ETHICAL ISSUES IN ANAPHYLAXIS

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INTRODUCTION

Anaphylaxis is “a serious, generalised or systemic, allergic or hypersensitivity reaction that can be life-threatening or fatal.”1 All international guidelines on anaphylaxis, including the South African one, emphasise the importance of early administration of adrenaline, either by intramuscular injection or auto-injector, into the outer thigh muscle. The International Consensus on (ICON) anaphylaxis published in the WAO Journal lists a number of unmet needs in anaphylaxis, one of which is that increased awareness of anaphylaxis is required, not only among health professionals, but also among patients, caregivers and the general public.1

CASE SCENARIO

Henry, a 3-year-old boy, is enrolled at a crèche. He is allergic to peanuts and his mother asks the staff to inform the other children’s parents not to give them peanut butter sandwiches to bring to the crèche. The staff refuse to do so, and Henry’s mother consults you as his doctor. What are Henry’s rights in this scenario and how would you advise his mom?

RISK, UNCERTAINTY AND ALLERGY

The key question in this scenario is to try to identify the risk of a severe reaction should Henry be exposed to peanuts and/or peanut butter at school. To this end, a careful and detailed history is required, together with appropriate allergy testing. Depending on the history of previous reactions to peanuts, the most appropriate test may be specific IgE to peanuts (including rAra h2) or a skin prick test. A food challenge may be necessary if the history and allergy tests do not suggest that Henry is at risk of a severe reaction to peanuts. As it is often challenging to quantify the risk of peanut allergy, the risk of anaphylaxis is difficult to estimate. This causes severe anxiety and uncertainty when counselling families of affected children as to this potential risk. The clinician has to weigh up what is in the best interests of the peanut allergic child (beneficence) against the potential harm that may be caused by singling the child out and the stigmatisation that may result (non-maleficence). To what extent should clinical decisions include the preferences of the parents (respect for parental autonomy)? Making parents the primary decision makers may result in excessive parental anxiety and reduced quality of life.

The parental uncertainty is illustrated by two cases quoted by Wendy Hu and her co-authors.2 The first case involved a 20-month-old boy who developed urticaria on his face after contact with peanut butter, but without any systemic symptoms, at the age of 12 months. He subsequently avoided peanuts, although his family continued to eat them. His skin prick test to peanut was positive (9 mm; >3 mm considered positive). He did not receive an adrenaline auto-injector, a decision with which his mother was comfortable. The second case was that of a 23-month-old boy who also developed facial urticaria and swelling of the lip and eyes after contact with peanut butter at the age of 9 months. He too did not develop systemic symptoms, but was given adrenaline at the local hospital. His skin prick test to peanut was 9 mm but an adrenaline auto-injector was prescribed for him, and his mother felt this was the safer option.2 Underpinning the different management decisions of these two children is the uncertainty regarding the risk of anaphylaxis to peanuts.

How can health professionals, patients and parents cope with this uncertainty in allergy practice? Where possible, evidence-based medicine should be practised. If this is not available, as illustrated by the cases above, then the health professional should communicate the relevant information to the patient/parents, explaining the risks and benefits, together with a recommended management plan, and the final plan should be decided upon through shared decision making.3

FOOD ALLERGY AND ANAPHYLAXIS IN SCHOOLS

The tension around the management of food allergy in schools involves respecting the confidentiality of the food allergic child and avoidance of stigmatisation, while also avoiding risk and harm to him/her. The food allergic child has the right to be educated in a safe environment and exposure to food allergens may cause harm. At the same time, it is important to respect the rights of other (non-food allergic) children.4

Most guidelines on food allergy policies in schools address two issues:
1. Management of an emergency situation (anaphylaxis); and
2. Prevention of exposure to and/or accidental ingestion of a food allergen.4

The school should have an established policy and guidelines on the management of anaphylaxis. The policy has to address the training of staff to recognise the emergency...
and to treat anaphylaxis by means of injectable adrenaline. Educators and staff have a right to be informed about the allergic problems of the children in their care and to be properly trained in managing allergic emergencies. The policy should also include indemnification of the person administering the injection.

Prevention of exposure to food allergens may be achieved by strict policies that forbid any sharing of food or food containers between children and the creation of “allergen-free” areas in canteens or classes. Completely banning food allergens such as peanuts from schools or crèches is usually not effective. Although this may well reduce allergen exposure, it infringes on other (non-food allergic) children’s rights.

The ethical principle of respect for autonomy and its corollary of confidentiality applies to the food allergic child. These children are frequently the targets of bullying, discrimination and harassment. Experts advise that care should be exercised to prevent the isolation of the food allergic child from other children. A number of studies from a group in Canada have looked at the issue of stigmatization of children with food allergies in school. When asked to depict their experiences through drawings, the children illustrated their feelings of being different, excluded, “other” and panicky when other learners brought in allergenic foods or had food fights in the school cafeteria. They were unable to join their friends at school camps and felt robbed of spending time with them. “A life-saving tool (e.g. EpiPen) represented a differentiating object that meant disclosure was more challenging. Hiding food allergies to fit in, through non-disclosure or concealing life-saving tools, placed children at higher risk and very often resulted in them feeling more anxiety.” The children understood that their food allergy was a potentially life-threatening condition, which made it “a big deal”.

