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# **“Because it kind of falls in between, doesn’t it? Like an acute thing and a chronic”: the psychological experience of anaphylaxis in adulthood**

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**Abstract**

Anaphylaxis is a serious, rare condition increasing in prevalence. This study explored the psychological experience of adult-onset anaphylaxis from patient, family and staff perspectives. Semi-structured interviews were conducted with twelve participants. Two global themes emerged from thematic analysis: 'controllability' ('an unknown and distressing experience', 'the importance of control over triggers' and 'responsibility but no control: the impact on others') and 'conflict' ('rejecting illness identity', 'minimisation of risk', 'accessing specialist care: running in slow motion' and 'patient-centred versus service-centred care'). Findings highlight the importance of perceived control and emphasise the presence of conflict in the experience of this complex, episodic condition.

Anaphylaxis is a potentially life-threatening allergic reaction, rapid in onset and often characterised by respiratory compromise, hypotension, and, in severe cases, collapse (Sampson et al., 2006). The prevalence and incidence of anaphylaxis have risen in recent years. Indeed within the UK, hospital admissions for anaphylaxis increased from 1 to 7 cases per 100,000 per annum from 1992-2012 (Turner et al., 2015). As anaphylaxis is seldom recognised and often misdiagnosed (Tang et al., 2009), it is likely that these figures underestimate the true extent of the condition. Medications, venom and diagnostic agents are common causes of anaphylaxis, in addition to exercise, with or without food ingestion (Barg et al., 2011; Greenberger et al., 2007). In

30-60% of referrals, the trigger remains unknown and idiopathic anaphylaxis is diagnosed (Simons et al., 2011).

NICE guidelines (NICE, 2011) recommend that individuals with suspected anaphylaxis should be referred to a specialist allergy service for assessment, monitoring and treatment. Management of anaphylaxis includes avoidance of triggers, use of self-medication, e.g. adrenaline auto-injectors (AAIs) such as EpiPens®, and written treatment plans (British Society for Allergy and Clinical Immunology (BSACI), 2006; NICE, 2011). Allergy services have a crucial role in the long-term management of anaphylaxis. Recently, it has been argued that the Health Service could do much more to meet the psychological needs of individuals with anaphylaxis and their families (Rouf et al., 2012).

Research on the psychological experience of anaphylaxis is limited. A small number of studies have considered the psychosocial impact of anaphylaxis with a definitive cause in children (Rouf et al., 2012) and young people (Akeson et al., 2007; Gallagher et al., 2012; Herbert and Dahlquist, 2008; Hullmann et al., 2012), however the psychological impact of experiencing anaphylaxis for the first-time in adulthood is relatively unknown. Studies of children and young people suggest anaphylaxis is associated with impaired quality of life and anxiety, particularly amongst parents and carers (Akeson et al., 2007; Kastner et al., 2010; Rouf et al., 2012). Such findings

suggest the importance of considering the impact of anaphylaxis on families, but may also indicate greater psychological burden in adults. Indeed, adult survivors of drug hypersensitivity reactions have reported impaired health related quality of life (HRQoL) (Baiardini et al., 2015). Adults with food induced anaphylaxis have also reported significantly higher comorbidity than controls, with 12% meeting diagnostic criteria for PTSD (Chung et al., 2011).

Whilst these studies highlight a detrimental psychological impact of anaphylaxis, the in-depth, qualitative experience of adults living with this condition remains relatively unknown. Research has also not explored the perspective of individuals providing support, for example, family members and healthcare staff. Exploring adult-onset anaphylaxis from these different perspectives would enhance our understanding of the psychological experience of this condition, and potentially generate practical recommendations for service improvement (Kendall et al., 2009). Furthermore, qualitative research may be more appropriate in exploring novel or under-researched areas as there is an increased emphasis on inductively, rather than deductively, derived experiences. This is the first qualitative study to explore the experience of adult-onset anaphylaxis using a multi-perspective approach.

