

Risk, rationality, and regret: responding to the uncertainty of childhood food anaphylaxis

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Risk and uncertainty are unavoidable in clinical medicine. In the case of childhood food allergy, the dysphoric experience of uncertainty is heightened by the perception of unpredictable danger to young children. Medicine has tended to respond to uncertainty with forms of rational decision making. Rationality cannot, however, resolve uncertainty and provides an insufficient account of risk. This paper compares the medical and parental accounts of two peanut allergic toddlers to highlight the value of emotions in decision making. One emotion in particular, *regret*, assists in explaining the actions taken to prevent allergic reactions, given the diffuse nature of responsibility for children. In this light, the assumption that doctors make rational judgments while patients have emotion led preferences is a false dichotomy. Reconciling medical and lay accounts requires acknowledgement of the interrelationship between the rational and the emotional, and may lead to more appropriate clinical decision making under conditions of uncertainty.

this intervention in preventing death is, however, unproven, and it is not entirely clear which families would benefit from such an intervention. As Ewan and Clark, who have published recommendations for managing childhood food allergies in the UK, have noted: “The lack of data on who needs to carry epinephrine makes decisions on management difficult for the allergists and impossible for the non-expert”.³

Patient based choice has been advanced as a way to address situations where the harms and benefits of a treatment are uncertain, or where decisions are “sensitive” to patients’ preferences.⁴ Patient preferences have, however, only very recently been given an explicit role in clinical decision making.⁵ Patient “preferences” are still an ambiguous category; they may be construed as whims, subject to transient emotions, and are non-binding on clinical decisions. Despite recent initiatives to increase consumer participation in health care, incorporating patient values is still at a formative stage.⁶ This state of affairs reflects a fundamental difficulty: that of reconciling patient accounts of illness with the so called rationalism of clinical medicine. To parents, the personal sense of control afforded by an autoinjector may outweigh the possible impact on their family’s quality of life by carrying and maintaining the device. The care and concern shown by teachers and child carers in preventing and learning how to treat allergic reactions may create a communal sense of safety and security that mitigates the burden of these additional responsibilities.⁷ To clinicians, these arguments may appear emotive when compared to the unknown effectiveness of autoinjectors, the possibility of harm from misuse and misperceptions of protection, and the financial and other costs borne not only by the family but society as a whole. To illustrate and examine these alternative views, we present the cases of two young children with peanut allergy, Dylan and Jarred (both names are pseudonyms), and include their mothers’ accounts of their experience.

Risk and uncertainty pervade clinical medicine, and cannot be eliminated by conscientious medical care or accumulating scientific knowledge. In the case of peanut allergy in children, anxieties are heightened by the possibility of a rare but unpredictable and catastrophic outcome. Food allergy itself is not uncommon; the prevalence of peanut allergy is increasing, with one per cent of children affected.¹ While the majority of food allergic reactions in young children are mild, such as hives, they may very rarely result in death. Severe and potentially fatal reactions, or *anaphylaxis*, require treatment with injected epinephrine. As there is no “cure” for food allergies, the principal management strategy is avoidance of the food allergen. Unfortunately, peanuts are difficult to avoid as they are a common food and a frequent ingredient in processed and preprepared foods. Small amounts of peanut protein (one mg), equivalent to one three hundredth of a peanut can provoke reactions in very sensitive individuals.² Given this situation and the suggestion from analyses of fatal cases that early treatment may prevent death, there is pressure for epinephrine autoinjectors, or spring loaded syringes with a preset dose of epinephrine, to be made widely available to children with food allergies and their carers or parents. The effectiveness of

CASE STUDY—DYLAN

Dylan, a 20 month old toddler, was referred to a paediatric allergy clinic for assessment of his peanut allergy. At 12 months of age he developed facial contact urticaria to peanut butter, which spontaneously resolved *without* respiratory or other symptoms. Since then, he has not had further reactions or eaten peanuts, although the rest of the family often eat peanuts and nuts. Dylan is regularly cared for by his grandparents and does not attend child care. At this

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consultation, his skin prick tests showed a nine mm (greater than or equal to three mm is considered positive) reaction to peanut. It was recommended that he continue to avoid peanuts, and be reviewed annually with skin prick testing. If these remained positive without other clinical reactions, formal food challenge would be considered at school entry. An emergency epinephrine autoinjector (self or carer administered adrenaline) was *not* recommended.

