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The MMR vaccination and autism controversy in United Kingdom 1998–2005: Inevitable community outrage or a failure of risk communication?

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Abstract

Background: The report of an hypothesised link between measles–mumps–rubella (MMR) vaccination and autism in 1998 became a major public health issue in the United Kingdom (UK), leaving most experts surprised by the overwhelming influence it had on public opinion about MMR vaccination. Coverage rates fell dramatically, and did not start to recover until 2004. Could this public reaction have been predicted?
Methods: We used Sandman's model of components predicting community outrage to assess the MMR controversy.
Results: The controversy fulfilled all of Sandman's 12 primary components and six of the eight additional components.
Conclusions: The Sandman model provided a useful framework to analyse this controversy and explained a significant portion of the community reaction and subsequent fall in vaccination coverage rates.

Keywords: Risk communication; Vaccination; Measles mumps rubella; Autism

1. Introduction

Like all medical interventions, vaccination is a subject that requires careful communication of risk. Public concern about that risk has the potential to be amplified [1,2], particularly via the anti-immunisation lobby which occasionally receives significant press coverage. The report of 12 children with an hypothesised link between measles–mumps–rubella (MMR) vaccination and autism in 1998 by Wakefield et al. became a major public health issue in the United Kingdom (UK) as the popular media ran with such a dramatic story [3]. The effects of this were far more than the usual anti-immunisation rhetoric. Parents were gravely concerned about the vaccine and measles coverage decreased, in some areas to levels below those which maintained herd immunity. Herd immunity is the level of population immunity above which sustained transmission is unlikely—this is estimated at >90% for measles and mumps and >85% for rubella. In fact, MMR coverage dropped to its lowest point since the program was introduced in 1988 after this controversy, falling from 92% in 1995–96 in England to 80% in 2003–2004 [4] (Fig. 1) and in London to as low as 58%. Later, outbreaks of measles and mumps occurred throughout the UK. [5,6]. The effects were felt outside the UK in the USA, Australia, New Zealand and elsewhere, but nowhere were coverage rates so adversely affected [7]. Recent research from New Zealand showed that parents who chose not to immunise their children often cited a possible link between immunisation and autism [8]. Furthermore, as recently as July 2002, one-third of health providers in New Zealand still had significant uncertainty about whether MMR caused autism [9]. This is therefore a worthwhile

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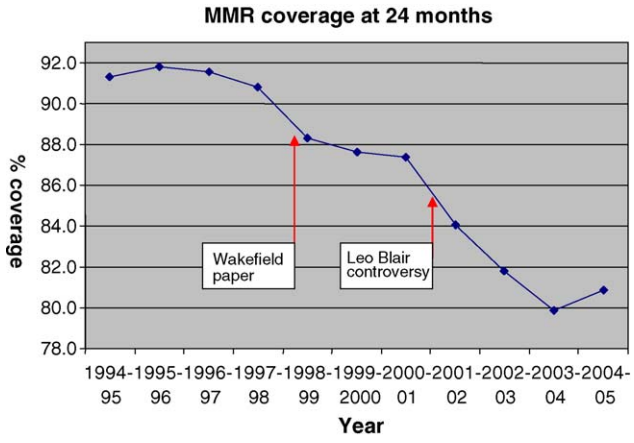

Fig. 1. MMR coverage at the age of 24 months in the United Kingdom 1994–2004 [4].

subject to analyse. On the basis of published information, we tried to determine why the controversy generated so much public outrage—was it an inevitable reaction or did risk communication fail? As the scenario will probably be played out again, just as MMR followed a similar path to the pertussis vaccine controversy 2 decades before, we also suggest ways to improve risk communication in the future [10].

2. Factors responsible for causing high alarm

Sandman's model of components explaining community outrage (see Box) provides a useful way of reviewing the components of these events which increased the perception of hazard in the community [11]. These well-established rules of thumb are based on a large body of research about people's perception of health risks [12,13].