## **Method**

### ***Design and participants***

A qualitative multi-perspective interview design was adopted, as this approach is particularly useful for generating rich data to understand experience and needs (Kendall et al., 2009). Recruitment took place via a specialist allergy clinic in a National Health Service (NHS) hospital in the Midlands, UK. Seven participants were adults with a diagnosis of adult-onset anaphylaxis (idiopathic or known trigger). The majority (n=5) had experienced a single anaphylactic reaction, however some (n=2) had experienced two or more episodes. Other participants included nominated family members (n=3) and two female nursing staff members (see table 1 for demographics). Braun and Clarke (2013) suggest that interview data from between six-ten participants allows for meaningful exploration of patterns in experiences, whilst retaining a focus on individual experience.

>>INSERT TABLE 1 HERE<<

Owing to the nature of the target population (small and hard to reach), convenience and snowball sampling techniques were employed to recruit participants (Shaghghi et al., 2011). A clinician based within the allergy clinic acted as a gatekeeper and identified potential participants using inclusion criteria. Inclusion criteria included: English-speaking adults aged 18+ with a first diagnosis of anaphylaxis in adulthood (known/unknown trigger), currently accessing a specialist allergy service;

adult family members of recruited adults with anaphylaxis, and staff from the allergy service. Participants who expressed an interest in the study to the gatekeeper were asked if they were happy to be contacted by the research team and sent an information sheet and consent form. Once participants with anaphylaxis had consented to take part, they were invited to nominate a family member (or friend) who could be approached with information about the study. The research team provided study information to all clinic staff, including contact details for members of the research team if staff wanted to participate. The study received NHS ethical (reference: 15/NW/0030) and NHS Research and Development approvals (reference: WAT191214).

### ***Data collection***

One-to-one, semi-structured interviews were conducted with participants by EW and CT. All interviews followed the same interview schedule (available on request), using a conversational approach and active listening to allow participants to shape the direction of their interview. Interviews with patients and family members focused on the meaning of anaphylaxis, both prior to and following the first anaphylactic episode, responses to and coping with the first episode, impact and management of the condition and experiences of care. Staff interviews explored experiences of anaphylaxis, perceived impact of episodes and coping in patients and families, experience of psychological distress in patients and families and perceived confidence

in managing this. The use of broad questions with prompts allowed for the exploration of issues which may have emerged unexpectedly (Kvale, 1996). All interviews lasted approximately 40 minutes, were audio recorded and transcribed verbatim. Interviews were conducted face-to-face, except one conducted via telephone. Face-to-face interviews were conducted either at the allergy clinic, the University, or participants' own home.

### ***Data analysis***

Following familiarisation with the transcripts, contextualist thematic analysis was performed (Braun and Clarke, 2006). Contextualist thematic analysis focuses on people's lived experiences and the meanings they associate with this (Braun et al., 2014). Several members of the research team were involved in the analysis: EW, CT, EB, BM and LSE. This approach was taken to facilitate convergence between researchers and thus to enhance the validity of identified themes (Cresswell & Miller, 2000). Initial coding was undertaken independently by the researchers and emerging themes were then discussed and agreed in collaboration. Early interpretations were checked against participants' narratives for explanatory detail. As the analysis progressed, themes were compared and contrasted. Theme titles were amended as appropriate and coherent relationships between (and within) themes were identified. The themes developed through the analysis appeared to cut-across the three different participant groups, thus indicating their importance. However, for transparency, key

quotes have been presented to accompany themes, with additional quotes provided (see supplemental file).

## **Results**

Two global themes emerged from the analysis: 'controllability' and 'conflict'. The first global theme of 'controllability' reflects participants' accounts of the salience of control in their experiences of anaphylaxis and was comprised of three sub-themes: 'an unknown and distressing experience', 'the importance of control over triggers' and 'responsibility but no control: the impact on others'. The second global theme of 'conflict' reflects participants' conflicted experience of anaphylaxis and its management and was comprised of four sub-themes: 'rejecting illness identity', 'minimisation of risk', 'accessing specialist care: running in slow motion' and 'patient-centred versus service-centred care'. Themes and illustrative quotations are presented below.

### **Controllability**

#### ***Sub-theme: an unknown and distressing experience***

Most participants had limited previous knowledge of anaphylaxis and were unable to relate their physical symptoms to a possible anaphylactic reaction during their first episode. Even when participants were aware of anaphylaxis and had some knowledge of the symptoms, they described their own experience as being unexpected and had not linked their experiences with their working knowledge of

anaphylaxis. All participants recounted the experience as being distressing, largely due to the sudden onset and unfamiliar symptoms.