DYLAN'S MOTHER

With everything that you read and see on TV, peanut allergy was always on the back of my mind. To see whether it would be OK to give him peanut butter, I put some on his face when he was 12 months old and it came up all red and itchy. At the allergy clinic they said he has a moderate to high allergy, but he's never had peanut, so we just don't know what would happen if he did have some. I had heard about [autoinjectors] from a friend of my sister in law whose son has severe peanut allergy, so I was waiting to hear what the specialist would say. I suppose that if you had to, you would give it, but I just can't see it, I hate seeing him have needles for any reason. On the other hand, if he didn't have to have one it would be easier, for my parents too, as they mind him everyday. With their ethnic background they have nuts in their meals and I like to eat them too. But we have to be very careful all the time—we eat away from him and keep the peanut butter out of reach. Friends have told me that I gave Dylan his allergy by eating nuts when I was pregnant. Now I'm pregnant again I'm eating less of them—you just don't know, and I'd rather not risk it.

Perhaps I worry too much, but the thought that he might have a serious reaction really scares me, I'm so scared about what might happen, that his airways might get blocked. The other day he started to rub his eyes and sure enough we had just eaten a peanut butter sandwich, so for the next half hour I was constantly watching him. Nothing happened, but luckily we live close to the hospital and we would have taken him there if it had got worse.

CASE STUDY—JARRED

Jarred, a 23 month old toddler, was also referred to the same clinic. At nine months of age, peanut butter touched his face and he developed local urticaria, lip and periorbital swelling, *without* respiratory or systemic symptoms. His parents took him to the local hospital where he was placed on cardiorespiratory monitors and given epinephrine injections. He was then referred to a paediatric allergist who prescribed an epinephrine autoinjector. Since then he has avoided peanut and has not had further reactions. Peanuts have been removed from the household and the family's diet. After Jarred's enrolment, the child care centre he attends two days a week completely banned peanuts, nuts, and any foods labelled "may contain nuts". At this consultation, skin prick tests showed a nine mm reaction to peanut. Jarred was also recommended to continue avoiding peanuts. Although Jarred's mother was advised that the risk of death was extremely low, she wished to continue Jarred's autoinjector prescription.

JARRED'S MOTHER

I had heard of anaphylaxis and I knew that some foods could be deadly, but you just don't think that it could happen to you. When he was nine months old we were sitting together eating when he lunged for my peanut butter sandwich—I grabbed his hand but before we could wipe it he put his hand on his face. Over the next 10 minutes his eyes and face started to swell but it didn't dawn on me straightaway. He didn't have any breathing problems, but when we got to hospital they put him on a monitor and it took two shots of

[epinephrine] to get the swelling down. I wish I had known more about what to do, but in hindsight we were just lucky that it happened this way and he didn't eat any of it. As he's never eaten it we just don't know how he could react, so we play it pretty safe. The autoinjector allows me to feel more in control, that I can help Jarred before the ambulance comes. The first specialist we saw was very definite about their advice; "This is what could happen, this is what you have to do, you must have an autoinjector with you all the time, just in case". That's how I feel about it too—it's a safety net, so I'm not totally helpless. This time we saw another specialist and they were more relaxed about it: "I'm not really sure he needs an autoinjector". But you just don't know what could happen.