The usefulness of models like Sandman's is that they emphasize that 'experts' (the medical profession, the Government or public health officials) often focus only on 'hazard' or how dangerous a procedure is, that is, the probability of an adverse event based on the scientific evidence and the severity of the event, e.g. fatal or non fatal, permanent or temporary. In contrast, members of the public take a different approach, with a more personal response in which the perception of the hazard is affected by the degree to which it provokes 'outrage' or how worried, frightened or angry it makes them. For example, the MMR controversy represented a low or no-hazard + high outrage situation. If young children are struck with a lifelong debilitating neurological disease, autism, the degree of community outrage at the outcome is high and the risk perceived by the community will be greatly underestimated if the experts analyse hazard alone. The general public in this and other high outrage cases will pay less attention to the actual probability of the hazard while their level of outrage is high; consequently, there is a significant gap between the perception of risk between the experts and the public. As such it becomes the role of public health to work on decreasing outrage with risk communication. In a high hazard + low outrage example such as high incidence of road deaths in young men the opposite is true; the public health message is to increase community outrage by raising the alarm.

Sandman's model of public risk perception [11]

Public risk perception = Hazard + Outrage

Hazard = scientific estimate of risk of mortality or morbidity, e.g. risk of death from meningococcal infection

Outrage = factors that make the public worried, frightened, angry or otherwise upset, e.g. the emotional reaction to death of young people from meningococcal infection

In this controversy all 12 of Sandman's primary components predicting community outrage were present, as were six of the eight additional components (Figs. 2 and 3).

3. Primary components of Sandman's model and how they applied to the MMR controversy

There are 12 primary components in Sandman's model. These are shown in Fig. 2 with some non-MMR illustrative examples and degree to which the component applied in the MMR controversy.

3.1. Exposure coerced

Although the parents' choice to vaccinate their children with MMR was voluntary, there were components that may have led to a feeling of coercion, in that general practitioners were reimbursed for having good coverage rates in their practices and the cost of the alternative suggested by Wakefield (use of single rather than combined vaccines) was refused support by the National Health Service. While the grounds to refuse to reimburse individual vaccines were scientifically valid, many parents did not perceive them as such. The feeling of coercion probably related to the fact that parents felt the Department of Health was telling them what they had to do and was controlling their access to free vaccines.

One parent stated: "I object strongly to being told what and when to inject my child" [14].

3.2. Agent produced

&

3.3. Agent exotic

The fact that a drug or vaccine is manufactured or not 'natural' is always an issue. In the case of MMR vaccine, much of the discussion surrounding its alleged dangers related to a composition of three live viruses together in the one vaccine. Wakefield had pointed to this combined vaccine as the basis of his concerns. Within anti-vaccination rhetoric, there

Increases outrage if:	Applies in MMR controversy	General examples
3.1. exposure coerced	+	Voluntary military service vs. compulsory military service
3.2. agent produced	+	Fluoride in ground water vs. fluoride added to water supply
3.3. agent exotic	+	Natural infection with varicella due to childhood exposure vs. vaccination
3.4. agent memorable	++	Severity of birth defects caused by Thalidomide make the drug memorable
3.5. consequence dreaded	+++	Some illnesses are more dreaded e.g. AIDS or cancer than myocardial infarction even if the prognosis is similar.
3.6. consequences catastrophic	+++	Catastrophic vs. continuous. People tend to fear a low-probability high mortality event such as a plane crash more than a long exposure to high probability lower daily risk such as car travel
3.7. uncertainty regarding true hazard	+++	Exposure to telephone towers vs. exposure to tobacco smoke
3.8. hazard controlled by others	+	Exposure to factory pollution vs. choosing to smoke
3.9. exposure unfair	+	A group exposed to greater risk than others due to gender, age poverty or race e.g. indigenous people's poor nutrition
3.10. Morality; are assurances & control efforts morally relevant?	+	Some risks are morally unacceptable e.g. imagine the police stating that due to cutbacks an occasional child molestation is an acceptable risk
3.11.sources untrustworthy	++	Consumers would be more likely to believe an independent report about the safety of a particular model of car than a salesman's opinion.
3.12. process unresponsive	+	Asbestos manufactures were unresponsive to community concerns until successful litigation

Fig. 2. Primary components predicting community outrage from Sandman's model.

is a strong tendency to present vaccines as toxic chemical soups with exotic-sounding ingredients which harm children. Undoubtedly, this framing contributed to concern about the vaccine.

3.4. Agent memorable

The memorable part of the risk in this instance was the outcome (autism) rather than the vaccination itself. Images of 'damaged' children are particularly memorable. There were many tragic accounts of families lives turned around by their child's disability while very few of children suffering the consequences of measles, for example. Research has demonstrated the degree to which easily recalled, highly visible events (in this case, autism) are associated with altered perceptions of that risk. In surveys, the memory of the link to autism was probably the public's strongest memory about the stories they had seen [14].

