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## CASE REPORT

### QUALITY OF LIFE OF PARENTS OF CHILDREN WITH FOOD ALLERGIES: MEALTIMES A TREAT OR THREAT

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#### ABSTRACT

**Introduction:** Allergy to food in children affects 6% to 8% and is increasing in its prevalence with a global prevalence of 2-3.5%. Studies have shown that parents of children with multiple food allergy (FA) have a lower quality of life (QOL). The FAQOL of primary care givers is dependent on accurate perception of reaction severity, the number of allergens, the type of food allergy and self-regulated intervention.

**Case report:** A report on a case of a 3 year old boy with allergy to cow's milk, eggs, chicken and nuts and had eczema. He had an anaphylaxis reaction to egg at the age of one.

**Discussion:** Anaphylaxis is an IgE mediated response and can be life threatening. Parents remain stressed after they have experienced their child's anaphylaxis reaction and suffer social and psychosocial factors that have a negative effect on their QOL. Empowered caregivers have lower FAQOLs and is associated with increased stress, anxiety and burden of vigilance which is reflected in their children as they treat meals as "recurrent threats". Anaphylaxis occurs when parents are not in control and therefore have lower FAQOL scores. Strategies for dealing with food challenges in a supervised hospital setting are important to improve FAQOL scores. The main treatment is food avoidance but new therapies are emerging. Provision of adrenaline auto injector has an impaired effect on FAQOL. There are various tools that are used to measure FAQOL. Vaccines made in egg can be given to children with egg allergies and have reported higher QOL. There is lack of information in managing food allergies outside the home which may be the reason for lower FAQOL.

**Conclusion:** The FAQOL of care givers is dependent on various factors. FAQOL scores would improve if public places and schools had policies for allergy avoidance.

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## INTRODUCTION

Food allergies in children affect 6 to 8% of the UK population and are increasing in prevalence (Sicherer and Sampson, 2010). A Meta analysis study showed global prevalence of 2-3.5% allergic response to milk, eggs, nuts and fish, supported by oral challenge tests (Rona *et al.*, 2007). Food allergy is any food that evokes an adverse reaction, and it can be IgE mediated or cell mediated, or both (Rona *et al.*, 2007). For this case of a 3 yr old boy, the known food allergens (FA) are cow's milk, egg and peanuts. FA that is mediated by IgE

is life threatening, leading to anaphylaxis (Rona *et al.*, 2007). Symptoms of anaphylaxis are: major i.e. respiratory difficulty and hypotension or minor features like itching, erythema, urticaria, angioedema, asthma, rhinoconjunctivitis, nausea, vomiting, abdominal pain, palpitations and sense of impending doom (Branum and Lukacs, 2009). These reactions can occur even when a small amount of food is ingested or sniffed or has been a source of contamination. Hence, it is very important for parents to always be on guard so that their children are not exposed to the foods that they are allergic to. In having to be so vigilant, parents' quality of life suffers tremendously. Quality of life (QOL) is defined as "well being which is determined by both objective and subjective factors, across a number of life domains which are deemed as important in ones culture and time" (Wallander, 2001). "QOL represents the functional effect

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of an illness and its consequent therapy upon a patient as perceived by the patient. Four domains contribute to the overall effect: physical and occupational function; psychological state; social interaction and somatic sensation” Spilker, 1990). It has been stated, that quality of life is good, when “the hopes of an individual are matched by experience” (Calman, 1984). Living with children with food allergies with limited treatment options and the ubiquity of complex and processed foods in society brings about stress in familial relationships, often with limitations in social activities due to food restrictions (van der Velde *et al.*, 2013; Ostblom *et al.*, 2008). Studies have shown that FA parents face a mammoth task of planning and organizing meals for their children, and reading of small printed supermarket food ingredient labels could be very time consuming (van der Velde *et al.*, 2012; Valentine and Knibb, 2011). Foods suitable for food allergic children are usually expensive and available in only specialist shops. Parents or caregivers suffer constant stress of being prepared in case of adverse reaction. Parents are always anxious, educating and training caregivers who look after their children. All these factors have a negative effect on the food allergy related quality of life (FAQOL) of the primary caregiver (Warren *et al.*, 2015). However inspite of having FA with egg, children can safely have MMR vaccine in a normal setting as there is no increased risk of adverse reaction as shown by a study (Aickin *et al.*, 1994).

