

## Food allergy and anaphylaxis — dealing with uncertainty

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*Reducing the growing burden of food allergy requires a chronic disease management model, clarification of responsibilities, and better communication of both risks and uncertainties*

Food allergy and anaphylaxis are increasing in the Australian community, particularly in preschool-aged children,<sup>1,2</sup> although, paradoxically, mortality occurs almost exclusively in school-aged children and adults.<sup>3</sup> Food allergy and anaphylaxis are high-stakes and highly uncertain issues, where the outcome may be the sudden and unpredictable death of a child.<sup>4</sup>

The concept that a patient is “at risk” inevitably invokes uncertainty. It is possible to prospectively identify those at risk by virtue of having food allergy, but diagnostic tests are not highly predictive of anaphylaxis. The population with food allergy is substantially larger (about 10–20-fold) than the population who will experience anaphylaxis. Patients and their carers therefore live with being at risk, while not knowing exactly what the nature or extent of the risk is.

In clarifying what we mean by “anaphylaxis risk”, the conventional wisdom in risk communication literature is to avoid essentially meaningless terms such as “potential risk” or “high risk” and to instead employ techniques that more accurately convey quantitative estimates of risk. This is risk as numbers, or “the probability that an event will occur, eg, that an individual will become ill or die within a stated period of time”.<sup>5</sup> Mortality figures for food anaphylaxis in New South Wales show that the numerical risk that a teenager allergic to peanut or tree-nut will die from anaphylaxis in the next year lies between 1 in 10 000 and 1 in 100 000 — in the same order as the chance of an Australian resident being murdered in the next year.<sup>6</sup> The risk that a child aged under 5 years will die from food anaphylaxis in the next year lies between 1 in 1 million and 1 in 10 million — the same order as the risk of death from being struck by lightning.<sup>6</sup>

However, there are problems with this numerical approach to risk assessment: the data to calculate probabilistic risk for anaphylaxis are either unavailable or not generalisable; numerically small risks are difficult to communicate; and death by lightning or violence is not necessarily viewed in the same way as a child dying from eating food. Due to its emotive characteristics, the risk of food anaphylaxis is likely to be appreciated by experiential rather than analytical cognitive processes,<sup>7</sup> which are intuitive, automatic, and greatly influenced by associations and affect. Fear of the unpredictable death of a child may outweigh any rational consideration of its numerical likelihood. Care must therefore be taken when discussing anaphylaxis risk with patients and parents, with a key consideration being the need to sensitively communicate uncertainty as much as communicate risk.

As food is essential, some exposure to risk is unavoidable. Although food labelling is becoming clearer, there are persistent uncertainties about mislabelling and cross-contamination with allergens, coinciding with broader concerns about food quality and production, and societal expectations that parents and others will provide safe food for children. Accordingly, food allergy is as much a sociocultural as a medical issue, and, for some, the constant obligation to make careful decisions about what to eat or feed their

child, together with ongoing uncertainty about the risks, can create an enormous burden.

Reducing this burden requires a coordinated and intersectoral response, from consumers, the health care, teaching and childcare professions, the food and pharmaceutical industries, and statutory bodies at both state and federal level. Clarification of responsibilities is required for food labelling and production, care in schools and preschools, anaphylaxis education (involving anaphylaxis recognition and risk minimisation, as well as correct use of EpiPen autoinjectors [CSL Limited, Melbourne, Vic]), and monitoring EpiPen use. It is encouraging that, in recent months, the Victorian Government has announced legislation mandating a school anaphylaxis management standard<sup>8</sup> and the Western Australian Government has committed \$6.6 million to a program of interventions.<sup>9</sup> Nevertheless, as with other “messy” and uncertain problems, pure science and rationality alone are not sufficient.<sup>10</sup> In formulating policy, the process of representation, clarification of common aims and interests, and debate over what we mean by “anaphylaxis risk” may be more important for developing a coherent and coordinated framework for action than would identifying an elusive “right” response.

At the service provision level, there has been a tendency for medical treatment of an acute emergency to be the focus of food allergy management. Emergency treatment itself brings additional uncertainties — guidelines for EpiPen prescription leave much to individual judgement, and one study found that only 2% of doctors in a major Australian paediatric teaching hospital could correctly demonstrate all steps in EpiPen administration.<sup>11</sup> Fortunately, despite the many uncertainties, most food-allergic patients are generally well and the EpiPen is appropriately unused. Nevertheless, it is more appropriate for food allergy, with its unpredictable “exacerbations” or reactions, and its requirement for community management of risks, to adopt a chronic disease management model, centring on self-management, patient and carer education, continuity of care and multidisciplinary services. Such an approach, including ongoing support from dietitians and nurse educators, is likely to reduce the uncertainties of daily management.

The need for parent and carer education is evidenced by an Australian survey of EpiPen use, which found that only 29% of parents administered the EpiPen when indicated.<sup>12</sup> Parental satisfaction with information provision is also associated with less seeking of second opinions.<sup>13</sup> Thus, adequate parent and carer education and follow-up may ease pressure on referral services, which currently have 10–14-month waiting times for hospital paediatric allergy consultations.

The uncertainties surrounding food allergy arise from a lack of scientific, epidemiological and personal knowledge, the need to negotiate between different sectors and interests, and ambiguous language and concepts that are difficult to communicate. Different responses are required at interpersonal, service delivery and policy

levels. While some uncertainties are irreducible, patients and carers are also experiencing unnecessary uncertainties. What is certain is that food allergy has become a significant concern for public health, paediatric and general medical practice.

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