Additionally, because of the success of the vaccination program, there was a general lack of experience of measles itself and of its potential for severe complications, such as death or encephalitis. Few current parents would have seen cases of measles or its complications, and little or no media attention was directed to them, because without a human face they added little to the drama of the story.

3.5. Dreaded consequences

The dreaded consequence (autism) needs little explanation. When Andrew Wakefield proposed and publicised a link between vaccination and autism possibly parents felt he was sympathetic to their fears: he acknowledged the concern

Increases outrage if:	Applies in MMR controversy	General examples
4.1. affects vulnerable population	++	Environmental tobacco smoke exposure is considered worse when children are exposed
4.2. effects delayed	+	Risk of future cancer due to exposure to toxins
4.3. substantial risk to a future population	-	Risk of future birth or genetic defects
4.4. victims identifiable	+++	Victims of a disaster such as 9/11 are more easily identifiable than the annual road deaths
4.5. not preventable	++	An increase in a preventible condition such a smoking associated lung cancer creates less outrage than an increase in a cancer of unknown cause such as leukaemia
4.6. few benefits	+ (perceived)	The benefits of pasteurizing milk are difficult to illustrate after its widespread adoption as few are familiar with the diseases associated with un-pasteurized milk
4.7. substantial media attention	+++	Avian influenza deaths vs. annual influenza deaths
4.8. no opportunity for collective action	There was opportunity for collective action but in this case it promoted outrage rather than alleviating outrage.	Neighborhood watch programs to deter crime

Fig. 3. Additional components predicting community outrage from Sandman's model.

and was trying to prevent it, even if it was scientifically unfounded. In contrast, the Department of Health, emphasising safety of the vaccine and lack of evidence of any association with autism, may have been seen as dismissive of parents' fears and doing little to address the problem of autism even if it was unrelated.

3.6. Catastrophic consequences

The catastrophic consequence was the suggestion that there would be an 'epidemic' of autism due to the continued use of combined MMR.

3.7. Uncertainty regarding true hazard

A major stumbling block was the fact that vaccination does have real, though rare, risks and from a scientific point of view (especially early in the debate in 1999–2000) it was not possible to give a 100% guarantee that MMR vaccination did not cause autism albeit very uncommonly. Although uncertainty may increase concern in the short term, giving unrealistic reassurances erodes long-term trust [15].

3.8. Control; individual control vs. control by others

Despite the fact that parents ultimately make the choice for or against immunisation, the issue of choice over vaccine options became central to public disquiet in the MMR controversy. Wakefield had suggested that separating out the measles, mumps and rubella vaccines might reduce the inflammatory bowel disease and autism risk because it would avoid the combination of live viruses. For a number of reasons, including the need to maintain good disease control and the strong evidence for MMR safety, the UK government did not supply separate vaccines. Public and media outrage focused on this refusal as a lack of choice available to parents wanting to protect their children. It was this issue that fuelled the outrage within the community.

Another factor was that the parents had to make the choice about MMR for their child, potentially increasing the sense of responsibility and anticipated guilt. Two studies have suggested parents are more emotionally affected by the thought of immunising causing subsequent harm 'an act of commission', than harm occurring from the disease itself due to not vaccinating 'an act of omission'. [8,16]. When the media reported the controversy as if each side had equal support, it changed parents' perception that immunisation was the norm, although it remained the norm throughout (national MMR coverage rates even at their lowest were 79.9%). This may have made parents feel the decision to immunise was deviating more from community and medical practice norms than it was in reality, potentially increasing the influence of omission bias.

3.9. Fairness; exposure unfair—innocent children/parents struck

Autism affects children and their parents through no fault of their own. It is thus perceived as particularly unfair.

Even so, many parents of autistic children feel guilty that they may have unknowingly contributed to their child's illness.

3.10. Morality

The morality of the situation related to the condition of childhood autism; how many children affected by autism would be an acceptable risk with this hazard? It seemed that, because of the emotion surrounding it, the community was demanding not only zero risk but also a guarantee of zero risk.

3.11. Trust—untrustworthy sources

The trustworthiness of official assurances about the safety of MMR had been undermined by the earlier bovine spongiform encephalopathy (BSE) (mad cow disease) affair, in which constant and emphatic reassurances by the Government that beef was safe were later disproved. In addition, there had been what was what described by Dr. David Salisbury as "a long tradition of vaccine scares in this country" [17] representing a history of vaccine scepticism that was well embedded within the public psyche and made it difficult for the public to accept reassurances from the Establishment.