One patient explained that although she was aware of food allergy, she had not realised the diverse range of anaphylaxis triggers:

*"I'd never heard of anaphylaxis with regards that sort of thing anyway. I knew people had reactions to food but I didn't really know." (Patient 5)*

A number spoke about experiencing intense fear during their anaphylactic reaction:

*"...to tell you the truth, the thought went through my mind, I thought, "I'm gonna die here and I haven't said goodbye to my kids," because it was just so frightening for it just to happen just like that and it was really, really frightening." (Patient 6)*

Awareness of the seriousness of what happened to them did not arise until they had recovered. Even those patients with some prior knowledge of anaphylaxis had difficulty making sense of their symptoms during their reaction. This difficulty, and sense of unreality, was shared by their family members:

*"I couldn't believe it because he's, he's now 65, he's never had anything like this before and he's been stung many, many times before by all sorts*

*of things. So it was just a bit of a shock that he developed it so late in life. I wouldn't have expected it." (Family member 1)*

Staff participants reiterated the sense that an anaphylactic reaction fell significantly outside the realms of usual experiences of illness for patients and their families, highlighting the particularly distressing nature of anaphylaxis:

*"But the flood of emotions must be terrifying. Because your body just goes into crisis. Everything's about to shut down, and the fear and the panic, along with the crashing blood pressure, it must be really quite shocking for people." (Staff 1)*

***Sub-theme: the importance of control over triggers***

All participants explained that perceived control over triggers was central to their ability to manage and cope with anaphylaxis. When triggers were unidentified, this was highly aversive and the sense of the unknown caused patient participants to reflect on the loss of control they felt in attempting to prevent a future reaction. Even when triggers had been identified, participants varied in how much control they felt they had over their exposure to them.

Patient 2 described the difficulties of coping with idiopathic anaphylaxis and not having control over her triggers as:

*"... a really, really peculiar thing, because it's not like you can say, like with my daughter, she can't eat dairy, she can't eat eggs, she can't eat nuts. That's fine. Other than that she's well. Whereas with me, there's just no way of knowing." (Patient 2)*

The importance of perceived control was further exemplified by patient 4:

*"I think the ones that are suffering with the grass or pollen allergies are probably a lot worse off, because they can't escape it can then? I can 80% avoid bees but other allergies you can't." (Patient 4)*

Where triggers were recognised, perceptions of controllability were enhanced through the adoption of appropriate coping strategies. This was explained by family member 2:

*"So that was something Jane then thought, "Right, that's fine, we can do that, it's done, it's been proven, draw a line under it, here's my EpiPen®, put it in your pocket." (Family member 2)*

The importance of controllability, in terms of perceptions and subsequent behaviours was summarised by the allergy clinic staff:

*"Because it's just a case of, I suppose, with anything that is perceived as a threat, it's how far you can control your exposure to that threat, isn't it?" (Staff member 1)*

***Sub-theme: responsibility but no control: the impact on others***

Family and friends were perceived to have important roles in the preventative and reactive management of patients' anaphylaxis. There was a clear role for family and friends in supporting patients in the avoidance of triggers but also in promoting a timely and appropriate response in the event of a further episode. Patients and family members felt that family experienced this as a burden and, in some cases, assumed more responsibility than patients themselves in relation to the condition. This assumption of responsibility by family members could be actively resisted, particularly where there was conflict in relation to 'responsible' behaviours between patients and family (e.g. not carrying an EpiPen®):

*"And of course, my family are quite adamant, it's always got to be strapped to my person 24/7. But it just doesn't happen, because, well, I'm a bit more relaxed about life than that, you know. I'm not an anxious kind of person. But they said they'd never forgive me if I die from a wasp sting." (Patient 1)*

*"I guess the only other thing is just the feeling of helplessness that you have when you are the family member in so far as the allergen is, is there and you just have to, kind of, avoid it, which is easier said than done sometimes. And particularly if your family member who doesn't*

