  - Overprotective families
  - Parents who are suffering from high levels of stress and worry
  - Limited family activities

- **Competence**
  - Feel constrained or restricted because of their allergy
  - Are fearful, uncertain or insecure in new situations

- **Physical**
  - Altered physical self-concept due to their food allergy
Confidence and ‘the belief in one’s capabilities to organize and execute the courses of action required to manage prospective situations’ has been defined as **self-efficacy** (Bandura, 1996 p. 2)

Parental confidence or self-efficacy in managing food allergy for their child may be able to explain some of the impact of food allergy on HRQoL.
N=434 parents

Greater quality of life was significantly related to greater self-efficacy for food allergy management, better mental health, lower perceived likelihood of a severe reaction.

Greater quality of life was significantly related older age in parent and child and fewer number of allergies.

Significantly poorer quality of life was reported in parents of children who had asthma, eczema, egg allergy, history of anaphylaxis or hospitalisation due to food allergy.
Parents least confident in:

- Managing social situations
- Seeking information about food allergy

Parents most confident in:

- Treating an allergic reaction
Food Allergy - Interventions

Sicherer et al., J of Pediatrics, 2012, 160, 651-6
• A food allergy educational programme can increase number of correct steps for AAI activation by parents of children with food allergy and significantly decrease number of allergic reactions (www.cofargroup.org/)

Baptist et al., JACI 2012, 130, 263-265
• A self-regulation intervention aimed to help parents identify potential concerns about their child with FA and contemplate coping mechanisms improved certain aspects of QoL: anxiety about FA; being able to treat an allergic reaction
Polloni et al., PAI, 2014, 26, 87-90

- Assessed reasons for 100 psychological treatments for FA for children, adolescents and family members:
  - 40% - Emotional and social problems such as anxiety, worry, fear, stress, social isolation, poor self-esteem
  - 40% - Difficulty managing FA, poor coping strategies for diet or treatment
  - 18% - Eating problems, restricted diet, fear towards food
  - 2% - Behavioural problems
Food Allergy - Interventions

**Knibb, 2015**

- Assessed effectiveness of using CBT with parents of children with food allergy

**Cognitive Behavioural Therapy**
- Focuses on thoughts, behaviours, emotions and physical symptoms
- What is causing and maintaining the problem?
- How can we change behaviour and thoughts in order to improve how we feel?

**Excellent research evidence base for its effectiveness for:**
- Anxiety; panic
- Worry and Generalised Anxiety Disorder
- Depression
- Obsessive Compulsive Disorder
- Post Traumatic Stress Disorder
Typical case study:

- John is a 9 year old boy with allergies to very small quantities of peanut, milk and egg. He also has asthma. His asthma is generally well controlled; he has an adrenaline autoinjector, anti-histamine, a salbutamol inhaler and a beclomethasone inhaler.

- John’s mother Kate likes to have the control of looking after John and his allergies. She gets worried if John is not with her and is very anxious if she has to ask a friend to look after him. She does all food shopping, reading of food labels and cooking herself.

- They don’t eat out very often but when they do Kate looks on the Internet to check out where they are going to eat and talks to the chef at the restaurant. They do not often go out on social occasions as it is too much effort to plan.
Typical case study:

• Kate feels anxious a lot of the time about her son and worries that he might eat something that will kill him if she is not around to make sure he is ok. She is terrified of the thought of having to give him his Epi-Pen. She isn’t sure if she would know when to do it and how to do it.

• Kate constantly checks her mobile phone when John is at school, in case school ring. She doesn’t trust that school would know what to do if John had a reaction and she is worried he might be bullied because of his food allergies. Kate often asks John if he feels ok after eating and will check him 4-5 times in the night to make sure he is ok and still breathing. Her greatest fear is that her son will die.
Early FA experiences
- Child had anaphylactic reaction when very young
- Seeing child unwell and in distress due to symptoms
- Took a long while to get a diagnosis of food allergy

Core beliefs about self, others and the world
- I am a bad mother; I can't control others; the world is a dangerous place; I am a failure as a parent