At the preschool they're very good, they've banned all peanuts and nuts and foods that are labelled "may contain traces of nuts". At first a lot of parents complained—they couldn't understand why they had to go through all that for one child. You have to explain to them that if they were in the same situation they wouldn't like to be isolated and not be able to play with other children. We just don't know how much food could set him off. The teachers were great, they said that he was entitled to have the same fun and opportunities as everyone else. But it's very black and white there—they know Jarred is their liability, but they would rather leave the risk taking to me in giving him foods that are labelled "may contain nuts". It was getting to the stage where even frozen peas would be labelled like this. You've just got to weigh up in your own mind which risks are worth taking. It helps to know that something is a one in six or a one in six billion chance, you just try to be as sensible as you can. For example, frozen peas are low risk and it makes my life easier to use them. But muesli bars are high risk because they can contain nuts that you can't see, they are made in factories with nuts, and there are alternatives to eating them.

We don't have any peanuts or nuts in the house and I try to avoid situations where Jarred will miss out on something that everyone else is having. All our family and friends are used to it now and don't give Jarred any food without asking first. Even his four year old brother tells everyone: "Don't give Jarred nuts—that'll dead him!" Although it's a bit extreme, it's better than being complacent, although there is that snowball effect when you start involving other people.

The biggest fear is that he could be having a reaction and he can't tell us—he can say "ow belly" but he can't say "my throat is closing". My next big hurdle is primary school, where there's less control. We're just trying to lead a normal life, but kids are always going through different stages and you just have to keep dealing with them.

THE LIMITS OF RATIONALITY IN CHILDHOOD FOOD ANAPHYLAXIS

In much of clinical medicine, rationality is viewed normatively; rational thought is seen as being legitimate and correct, whilst to be "irrational" is to be judged pejoratively. As a result, medicine has tended to respond to uncertainty by proposing models of *rational decision making* such as evidence based medicine (EBM),⁸ clinical practice guidelines,⁹ and the application of economic decision theory to clinical problems.¹⁰ These offer an attractively ordered and controlled image of decision making and may also assuage current pressures for the medical profession to be more accountable. Rather than removing uncertainty, however, rational decision making may increase awareness of uncertainty, by drawing attention to the lack of "good" data. When there is a heightened sensitivity to danger, the absence of satisfactorily certain recommendations may thus *increase* the dysphoric experience of uncertainty. What then, is the basis for the limits of rationality in childhood food anaphylaxis?

There are many accounts of rationality; Jungermann's typology of substantive, formal, and procedural rationality¹¹ is adopted here for its relevance to clinical medicine. A judgment is *substantively* rational if it is realistic, or corresponds to the real world. Rational decisions are then *objective*, in the sense that objectivity relates to a reality that is independent of the observer. This realist ontological position pervades medical thinking about disease and treatment,¹² although in clinical medicine physical states are always inferred from subjectively interpreted external clues, such as patient history, physical signs, and investigations. Although the physical reality of peanut allergy is unquestioned by both doctors and patients, realism is more problematically applied to risk. As in Jarred's case, doctors may refer to population studies and advise that the "objective" risk of food induced anaphylaxis in young children is extremely low.¹³ Such epidemiological data may have little meaning to parents, who may judge risks very differently. Expert opinion also differs; there is ongoing controversy regarding the prevalence, incidence, and "risk" of anaphylaxis, so it is not surprising that medical recommendations vary.^{14 15} Moreover, risk interpretations are intersubjective, influenced by family and friends, mass media, and experiences of medical care. Thus, the local hospital's emergency response to Jarred's initial allergic reaction is likely to have shaped his mother's beliefs about the reality of the risks. These arguments may constrain rather than preclude the existence of a single external reality, but as our ability to know or measure risk is constrained, the practical application of substantive rationality will inevitably lead to debate about what is "real" or "objective".