*take it very seriously it is difficult and it can be a bit, erm, you can feel powerless to protect them.” (Family member 1)*

The responsibility assumed by family was exacerbated by the particular features of an anaphylactic reaction, particularly the severity and speed, with the potential that the patient may be unable to respond themselves as required:

*“And how to use the Epi-pen®. Because my husband wasn’t told. And he’s very likely to be the one who’s going to use it. Isn’t it?” (Patient 7)*

This highlights a significant issue in relation to information and training for family members. In turn this may aggravate perceptions of controllability for patients, who fear the loss of control during an anaphylactic reaction, and family, who do not feel they have been provided with the necessary training or information to respond during an emergency situation.

The helplessness engendered by this, for both patients and their families, was recognised by staff:

*“I think it’s quite stressful, because we are asking people who are not medically trained to look out for the first signs of an anaphylaxis. And a lot of the time, these people are very close to the person who had the anaphylaxis, so they don’t necessarily know what they’re looking for.” (Staff member 1)*

## Conflict

### ***Sub-theme: rejecting illness identity***

The majority of patients wanted to put their anaphylactic reaction behind them and resisted being labelled as 'ill'. Patients who had only experienced a single reaction, and those who had experienced repeated episodes, all expressed the need to minimise their identity as someone who was ill and attempted to retain congruence with a 'healthy' identity:

*"When you've got something like this that goes on, you can't just go round saying "I feel awful" all the time, really, can you? Because that's just so boring, for me as well. Because then that defines you who are. Because then you start thinking of yourself as somebody who's ill."*  
(Patient 2)

*"I mean, apart from the fact that I'm totally- carrying around the EpiPen® and anti-histamine tablets wherever I go, I don't want it to have an effect on my life; I want to get on with my life and live it and try and put it behind me." (Patient 6)*

The rejection of an illness identity was recognised by family as a mechanism to prevent any 'illness identity' defining them and the responses of others towards them:

*“I think it was potentially a combination of, erm, not wanting, not wanting to change things and just not wanting anything to impact on his way of life.” (Family member 1)*

***Sub-theme: minimisation of risk***

There were instances where the rejection of illness identity was reflected in risky behaviours – for example, patients who did not routinely carry an AAI. The dissonance between having a life-threatening condition, evident only in the presence of a trigger, and the minimisation of risk based on a rejection of illness, became further aggravated as the time since an anaphylactic reaction increased:

*“As two years went by without anything happening, you think, “Oh, well, maybe it’s alright,” don’t you?” (Patient 3)*

Without clear identification of a trigger, or multiple triggers in combination, there is no reduced risk to patients over time. It is clear, however, how common-sense reasoning could encourage this perception of reduced risk:

*“I think the experience of it means that, I suppose in some ways it’s more immediate because you’ve experienced it. But on the other hand, you’ve been through it and successfully survived, so the prospect of imminent death recedes a little bit.” (Patient 1)*

In these instances, common-sense reasoning was associated with greater risk taking:

*“Yes, but of course I didn’t carry it. I took it with me, but I didn’t have it on my person all the time, because it’s not at the forefront of my mind at all.”*

*(Patient 1)*

*“If you’ve never seen anyone get into really significant trouble with it, and you’ve been okay yourself even though you’ve had it, I can see how that would just reinforce your attitude that it’s not that big a problem.” (Family member 1)*

*“They don’t tend to carry them, no. Some of them do, some of them don’t, but it’s interesting if they’re in date, or if they take them everywhere they go. I don’t think that they do. I don’t know whether that fear wears off. Do you know what I mean? (Staff 2)*

***Sub-theme: accessing specialist care: running in slow motion***

All participants highlighted difficulties in accessing specialist care. Outside the allergy clinic, healthcare professionals’ knowledge of anaphylaxis was perceived as limited, and their advice untrustworthy. Long waiting times to access the allergy clinic left patients and family members feeling frustrated, vulnerable and reinforced their feelings of uncertainty about their condition. The contrast between the acute emergency of their anaphylactic reaction and the subsequent delays when attempting to access specialised help was significant.

