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Title: 'I haven't said goodbye to my kids'

Byline: Béré Mahoney, Eleanor Bradley, Elaine Walklet and Steve O'Hickey on the hidden psychological challenges of living with anaphylaxis in adulthood.

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Dr Béré Mahoney is a Chartered Psychologist and Senior Lecturer in the School of Psychology, University of Worcester. She has diverse applied research interests in addition to how individuals with adult onset anaphylaxis respond to and manage their condition. These include women's experiences of reconstructive surgery following mastectomy, and the links between sexuality, victimisation and culture.

Eleanor Bradley is a Chartered Psychologist and Professor of Health Psychology at the University of Worcester. She has worked across University and NHS environments, focusing research on understanding the experiences of people in receipt of and delivering healthcare, particularly amongst changing practice and organisational developments.

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Lead: People diagnosed with anaphylaxis in adulthood face unique, but largely ignored, psychological challenges. Psychology offers insights for understanding their needs, and the development of interventions to help this growing group live with severe allergies.

An allergy presents psychological and social challenges for individuals and their families, and research on such challenges has focused on common, severe allergies among those who may be more physically vulnerable; namely, food allergies in children and young people. Yet the number of people in the UK diagnosed with anaphylaxis – the severest and potentially life-threatening type of allergic reaction – is growing, and the challenges they face have been under-researched.

To address this, the Anaphylaxis Campaign – the UK’s largest charity dedicated to supporting individuals at risk of severe allergic reactions – launched their ‘Year of the Adult’ in 2017, to improve support for the growing number of adults who have been living with anaphylaxis since childhood, as well as individuals who have developed the condition in adulthood. We greeted this with interest, as we have been conducting research with individuals with adult-onset anaphylaxis since 2014. Despite the wealth of psychology research which focuses on the role of psychological factors in treatment adherence, we know little about how adults manage their anaphylaxis in their daily lives or the psychological factors associated with these management strategies. Medical and nursing colleagues from allergy services told us of differences they noticed when supporting individuals diagnosed with anaphylaxis in adulthood compared to those encountered with younger patients and their families. They asked us to help them find out more about what it is like for this group and their families to live with anaphylaxis, and how they could improve the support they provided.

Different for adults?

We found some common psychological challenges for children, young people and adults. Failure to carry an adrenaline auto-injector (AAI) is commonplace, and many individuals and family members are unable to demonstrate correct use of their AAI. False optimism, in which individuals believe their risk of further anaphylaxis is reduced over time, is a potentially unhelpful health belief that can be held by individuals with anaphylaxis. The very nature of anaphylaxis exacerbates the likelihood of false optimism, given that individuals may have spent long periods of time without experiencing anaphylaxis or, indeed, may only ever experience a single severe episode of anaphylaxis. Family anxiety about how to support the individual with anaphylaxis (adults, children and young people) is also very common.

But we did also uncover distinct and relatively hidden psychological challenges faced by those living with anaphylaxis diagnosed in adulthood, their families and the staff supporting them. Here, we describe insights from two of our research studies – one involving interviews with people referred to a specialist NHS allergy clinic with adult-onset anaphylaxis, along with family members and specialist allergy nursing staff, the other a mixed methods evaluation of our training workshop for health care professionals on psychological barriers and facilitators to self-care adherence when working with anaphylaxis.

Existential searching

Pull quote: *‘I’m gonna die here and I haven’t said goodbye to my kids’*

We found that health professionals sometimes assume that adults are more able to accept their anaphylaxis and consequent treatment recommendations, due to their relative psychological maturity. As one health care professional told us, there may be an assumption that adults with anaphylaxis are the ‘easy... EpiPen and go’ patients. Our research suggests that this is often not the case.

Simply put, adults have more ‘psychological baggage’ than children. Adults have years of common-sense reasoning and beliefs about life, death and health that they use to make sense of their anaphylaxis. As with other long-term conditions, this can lead to unhelpful beliefs and behaviours around their anaphylaxis, which may shape their reactions to it. There are long-lasting implications for their management and self-care behaviours.