The initial media portrayal of Andrew Wakefield as a noble crusader for truth opposing the uncaring Government, the medical profession and profit-focused vaccine companies, furthered scepticism about the trustworthiness of these sources. As one parent stated: "the more insistent the Government became, the more we distrusted their advice" [18]. In addition, media focus on commercial interests of vaccine producers and incentives for general practitioners to meet coverage targets further decreased community perception that these groups had the individual's best interests at heart. Newspapers ran articles titled "GPs paid to meet vaccination targets for MMR" [19]. Further speculation about the Government's credibility occurred when the Prime Minister refused to disclose whether his son had received MMR vaccine. This permitted speculation that the Prime Minister was privy to information about the safety of the vaccine unavailable to the public, or that he was not vaccinating but was not prepared to acknowledge this discordance with his department's reassurances.

Such media reporting framed Wakefield as the lone voice against the establishment in a David and Goliath struggle.

3.12. Unresponsive process

Although the Department of Health was vigorous in its response to the issues, its staunch emphasis on science and on experts may have contributed to a feeling on the part of the public of a being fed a 'party line' and being misled.

4. Secondary components of Sandman's model and how they applied to the MMR controversy

The eight secondary components in Sandman's model are shown in Fig. 3. Six of these were important in this issue.

4.1. Affects vulnerable populations

All health risks in children are considered important in the community and this was no exception.

4.2. Effects delayed

Linked to the unseen nature of vaccine effects is the notion that vaccines plant a chronic and irreversible 'seed' of long-term and hidden damage. The worry for some, that the diagnosis of autism might not be made until the child was 3 years old, clearly aroused additional fear as this was some time after the child had received the MMR vaccination.

4.3. Substantial threat to future populations

This was not relevant in this case.

4.4. Victims identifiable

The clearly identifiable autistic children and their parents provided a very powerful image in the controversy. Lack of a similar emotive group of victims for measles was important.

4.5. Not preventable

This was relevant as the causes and ability to prevent autism are not known, thus allowing the controversy to begin.

4.6. Few benefits

Although the benefits of MMR vaccination are well documented the difficulties were two-fold. Firstly, it was difficult to briefly and simply explain the concepts of individual risk, herd immunity, coverage rates and the possibility of outbreaks to the public. Secondly, the lack of coverage the media gave to these 'dry' scientific arguments meant that the public was not fully informed.

4.7. Substantial media attention

The media attention to this story was very substantial, with over 561 stories in an 8-month period recorded by a monitoring group [14]. More than two-thirds (66%) of the stories mentioned the possibility of a link between MMR vaccination and autism, while only 25% mentioned Andrew Wakefield's research as a source. When they surveyed the public 53% assumed that, as both sides of the argument received equal media attention, there must be equal evidence for each side

and that the scientific community was equally divided, which was quite wrong [14].

In addition, the influence of the Internet must be considered. Stories of Wakefield's work were posted not only on sites related to the anti-vaccination lobby but also on autism support group sites, some of which continue to endorse his work.

4.8. Opportunity for community action

The opportunity for community action clearly existed. This in fact continued to drive the controversy as the community action was based primarily among those opposed to immunisation. While the original model suggests this should allay outrage, in this case it probably did more to inflame it.

5. What could have been done differently to communicate risk and minimise outrage?

This was an extremely difficult case for The Department of Health to handle, given the way the press reported the events and the emotion involved. As Elliman stated: "it is much easer to create doubt and damage a vaccine's reputation than it is to restore it" [20]. In 2005, the claim of a link has essentially been withdrawn, MMR immunisation rates have begun to recover [4] and community trust appears to be increasing.

Although the department strongly supported the use of MMR, it never made its use compulsory. Allowing immunisation with MMR to be the parent's choice was probably a factor in lowering outrage, even though separate vaccines were not funded.

It was important not to over-reassure to the point of being perceived as unconcerned about parents' anxieties. In the early stages more emphasis probably could have focused on listening to people's concerns, being open and understanding, while acknowledging the concerns and responding in a sensitive way.

The outstanding feature of the argument which made it so memorable was the fact that autism was the outcome, because autism is dreaded. An important aspect of risk communication is to address such issues and to discuss them openly, while acknowledging every parent's fear of such a condition [15]. Failure to acknowledge and discuss an issue, however speculative, may allow parents to uncritically accept misleading information, believing all doctors agree. Critics and mavericks are the most credible when they are the only opinion presented.