Formally rational actions are in agreement with the values and beliefs of the individual taking the action, and are internally coherent. This is similar to instrumental rationality, where actions further the achievement of chosen goals. Each of the accounts, medical and maternal, in our cases is logically consistent. Clearly, however, goals can vary between and within groups; what is rational to one may appear irrational to another. Clinicians may weigh up the cost effectiveness of an epinephrine autoinjector against demands for other possibly more effective therapies, but parents may wish to ensure the safety of their allergic child by utilising all plausible methods to do so. Parental requests may then appear "irrational" to doctors. In Jarred's case, the allergist first consulted by the family appears to be at odds with their current allergist. Seen individually, decisions may be formally rational, but will appear collectively inconsistent.

A decision is *procedurally* rational when there has been a diligent and unbiased search for information, which is considered together with the preferences of affected parties and the possible consequences of each option. Options may then be ranked in order of optimality. In a society where agreement between dissimilar groups is required and democratic participation valued, procedural rationality may appear to be a type of procedural justice, and underlies ideas such as patient based choice. Incorporating diverse narratives, such as our cases, may thus promote stakeholder involvement and engender consensus.

Nevertheless, procedural rationality has many constraints. An unbiased search for information, although ideal, is difficult if not impossible to achieve in practice. Data collection incurs a cost, and where there are many stakeholders (which here also include non-allergic children and their parents, teachers, child care workers and others), the pursuit of complete information from all sources may be irrational in itself.¹⁶ Biases will occur, depending on which sources are used, what questions are asked, and what evidentiary weight is given to each type of information. The information used in decision making is therefore likely to be

restricted, and restricted to those with a greater political voice. Procedural rationality also does not answer the question of how incompatible interests may be reconciled.

There are other practical difficulties with being "rational". Human reasoning is subject to "bounded rationality".¹⁷ As we are cognitively unable to process all relevant data in complex situations, we may then construct simplified models or *heuristics* in order to make judgments.¹⁸ Although heuristics may expedite decision making, they also result in systematic biases in the estimation of probabilities. Small probabilities, such as risks from measles vaccination, may then be ranked out of proportion to their numerical magnitude when compared to other risks such as road safety.¹⁹ Heuristics affect doctors as well as lay persons,²⁰ and the choices that are made may be significantly influenced by how risk information is presented or framed, in terms of survival or death rates.

Of more concern, rational decision making works poorly where options are judged to be equally good, or where they cannot be ranked because they differ in incommensurate ways.²¹ Decision theory implies that a rational being would be able to trade off an undesirable outcome against some other object of value, provided the odds were sufficiently remote.²² It is unlikely, though, that parents would gamble the life of their child against a taste of peanut butter, even if the odds were vanishingly low. To attempt to impose rationality under such conditions would be irrational, or a form of "hyper-rationality" (Elster,¹⁶ p 31).

REASON AND EMOTIONS

Rationality fails to provide an adequate explanation for the response to peanut allergy in the cases presented here because it fails to account for emotions, and for the emotional attachment parents and all members of society have to children. Both the mothers speak vividly of their fears, and of their negative reaction to thoughts of having to give an injection or of socially isolating their child. In contrast, our medical histories are written in an emotionally neutral and "objective" manner. This style of writing reflects traditional medical views about the importance of objectivity and of the idea that emotions hinder clinical reasoning. The value placed on assuming a professional distance from the patient and their disease, however, promotes artificial distinctions between the emotions and reason; more recently Nussbaum and others have argued that the emotions represent valid evaluative judgments and are constitutive of human virtue.^{23 24}

Instrumentally, the emotions have a revelatory function (Stocker,²⁴ p 69). They arise from those elements of a complex situation that matter the most to the individual, especially where decisions are urgent. A "rational" counterargument might be that the emotions highlight insignificant factors, or those not grounded in evidence, leading to erroneous judgments. As previously argued, however, rational methods themselves are subject to interpretive bias, and can reduce the range of choices and types of evidence considered. Where rationality is constrained in situations of uncertainty and indeterminacy, emotions may paradoxically enhance rational behaviour by restricting the costly pursuit of unhelpful information, and can "tip the balance" where choices are otherwise equally ranked.²⁵ Thus, for both our mothers, a "rational" emotion based risk assessment may focus thoughts and facilitate decisions that are in agreement with desires, beliefs, and available information.