For example, we have found that people diagnosed with anaphylaxis in adulthood experience existential rumination in response to their original anaphylaxis episode and in subsequent self-management of their condition. An episode of anaphylaxis, similar to other near-death or life-threatening traumatic encounters or events, can be accompanied by near-death experiences (NDEs). Bruce Greyson, an American Psychiatrist and researcher on NDEs, describes these as ‘powerful psychological experiences typically occurring to an individual close to death or in a situation of intense physical or emotional danger’. Research with adults, children and young people who have undergone anticipated and unanticipated near-death medical events, suggests that their NDEs have core affective, cognitive, transcendental and paranormal components.

Indeed, some findings from the literature on NDEs echo our findings from people with adult-onset anaphylaxis. In our research, most reported being unconscious during anaphylactic shock, but a small number reported that they’d had thoughts about how their family would cope if they died. This fits what we know about other unanticipated life-threatening health events – people who experience these report more cognitive experiences, such as reviewing their life, whereas those whose life-threatening event is anticipated (e.g. linked to a pre-existing health condition) are less likely to report such thoughts.

Notably, evidence suggests that posttraumatic growth following a life-threatening health event, whether anticipated or not, seems more likely if the individual reports these sort of NDE thoughts. However, this growth isn’t something reported by the adults with anaphylaxis we interviewed, so whether psychological growth can follow an NDE during an unanticipated first episode of anaphylaxis in adulthood is unclear. It does appear, though, that children and young people can cope better psychologically with traumas compared to adults in the same situation. For example, our interviews suggested that those with adult-onset anaphylaxis might be more likely to experience the negative emotions of anger and guilt about their condition. Some appeared angry at the loss of their good health; for others, the cause of their anaphylaxis remained unknown, promoting a sense of uncertainty and insecure physical health. For those adults with anaphylaxis triggered by venom (e.g. wasp or bee sting), the source of the allergy may be known, but exposure to it in the general environment can remain unknown or extremely difficult to control. These features of anaphylaxis appear to be particularly meaningful for adults – we are driven to make sense of events and experiences, to derive certainty from unpredictable situations and to regain control through prescribed behaviours or treatments. For some, this may be a difficult psychological experience and it can lead to an ongoing sensation of vigilance.

Guilt and anxiety around others

Our research also found that some people experience feelings of guilt about their condition. These adults often ruminated about what could have happened if they had not survived their original anaphylaxis, particularly the consequences for their adult family members and children. One interviewee told us that during her anaphylaxis she remembers thinking 'I'm gonna die here and I haven't said goodbye to my kids... what's happening, if I just go now, am I gonna come back?'

Some adults also became acutely aware of the anxiety experienced by others around them, related to their anaphylaxis. One interviewee spoke about her first anaphylaxis episode, saying: 'My husband and my daughter were far more traumatised than I was'; another told us that 'Everybody else was more traumatised than me, I think'. Children and young people with anaphylaxis may appear much less aware of the broader impact of their condition.

Independence and risk

Many adults we spoke to found it difficult to identify with their anaphylaxis because they associated the condition with children. As one interviewee said, anaphylaxis is 'the peanut thing and... children really'. Such reasoning made it difficult for adults to accept their condition. Perhaps combined with greater independence, and the lack of ongoing or consistent physical symptoms, adults seemed encouraged to take risks with their self-management.

This is to be expected, as children's transition to adolescence and then into adulthood are known to be high-risk periods for those self-managing long-term conditions. Young people undergo this transition with prior experience of anaphylaxis, having developed psychological and physical strategies over time, often with the support of family. Those diagnosed in adulthood found themselves having to adjust rapidly from a perception of themselves as a previously 'healthy' adult, to an adult with physical vulnerability.