An ethical framework that would encompass safety concerns of food allergic children in schools is that of public health ethics. Here the concern is more the health of populations (children with food allergy) rather than that of individuals. Behrmann explains that this means that schools have to sanction policies to prevent the adverse health outcomes associated with food-induced anaphylaxis, just as other public health policies are enacted to protect other populations with health risks. This includes adequate prevention policies as well as training of staff to manage anaphylaxis emergencies.

**SABRINA’S LAW**

Sabrina Shannon from Ontario, Canada, was 13 years old when she died from an anaphylactic reaction to peanuts in 2003. She knew she was allergic to peanuts, dairy and soya, with a high risk of anaphylaxis. She was also asthmatic. She was a very responsible young woman who had even participated in a documentary on food allergies when she was 10 years old. On the fateful day of 29 September 2003, Sabrina elected not to take her usual home-made hypoallergenic lunch to school, opting instead for the school cafeteria’s French fries. She had eaten them without incident the previous week and once again ascertained that they had been cooked in vegetable, not peanut, oil. Unbeknown to her, however, the tongs that were used to dish up the chips had been contaminated by cheese curds.

After lunch Sabrina started to wheeze in class, but she thought it was an asthma attack. By the time her teacher had retrieved her EpiPen from her locker, Sabrina had collapsed and arrested. She was successfully resuscitated but suffered severe neurological damage and was removed from life support on 30 September 2003.

Subsequently, the Chief Coroner for Eastern Ontario called for comprehensive anaphylaxis management plans to be implemented in all schools in Canada and Sabrina’s Law was finally promulgated on 1 January 2006. The requirements of this law are that schools have to have adrenaline auto-injectors available in the school office and that staff and teachers have to be trained to recognise and manage anaphylactic emergencies, including administering the auto-injector. Similar legislation has been passed in Australia and the United States of America.

Although Sabrina’s Law aimed to protect students with a potentially life-threatening health condition in the school environment, it initially resulted in the stigmatisation of the very children it was intended to protect. A study by Dean et al. revealed “the tension between balancing physical safety with social well-being in a system that often finds the two mutually exclusive due to the disclosure process”. The authors believe that Sabrina’s Law was ultimately successful in creating awareness about severe food allergy and that this has been of benefit to the children and families affected by it. Awareness of a condition results in reduced stigmatisation and discrimination and eventual acceptance of such children as “normal”.

**DISTRIBUTIVE JUSTICE, RESOURCE ALLOCATION AND ANAPHYLAXIS IN LIMITED-RESOURCE COUNTRIES**

Access to highly specialised allergy services and investigations for anaphylaxis may be difficult in a limited-resource country such as South Africa. As an example, if every child with peanut allergy, regardless of risk, has to be issued with two adrenaline auto-injectors, the cost implications would be prohibitive. If, in addition, we advocate that every school should have an adrenaline auto-injector, the costs escalate. We would have to consider alternative options such as adrenaline ampoules and syringes, or pre-filled unsealed syringes, in guidelines. At the same time, we ought to advocate for increased resources for allergy in South Africa and also engage with the pharmaceutical
industry to make affordable emergency care available to patients and schools.

**LEGAL ISSUES AND ANAPHYLAXIS**

The legal issues involved in anaphylaxis include some of the discussion above, particularly with regard to schools' responsibility in preventing and managing anaphylaxis. Other issues have been previously addressed in *Current Allergy and Clinical Immunology*.9 They include medical liability and negligence in cases of fatal or near-fatal anaphylaxis. If a person dies as a result of anaphylaxis, especially where it is as a result of a medical intervention such as administration of an antibiotic, it is important to express regret and be empathetic, but not to admit liability without first consulting an authority skilled in risk management and/or legal advisor.9

Labelling of foods requires accurate information about the allergen content of foods in the public interest and legislation is required to enforce accurate labelling and testing by independent laboratories.10

**CONCLUSION**

Anaphylaxis is a potentially life-threatening allergic condition and its management includes both ethical and legal dilemmas. The main issues involve the degree of uncertainty regarding the risk of anaphylaxis and therefore, avoidance of harm. From a practical point of view, schools play a vital role in the avoidance of exposure to allergens and the emergency management of anaphylaxis in children. The health professional has an important role to play in advising patients and families about potential risk and the management options and in training patients, families and school staff in managing anaphylaxis. Another aspect of the health professional's role involves advocacy for food allergic patients. This role requires engagement with legislators, educational authorities, other health professionals and the pharmaceutical industry to ensure safe environments for food allergic people and affordable treatment of anaphylaxis.

**REFERENCES**


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