Emotions are also valued in themselves. The technical execution of medical care and providing advice could arguably be performed competently by following emotion free rules. Yet it is clear that emotions such as compassion and care for others are highly desired and widely accepted as

integral to good medical practice. For Jarred's mother, the expression of certainty by their first allergist could be perceived as caring behaviour. The risk in expressing uncertainty, albeit honest uncertainty, is that it may be interpreted as being less caring, unless an empathetic connection has otherwise been established.

Nevertheless, it is not suggested that emotions should be indiscriminately embraced in clinical decision making. Emotions should be appropriate to context, not conflict with important moral values, and not blind one to alternative arguments.²⁶ Emotions should also be carefully evaluated, for they can unjustifiably skew judgments. A state of "anaphylaxis anxiety" may—for example, drive parents to demand unwarranted restrictions on all aspects of a child's life, influence doctors to prescribe epinephrine autoinjectors unthinkingly, and ultimately reduce a family's quality of life for indefinite benefits. The strength of such emotions should not be underestimated; emotions are adaptive in that they advance the survival of the human species.²⁷ Threats to the safety of children activate deep seated fears and intensify perceptions of risk.²⁸ Given such biological significance, it is not surprising that "anaphylaxis anxiety" cannot easily be countered by appeals to heed the "objective evidence".

REGRET, BLAME, AND RESPONSIBILITY

One emotion that is particularly salient here is *regret*. Regret is the painful experience that results from an undesirable outcome. It can be felt in anticipation of events, and is made possible by counterfactual thought—the ability to imagine how events may have turned out differently under different circumstances, or choices. Compared to other emotions, regret is closely connected with reason and cognition, as it requires judgment about an event which may not have even occurred, and the mental construction of alternative scenarios. It is therefore described as "felt-reason" or "reasoned emotion".²¹ Regret theory^{29–30} was first postulated by economists attempting to explain why individuals consistently violated the axioms of rational choice. Simply put, rather than choosing options that would maximise their average expected value or utility, including estimations of monetary value, individuals will voluntarily sacrifice gains to avoid regret. Without regret, these choices are judged "irrational" because they are not optimal according to the available evidence. Anticipated regret may thus explain continued demand for, and provision of, epinephrine autoinjectors, despite uncertainties regarding the appropriate indications for prescribing and, in particular, *not* prescribing the devices. Furthermore, enduring regret, compared to transient regret, may be more likely to result from inaction rather than action.³¹ Hence regret at the death of a child who was not prescribed an autoinjector may be more deeply felt and persist longer than regret at having prescribed an autoinjector that did not prevent death, even though logically the two outcomes are largely equivalent. For parents, the thought of the unbearable regret from losing a child may drive energetic efforts to avoid accidental exposure.

Regret is all the more acutely felt when the person feels responsible for the negative outcome,³² which may happen regardless of whether they are held to be responsible by others. Clinical practice guidelines may recommend the prescription of epinephrine autoinjectors only to food allergic children with coexisting asthma and other risk factors. If, on following these guidelines a doctor does not prescribe an autoinjector for an allergic child, and that child unexpectedly dies from anaphylaxis, the non-prescribing doctor will still feel guilt and regret, however much the guideline may exonerate the doctor from blame. This may be because doctors feel partly responsible for the general welfare of their patients and are influenced by societal expectations that they

accept responsibility for those under their care, even when events are not completely under their control. In contrast, if parents of non-allergic children feel they are not responsible for other children, and that serious allergic reactions are unlikely, then they may not feel they are to blame if their child's peanut butter sandwiches are inadvertently eaten by an allergic child. Although the reaction may have been avoided if they had given their child an alternative school lunch, their experience of regret may be diminished.