### Clinical Presentation and Diagnosis

Egg allergy reactions are usually IgE-mediated immediate reactions and are characterized by urticaria, angioedema, vomiting, diarrhea and wheeze. Repeated reactions to foods usually do not necessarily escalate in severity and children with food allergies will react in a similar manner to their previous reaction (Baptist *et al.*, 2012). Children with atopic dermatitis will have a non-IgE mediated delayed reaction, which worsens after exposure to egg. These delayed reactions are diagnosed with patch testing, which has a high degree of specificity (95%) but a low degree of sensitivity (10%) (Allen *et al.*, 2007; Heine *et al.*, 2006). Food allergies in children are determined using a skin prick and/or allergen specific IgE blood tests but are not predictive of either the likelihood or severity of clinical reactions (Sporik *et al.*, 2000).

### Case history

This is a case report of a 3-year-old boy and was first brought to the hospital at the age of 1 year, with a marked urticarial reaction after eating egg for the first time. The reaction occurred immediately after eating a small amount of egg in egg. He rapidly developed a widespread rash and his mother was so worried that he immediately transported her to the hospital. En route he had stopped crying and then had an episode of unconsciousness, during which time he became blue. His mother had given him antihistamine before taking him to the hospital. The cyanotic episode had resolved by the time he was seen at the hospital. He was admitted, treated and discharged. On his next review her mother reported that he had swollen puffy red eyes and swollen lips after ingesting cow’s milk, chicken sausages and nuts. He did not like drinking soya milk but did accept soya yogurt. He tolerated omena and white

fish along with a range of vegetables, pork and beef but reacted to some bread. His history was suggestive of anaphylactic reaction after eating egg, with multiple food allergies: cow’s milk protein, peanuts, chicken and raw and baked egg. Results of skin prick test (SPT) revealed the same as shown in Table 1. He has been advised to avoid cow’s milk, eggs - raw and baked - and peanuts. His mother was advised to check labels for food very carefully, as it was imperative to avoid eggs, milk and nuts, and to purchase food products at specialist shops. He has been reviewed every six months to assess progress and nutritional state. His management plan included a diet free from dairy, raw and baked egg and peanuts, Dalvit once a day and use of oat or hemp or coconut milk with calcium supplementation. He also had eczema. He was prescribed emollients 50:50 white soft paraffin and Oilatum bath oil. He has been advised to wear cotton clothing, and use of non-biological soaps or the control of eczema. Recent visit showed a flare up of his eczema and was prescribed Daktacort cream along with emollients. He was prescribed Cetrizine for minor reactions

**Table 1. The results of skin prick tests**

	Wheal and Flare
Negative control	0 mm
Histamine control	3 mm
Raw Egg	18 mm
Egg White	5 mm
Fresh Milk	16 mm
Peanuts	11mm
Chicken	15mm

### Feeding History

The child was breast fed from birth to 16 months. He was weaned onto solids from six months of age. It was not a difficult process and he had no difficulty in chewing or swallowing. His mother noted that he was a baby who wanted to be carried a lot but did not have a history of gastroesophageal reflux or respiratory distress, cough or wheeze. He was up to date with all vaccination as per KEPI schedule

### Family history

The child is the younger of two siblings. His brother is allergic to cow’s milk and omena and has eczema. Both parents have eczema. Both parents work on a farm.

### DISCUSSION

The child has attended 7 clinics with 5 hospitalizations in a span of 3 yrs. Hospitalization was due to anaphylaxis. Loss of hours and economic resources for both the parents was significant. Various factors such as social and psychosocial have a negative effect on the QOL of the primary caregiver, which in most cases are mothers. Studies have shown that mothers have poorer FAQOL scores than fathers (King *et al.*, 2009; Bartnikas and Phipatanakul, 2015). Various studies have shown that mothers had greater empowerment but reduced FAQOL (Warren *et al.*, 2015; Howe *et al.*, 2014; Sicherer *et al.*, 2001). Empowerment, defined as “ a process through