The need to have a response to the Prime Minister's silence about his choice to vaccinate his son was clear, as at the time 70% of the public were aware of the issue—a higher figure than those aware of the reason for the controversy in the first place [14]. A response was required, as trust in the Government's reassurance of the safety of vaccination seemed hollow if the Blairs were not vaccinating their child [19]. This emphasised the fact that narrative information seems to capture the attention not only of the media but also of the public. Although the facts are important in the debate, as Hargraves states: "more science in the media does not lead to greater public understanding" [14].

Similarly, public health officials' withdrawal from participation in Britain's Channel 5 television discussion program after the biased Docudrama *Hear the silence* may have left the public feeling the department had no response, agreed with the views stated, or was hiding the truth[21].

Successful strategies to promote vaccination have involved showing images of children suffering from vaccine preventable diseases or historic images relating to outbreaks [15]. In this instance, providing a narrative that people could relate to, or showing parents with autistic children who did not see a link to autism, or parents whose children had suffered a vaccine preventable illnesses would have been powerful. Probably these techniques could have been used earlier and more frequently in the response to the controversy.

The media gave each side of the debate equal coverage. This shaped the public's perception about the scientific evidence. When media stories pitched parents against medical experts, it was clear that a more narrative and emotive response was required from the experts. It would have been worth emphasising that most scientists and doctors locally and internationally did not give credence to Wakefield's claims and were actively vaccinating their own children.

In such debates the key message is that vaccination protects children from disease [15]. In this case this should be combined with a message of compassion towards those with autism [21] (Fig. 4).

In summary, the MMR debate included many factors that led to a significant degree of community outrage and concern. Much of this concern can be explained and may have been predicted by Sandman's model. Most of the controversy was responded to efficiently, although again and again the public was swayed by genuine concern and by seeing stories and images they could relate to emotionally, rather than being presented with scientific facts.

6. Postscript

"Popular Media responds to drama, whether in the form of victims of vaccines or epidemics. It serves to reduce the complex ... arguments to ... human interest stories" [10].

Although 10 of the 12 authors officially withdrew their interpretation of the original paper [22], the issue of measles and mumps diseases only really made headlines again when outbreaks began in the UK in 2004, reigniting the newsworthiness of the story, because controversy and fears of epidemics make good headlines. At the same time, the tide changed in the media for Wakefield. Seven years after the initial report the tone is very different. The *Sunday Times'* report in February 2004, followed by a Channel 4 documentary

1. Asses how much hazard the community will perceive and plan for the reaction.
2. Do not over reassure.
3. Listen to public's concern –frightened people need compassion and understanding not just more science.
4. Be involved in the debate, withdrawing gives the wrong message – critics and mavericks are most credible when they are the only voice.
5. Acknowledge uncertainties and that this uncertainty is distressing.
6. Provide a narrative or human face to support your case e.g. parents supporting vaccination.
7. Be responsive – the risk communication must adapt to the issues- if a response is not working- e.g. Leo Blair no comment for privacy reasons – a new response is required , such as prominent people who are willing to publicly support vaccination.
8. Be clear about your key message and always return to it e.g. vaccination protects children from disease.
9. Draw attention to overwhelming medical, scientific and community support for vaccination. Media reporting in general will present a story as if the opinion is split, making outlandish theories seem to be more mainstream.
10. Broaden coalition of voices supportive of cause, such as general practitioners, parent support groups –not a single government body or 'experts' telling parents what they must do.

Fig. 4. Tips for risk communication highlighted by the MMR controversy.

alleging that Wakefield had not disclosed funding support that may have biased the results of the original study, or his own financial interest in recommending single vaccines, portrayed him not as the lone whistle blower but as the archetypal fallen hero [23].

Additionally, Tony Blair changed his 'no comment' position about his family to: "It is the responsibility of all of us, as parents, to ensure our children's health. Against measles, mumps and rubella, the combined MMR vaccine is the best way of doing that. And in making that statement, let me repeat that I would never ask any parent to do something for their child which I did not believe to be safe and right for my own children" [24], implying his child had been vaccinated.

In 2004–2005, 8 years after the controversy had begun, the first rise in annual coverage for MMR vaccination was seen (Fig. 1). Rates rose from 80% to 81% in England and Wales [4], and in 2005 a Cochrane review was published confirming that there was no credible link between MMR and any long-term disability including autism [25].

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