One participant spoke of her experiences during her acute episode of anaphylaxis in a GP surgery:

*"And the lady doctor was actually saying, "I've never dealt with this before," and I think that frightened me as well because I thought, "Blimey, I've walked in here to what I think is a place of safety," I was, "Thank goodness," thinking, "I'm so glad I'm so near to the doctor's and not in the middle of town," and then I could hear this doctor saying to the nurse and the receptionist, "Have you ever seen this before? Have you ever dealt with this?" and I was thinking, "Well, you know, you're the doctor, you're the one that's supposed to be helping me" (Patient 6)*

Hearing professionals' express uncertainty about the condition exacerbated participants' anxiety and could lead patients to rely on their own 'expert by experience' knowledge of the condition. This was further aggravated by long waiting times to access specialist care:

*"To have to wait 12 months to get to the allergy clinic to find out any result is a long time, and it's very, very worrying, and that could have a big impact on people and their families because you feel like your life's on hold because you need to know why it happened." (Patient 6)*

The conflict in accessing care for a condition that is both acute and chronic was identified by patient 2:

*“Because it kind of falls between, doesn’t it? Like an acute thing and a chronic.” (Patient 2)*

Family members also described the difficulties in accessing care:

*“It was like, you know, a rotating wheel through different departments but there was a long waiting time” (Family member 2)*

Allergy clinic staff empathised with the challenge of accessing appropriate care and its detrimental impact:

*“It can leave people feeling really quite vulnerable. In the time from discharge from their acute admission through to being seen in our clinics, there can be some delay, and if they’re unsure about what caused their anaphylaxis, or there’s just a period of time where they’re without an EpiPen® or they feel vulnerable, it can leave them quite anxious before they come to see us.” (Staff 1)*

***Sub-theme: person-centred versus service-centred care***

The challenge of delivering a specialised service to meet the complex, individual needs of adults affected by anaphylaxis was evident. Whilst some felt their needs were appropriately addressed, others highlighted a need for psychological support. The

practical difficulties associated with this, in the context of brief appointment times and long waiting lists was expressed by staff.

Despite the challenging context of service delivery, many patients praised the allergy clinic staff for their expertise and supportive approach:

*“I think the advice is exceptionally good, and I think the nurses are very good at getting the messages over. I feel very, very well-supported, and I think if I had a problem, that if I were to ring the clinic, I think I would get very good advice and help.” (Patient 1)*

For staff, a conflict between addressing patients’ physical needs whilst also acknowledging their psychological needs was evident and linked with busy and over-stretched clinics, thus highlighting the challenge of delivering person-centred care within a pressurised service:

*“You wouldn’t have time to talk. Thing is, you never ask the question because you wouldn’t have time to answer it. Because I’d be thinking, “Oh, I need to get you out.” (Staff 2)*

Time pressures within the specialist service may explain why some patients felt that there was insufficient attention to the psychological impact of anaphylaxis in the clinic:

*“Nobody really talks to you about how you felt. Nobody want- nobody, nobody ever said, “Well I understand you've been through a frightening*

*thing and let's try and understand it from the emotional side of things," they're more interested in the physical side of thing and nobody ever says anything to you about the impact on yourself or your mind or your family or anything around you. This is why I wanted to take part in this to be able to put the point of view over, you know." (Patient 6)*

In addition to patient need, at least one family member highlighted that they also had experienced distress following the anaphylactic reaction of their relative and would have liked further opportunity to discuss these feelings with a specialised clinic staff member:

*"I think my dad's probably quite an unusual case in that he's not that worried about it. But I think if it happened to me or other people then I think some sort of, erm, some sort of psychological support would be really useful because I, I'm aware of the fact that throughout this interview I've, I've talked about being anxious and worrying all the time." (Family member 1)*

## **Discussion**

This is the first study to explore the psychological experience of adult-onset anaphylaxis from the perspective of individuals with the condition, family members

and allergy staff. Across the participant triad, there were notable similarities in experiences. Adults with anaphylaxis and their families experienced difficulty gaining a sense of control over the condition. This was linked to the distressing nature of anaphylactic episodes and the variable extent to which triggers could be identified and avoided. Resistance from participants with anaphylaxis and limited information further compounded this issue for family members. In addition to controllability, conflict was also central to participants' narratives. This emerged as rejection of an illness identity and lowered risk perception in adults with anaphylaxis. The notion that risk reduced over time adversely affected self-management and was exacerbated by a contrast between the initial emergency experience and delayed access to specialised care.