which people gain greater control over decisions and actions affecting their health, (Warren *et al.*, 2015) and is believed to facilitate incorporation of medical knowledge into psychosocial functioning” (Bartnikas and Phipatanakul, 2015). It has been very strenuous for the mother, as her son is also allergic to cow’s milk and omena and has eczema and meal times are always a threat for her. A recent study has shown that both mothers and fathers of children with allergy had higher empowerment of the condition but report reduced FAQOL scores (Bartnikas and Phipatanakul, 2015). The study also highlights that life threatening anaphylaxis occurs when parents are not in control and that the empowered parents are more likely to have a lower FAQOL as they fear exposure outside the home and when children are not with them, i.e. vacations, restaurants, social activities involving food and leaving children in the care of others (Bartnikas and Phipatanakul, 2015). The feeling of fear and anxiety by parents is reflected in their children and they tend to treat meal times as a “recurrent threat” and thereby have a bad relationship with food (Indinnimeo *et al.*, 2013) in their formative years, where proper nutrition is very important. Kenya has poorer access to allergen-free food products than UK, N America and Canada where supermarket aisles are dedicated to allergy free products and parents don’t have to spend time and money into going into specialist shops. Canada has peanut-free schools and camps and have peanut free peanut butter readily available

Although anaphylaxis due to food usually occurs outside the home setting (Bock *et al.*, 2007), In this case it occurred at home when his mother was cooking egg fried rice. There is lack of information, uniformity and clinical proof in managing anaphylaxis in areas away from home (Bailey *et al.*, 2011; Barnett *et al.*, 2012; Young *et al.*, 2009). The main treatment for food-related allergies in children is food avoidance. Food challenges in a supervised hospital setting as for chicken, almonds and pistachios, are important to reassure parents and have shown to have improved FAQOL scores (van der Velde *et al.*, 2012; DunnGalvin *et al.*, 2010). However, new therapies to treat allergies are preferable to avoidance and include immunotherapy (oral and sublingual), use of cytokines and anti cytokines, monoclonal anti IgE antibodies and Chinese herbal medicines (Sampson *et al.*, 2006; Nowak-Wegrzyn *et al.*, 2011; Scurlock *et al.*, 2009). Studies have shown that the provision of an adrenaline auto injector (EpiPen) has an impaired effect on FAQOL, and training and retraining in its use should be of utmost importance (Pinczower *et al.*, 2013). However in Kenya we don’t prescribe epipen. Comparative studies showed poor QOL in the social relationships of parents with children with food allergies compared to parents whose children do not have food allergies (Valentine and Knibb, 2011). Milk and /or egg allergies, as in this have been associated with worse QOL, compared to peanut or tree nut allergies, even though this represents a high risk subgroup (Howe *et al.*, 2014). This may be due to egg and cow’s milk being ubiquitous in the diet of children under four and therefore may be difficult to avoid, leading to a lower QOL for parents as it is difficult to avoid both from young children’s diets, thereby leading to increased stress, anxiety and burden of vigilance (Cummings *et al.*, 2010). Howe *et al* have shown that FAQOL scores of primary caregivers are dependent on accurate perception of reaction

severity, the number of allergens, and the type of food allergy (Howe *et al.*, 2014). Worse QOL scores have been recorded in the study when caregivers have an inaccurate perception, a lower income, children with comorbid eczema, children with multiple food allergies, children with older age at onset of the initial reaction, and caregivers reporting their child had anaphylaxis (Howe *et al.*, 2014) as seen in this case. Baptist *et al* also suggested that self-regulated intervention as a way to improve FAQOL score in children with food allergies (Baptist *et al.*, 2012). Parents with children with food allergy (Both him and his brother) have a large psychosocial impact on their families. Anxiety, stress and depression are constant features and impact adversely on the child and the family due to “limited activities within the family, limited eating outside home, concerns regarding disease management at school, reactions of other people towards them and their child, previous allergic reaction to food and having witnessed an anaphylaxis reaction of their child” (Cummings *et al.*, 2010). Cohen *et al* have highlighted emotional issues that include “adverse reactions, frustration in dealing with others, sadness, constant pressure that their child may not overcome the allergy and not have a normal upbringing” (Cohen *et al.*, 2004). Various useful validated tools are available to measure disease specific QOL for parents, caregiver and child friendly tool for children to measure outcomes of food allergy (Flokstra-de Blok *et al.*, 2009). For this child’s parents the intervention can be tailored to the needs and circumstances of their family as both the children have multiple food allergies and eczema. These interventions should cater to their food related anxieties and then probably their meal times would not feel such a threat. FAQOL scores would improve if public places and schools have policies for allergy prevention in Kenya.

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