Psychological challenges for families

'We've sort of done our bit to try and protect him, but if he doesn't want to do it then that's up to him, it's completely up to him'

It is not uncommon for family members to express more anxiety on behalf of their relative with anaphylaxis, than the individual themselves. With adults, there is something of an 'adherence paradox': adults are more likely than children to have to self-administer their AAI, but their family members are likely to believe that there is little they can do to encourage the person to stick to their management plan or use their AAI, precisely because their relative is an adult. As the adult daughter of a parent with anaphylaxis we interviewed said, 'if he doesn't want to do it then that's up to him, it's completely up to him'.

Feeling unable to control the self-care behaviours of their adult relative seemed to distress and frustrate relatives: 'we know that we're not going to be there when it happens, the likelihood is we're not going to

be there... and you don't like to think of someone having to cope with something like that by themselves'. Individuals also seemed aware that their relative's years of good health before unexpected anaphylaxis could encourage their relative to be falsely optimistic and not carry their AAI: 'you've been OK 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'.

Relatives of adults with anaphylaxis also often shared a disbelief that anaphylaxis could be diagnosed for the first time in adulthood: 'he's never had anything like this before... So it was just a bit of a shock that he developed it so late in life. I wouldn't have expected it.'

Challenges for health care professionals

'They often don't carry them around, either... you'd think that after having a near-death experience, you would... I don't know why'

It is common for health care professionals to feel ill-equipped to train individuals with anaphylaxis to use an AAI, and many cannot demonstrate the correct use themselves. However, our research shows that practical support is not the only challenge – many health professionals make erroneous assumptions about the psychological needs of adults following anaphylaxis.

Health care professionals may perceive anxiety amongst this group of adults as normative – 'it's a trauma, so [patients should] expect to be anxious' – but not requiring formal support or input. This perhaps led some health care professionals seen by adults with anaphylaxis to be less guarded in their communication style with them than they might be with children. One patient recalled: 'I think the fear of using the pen – because obviously the doctor mentioned, "Oh, you could do yourself harm with that," sort of business, before they gave me one originally – means that I'm obviously afraid. I have fears of using it. I just hope I don't have to use it'.

While paediatric services for young people with anaphylaxis have relatively developed ways of recognising and supporting the psychological aspects of living with anaphylaxis, there is little or no equivalent service support for adults with anaphylaxis. We found that health care professionals supporting adults with anaphylaxis can perceive their role as more medical than psychological, with a focus on the technicalities of using an AAI. Interestingly, adults with anaphylaxis were often assumed to be rational decision makers in relation to the management of their condition. Some health care staff reported disbelief about the self-care behaviours of adults with anaphylaxis they had encountered (see quote above).

Psychological interventions

'I'm clinical, our job is to make sure they know what to do if they have an anaphylaxis. So we teach them signs and symptoms and teach them to use EpiPens.'

We need inclusive psychological interventions (health, counselling and clinical psychology) to enable adults who require formal, psychological support to access this as required. There is evidence that CBT can be used to help parents of children with anaphylaxis, so there may be merit in exploring how to transfer good practice from paediatrics to adult-focused work.

However, we must also be mindful of the evidence from this group which points to particular challenges, such as pre-existing common-sense models of illness and incongruence with the diagnosis of severe allergy in adulthood. Evidence from counselling and health psychology (e.g. Taylor & Lewis, 2018) shows emotion-focused therapy, systemic therapy and patient and practitioner behaviour change interventions could help. Further research is needed to identify those adults who may find it particularly difficult to adjust to their anaphylaxis.

There is a broader role for psychology in terms of developing training grounded in health psychology theory, to improve awareness about techniques designed to increase adherent behaviour amongst adults. The development of psychological mindedness amongst health professionals more broadly, through communication techniques and strategies, could address any early adjustment difficulties for those recently diagnosed, as well as identifying those in need of further psychological support for more complex adjustment and trauma. Toolkit resources and checklists for professionals, as they gain confidence in discussing psychological issues with patients, could prove particularly helpful. To end with a quote from a clinician attending one of our training workshop: 'I didn't realise the assumed knowledge and the assumptions about the way adults deal with emotions and medical experiences, compared to children. When in actual fact, with something like anaphylaxis, adults are as much in need – well, some are – as children.'