The findings of this study are consistent with previous research on adolescents which identified a blasé attitude towards anaphylaxis in young people, heightened concern amongst family members, and multiple barriers to effective self-management (Akeson et al., 2007). Indeed available research indicates that, across all ages, less than 30% of individuals with anaphylaxis carry an AAI (e.g. EpiPen®) at all times and only 44% are able to demonstrate the correct procedure for use (Goldberg and Confino-Cohen, 2000). Our findings support recent research which has identified that adherence to AAI's is adversely affected by high perceived barriers, experience of

survival from the first episode, inconsistent health professional advice and insufficient training (Herbert et al., 2016; Money et al., 2013).

Self-regulatory theory (SRT) (Leventhal, Nerenz & Steele, 1984) is a useful framework for understanding and predicting behaviour in people living with severe allergy (Jones et al., 2014; Knibb and Horton, 2008). According to SRT, illness perceptions reciprocally influence coping behaviours in the context of a health threat. Our findings are consistent with previous research utilising SRT which has found that participants who perceived their allergy to be unstable and episodic in nature were less likely to adhere to self-management behaviours (Jones et al., 2014). Time-line is an important element of the self-regulatory process and would appear to have significance for participants in this study since risk perception reduced over time. This appraisal may have common-sense acceptability for individuals with anaphylaxis, but appears to encourage 'risky behaviours' as well as increasing psychological distress amongst family members.

### ***Implications for research***

Further qualitative and quantitative research is needed to explore the complex illness representations held by adults with anaphylaxis and their family members. Specifically, research should address the impact of illness perceptions on management of anaphylaxis, including engagement with healthcare services and self-management

behaviours. . Additionally, it will be important to better understand the relationship between illness perceptions and quality of life in affected individuals and families.

### ***Implications for practice***

Further education and information on anaphylaxis management could benefit patients and families, but it is important that this information addresses identified barriers and illness perceptions. For example, AAI training should acknowledge and respond to the complex practical and perceptual barriers that lead to non-adherence (Horne, 2000). Indeed, the prescription of adrenaline injectors alongside an educational and motivational training intervention has been found to significantly increase accurate demonstration of use (80% vs 10%) (Quercia et al., 2014). Training in active listening and motivational interviewing could therefore help specialist allergy staff to identify illness perceptions during initial consultations and work collaboratively to promote behavior change. Additionally, the employment of peer support or peer-led self-management training could be helpful. This could be delivered in community settings by individuals with anaphylaxis and family members to increase perceived control and reduce conflict.

### ***Limitations***

Some limitations to the current study are acknowledged. Specifically, recruitment was from a single service and data were gathered from single interviews conducted at varying time points following diagnosis. Although the sample size was relatively small,

rich data was obtained and data saturation was reached (Morse, 2015). Future research should adopt a multi-site recruitment strategy to explore this area in other allergy clinics. Additionally, future research could employ a longitudinal interview design to examine changes in experience over time.

### **Conclusion**

This is the first qualitative study to explore the psychological experience of adult-onset anaphylaxis from multiple perspectives. Findings highlight the importance of perceived control in this complex, episodic condition. Conflict was also central to participants' perceptions of anaphylaxis and its management. Further research is needed to explore illness representations related to adult-onset anaphylaxis. Additionally, information, training and support derived from psychological theories should be offered to adults with anaphylaxis and their families.

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None Declared

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**Table 1.** Patient and family member demographic details.

Participant number		Gender		Age		Anaphylaxis trigger
<u>Patient</u>	<u>Family</u>	<u>Patient</u>	<u>Family</u>	<u>Patient</u>	<u>Family</u>	
P1	F1	M	F	65	33	Wasp venom
P2		F		38		Unknown (idiopathic)
P3		M		57		Food-dependent, exercise-induced anaphylaxis (FDEIA)
P4		F		ND		Bee venom
P5		F		65		Wasp venom
P6	F2	F	M	57	57	Codeine
P7	F3	F	M	61	67	Bee Venom