Formulation of dysfunctional assumptions:
- If he goes out on his own he's not in my control and if he has a reaction it will be all my fault, so I need to keep him with me and double check everything to make sure he never has a reaction by accident

Activating event/Critical incident
- Invited to a party / accidental reaction to food

Activation of assumptions

Negative automatic thoughts:
- The risk is too great, he could die
- He'll never have a normal life, it's all my fault,

Emotions:
- Guilt, worry, anxiety, fear, sadness, frustration, low mood

Behaviour:
- Check everything many times; don't go out, don't work

Physiology:
- Nausea, increased HR, headaches, IBS

Early non FA experiences

Pre-diagnosis

At diagnosis

Model of psychological impact of food allergy on parents
How the model helps

• Understanding of what is going on for Kate
• Understanding of how the vicious circle is maintaining the problem
• Understanding why Kate feels the ways she does
• Understanding of Kate’s views of the risks of her son having a reaction
• Understanding of what can be changed to break the vicious circle and how we might do that
<table>
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<tr>
<th>Target Statements</th>
<th>Interventions Used</th>
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| I would like to feel less anxious about my son having a bad reaction and be more confident in knowing what to do if he does | 1. Graded exposure to information about anaphylactic shock to reduce anxiety, including watching educational videos  
2. Psychoeducation about what might happen if a child goes into anaphylactic shock  
3. Role play using a trainer AAI with the parent and therapist  
4. Role play using a trainer AAI by the parent with their child |
| I would like to reduce the number of times I check my phone to see if someone has rung about my child, so that I can concentrate on my work | 1. Behavioural experiment to test out consequences of reducing number of times phone is checked |
| I would like to worry less about my child becoming more independent as he gets older and trust him to take more responsibility for his allergies | 1. Worry tree and thought suppression exercises  
2. Behavioural experiment to see what happens if:  
a. they allow child to read own food labels and decide what they can eat  
b. let child remember their medication and put their own creams on for their eczema  
3. Role play with child showing their friends how to use the trainer AAI in an emergency |
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| I would like to be able to leave my child with people and not feel guilty about this, so that I have more time for myself, and worry less when he’s not with me | 1. Psychoeducation and role play regarding how parent might teach someone else what they need to know about their child’s allergy and use of an AAI  
2. Behaviour experiment to test out consequences of leaving child with someone else  
3. Dysfunctional ways of thinking such as mind reading                                                                                     |
| I would like to be able to learn how to cope with things when my child is having a bad time with her eczema and not feel angry, upset or low | 1. Mood diary  
2. Positive data logging to raise mood and self-esteem  
3. Thought records for anger and to challenge negative automatic thoughts such as ‘I can not cope with this’                                                                 |
| I would like to look back on the time when my daughter was tiny and very ill with her allergy and not get upset about it and remember the good times | 1. Emotional writing and re-living to reduce grief associated with traumatic experiences  
2. Positive data logging regarding the positive experiences that occurred and the positive consequences that have occurred because of the food allergy, such as a better relationship with grandparents |
Effectiveness of CBT for parents of children with food allergy

Pilot study resulted in better QoL and reduced distress from baseline to 12 weeks. Cases were not significantly different to controls by the end of the intervention.

Larger numbers and longitudinal analysis is needed.

Improving education and information for parents and sufferers and use of CBT may be helpful for improving psychosocial outcomes. Ways in which aspects of CBT can be incorporated into general allergy clinic need to be developed.
Conclusions

Children and adolescents with food allergy (and their parents) do have poorer HRQoL than a healthy population, but only in some areas of QoL.

Quality of life in those with food allergy can be better explained by psychological factors such as self-efficacy and illness beliefs than food allergy characteristics or past allergy history.

Interventions based on psychological factors seem to be very effective.
Where next?.....

We still can not explain a large proportion of the variance in HRQoL in patients and families.

Illness beliefs, attitudes to food allergy, personality, level of acceptable risk and ability to cope needs further investigation to see if it will help explain some of the unknown variance.

Interventions that are cheap and accessible (eg online) need to be developed with patients and parents to ensure feasibility and take up.
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Thanks for listening
Any questions?

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