Conversely, the parents of an allergic child may feel entirely responsible, and deeply regret any action or inaction that could conceivably prevent a serious reaction, despite the triggering event being beyond their control. While society obliges parents to take primary responsibility for the welfare of their children, it is the quality of the emotional bond between parent and child that heightens regret. For many parents, mere knowledge of a potential risk is enough to invoke a sense of responsibility and motivate preventive actions. For others, the wish to avoid responsibility or blame for a negative outcome may be more important.

Responsibility cannot, however, be avoided easily in childhood anaphylaxis. It could be argued that responsibility for an event depends on whether the event is foreseeable and whether the responsible person has some control over its occurrence. Death from anaphylaxis cannot, however, be predicted with certainty, and many people can have some responsibility for a child at any point in the child's life. Dylan's parents, his extended family, and his doctors all manage his allergy, and in Jarred's case, the whole preschool community is also involved. Realistically, an outcome can rarely be blamed on one person. More generally, it could be argued that the welfare of children is the collective obligation of society; thus individualistic concepts of intention, agency, and control do not account for the diffuse nature of responsibility for children.

Given this notion of mutual responsibility, the impetus to avoid regret, the strength and value of emotions, and the limited application of rational decision theories, it is not surprising to read this statement from a prominent UK allergist: "In the absence of any meaningful treatments, allergists have no choice but to ensure the safety of their patients even if the 'number needed to treat' to prevent one case of fatal anaphylaxis is very high".³³

RECONCILING ACCOUNTS OF RISK

Several implications arise from the preceding discussion. Firstly, medical responses that are constructed wholly within a "rational" or "evidence based" paradigm will not address the risk of childhood food anaphylaxis to everyone's satisfaction. As a result, clinical practice guidelines, narrowly defined evidence based practice, and decision algorithms are unlikely to resolve the quandaries of daily practice for clinicians, or remove the sense of uncertainty that disturbs the lives of families with food allergic children. Rational descriptions of risk that exclude qualitative and emotion based evaluations will only partially explain the experience of risk, and the responsibility for risk.

Secondly, in comparing medical and parental accounts of illness, a false dichotomy is created by the contrast between what appears rational and objective on the one hand, and subjective or emotionally laden on the other. Linguistic conventions support the assumption that doctors *think*, while patients *feel*.³⁴ Yet behind the variation in medical opinion in Dylan and Jarred's cases are subjective interpretations of assumed realities and layers of emotional connection—from the anticipated regret of adverse outcomes to individuals, to the shared responsibility for the welfare of children. Parents also reason in a highly complex and rational manner; both mothers not only think about the immediate consequences of

having an autoinjector, but also weigh up the uncertainties, the nature, causation, and magnitude of the risks, and the effect of their actions on others. Recognising the value of each account, provides a richer understanding of the dilemma facing doctors, parents, children, and others.

To achieve this, novel ways of valuing stakeholder accounts need to be found, and the negotiation of meaning between individuals acknowledged. For doctors and patients, risks have meanings which are both rational and emotional, and these meanings are mediated between them in the clinical context. Rational risk assessments may put a situation into perspective through detached regard, but rationality alone leads to interpersonal disconnection. Emotional judgments can address the distancing of rational approaches and focus thoughts, but also shut out other perspectives. Both modes of thinking are important, and need to be evaluated on their own merits. Together, rather than alone, they offer a better explanation for human actions, and may lead to more appropriate clinical decision making under conditions of risk and uncertainty. Thus, Benjamin Franklin, the rational policy maker and scientist, gifted diplomat and observer of humanity, was moved to write: "In 1736, I lost one of my sons, a fine boy of four years, by the smallpox taken in the common way. I bitterly regretted that I had not given it to him by inoculation. This I mention for the sake of parents who omit that operation, on the supposition that they should never forgive themselves if a child died under it. My example shows that the regret may be the same either way, and that therefore the safer should be chosen."³⁵

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