

Children's health and the social theory of risk: Insights from the British measles, mumps and rubella (MMR) controversy

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Available online 30 May 2007

Abstract

Recent debates in the United Kingdom about the measles, mumps and rubella (MMR) vaccine and its alleged link with autism have centred on contested notions of risk. This paper presents findings from 87 parents' focus group and interview discussions of their decision-making about the vaccine in light of three streams of theoretical literature on risk (cultural theory, risk society, psychometric models of risk perception) and models of vaccination acceptance and resistance. In addition to the risks of infectious disease and autism, parents balanced other risk concerns—both biological and social—in making their decisions. Such decisions, made on behalf of children unable to choose for themselves, and in the midst of contradictory information and uncertainty, symbolised what it means to be a 'good parent'. To cope with uncertainty, parents sought explanations for why some children seem to be more vulnerable to adverse outcomes than others. Debates about *children's* risks may need special theoretical consideration beyond that offered by the current risk literature. Specific aspects of the MMR debate, namely, selecting between potentially competing risks, making risk judgements on behalf of dependent others, and tensions between private and public good, provide a platform for exploring how social theories of risk might be adapted for children's health controversies.

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Keywords: UK; Vaccination; Risk; Children's health; Decision-making; Vulnerability; Measles, mumps and rubella (MMR)

Introduction

Widely publicised reports associating the measles, mumps and rubella (MMR) vaccine with autism and bowel disease (Wakefield, 2001; Wakefield et al., 1998) sparked a large-scale controversy in the United Kingdom. This controversy hinges on questions of contested risk: Is there a real risk of autism? Who is responsible and trustworthy to make such a determination? What sort of evidence is required? Risk is an increasingly important theoretical concern across the social sciences, and

recent controversies (e.g., 'mad cow disease') have stimulated much theoretical discussion (Caplan, 2000; Murphy-Lawless, 2003). Likewise, vaccination debates, both general and particular, have stimulated the proposal of several models of acceptance and resistance (Baker, 2003; Greenough, 1995; Nichter, 1995; Rogers & Pilgrim, 1995; Streefland, Chowdhury, & Ramos-Jimenez, 1999), and a handful of papers on the MMR controversy have engaged with the social theory of risk (Brownlie & Howson, 2005, 2006; Hobson-West, 2003; Poltorak, Leach, Fairhead, & Cassell, 2005). Responses to vaccination campaigns range from active resistance, through passive acceptance, to active demand, and are influenced by diverse factors

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such as views about the legitimacy of externally imposed healthcare decisions, misinterpretation of public health messages, and trust in biomedical systems (Nichter, 1995; Streefland et al., 1999). Rogers and Pilgrim present the mass childhood immunisation (MCI) programme in Britain as ‘incompatible with the notion of the health promoting patient—an informed agent actively involved in taking responsibility for their health’ (Rogers & Pilgrim, 1995, p. 87) because the success of MCI is predicated on overriding dissent in order to achieve widespread compliance. Clearly, this critique can help to make sense of impasses between dissenting parents and health promoters, but it does not give adequate attention to those who actively demand vaccines as a means of protecting their children’s health.

This paper presents perspectives from parents across the full range of responses to MMR vaccination: those who actively sought the vaccine for their children, who passively complied with conventional medical advice, who dissented from MMR vaccination, and who had not yet made up their minds. Data from focus groups and interviews are presented in light of three key theoretical perspectives on risk (anthropological, sociological and psychometric), pointing to new avenues for theoretical development. In particular, I will argue that debates about *children’s* risks may need special theoretical consideration. Selecting between potentially competing risks, making risk judgements on behalf of dependent others, and tensions between private and public good (in the issue of ‘herd immunity’) are key issues currently under-considered in the risk literature.

Overview of the controversy

In 1998, a paper in *The Lancet* described a small group of children experiencing developmental regression, including autism, and gastrointestinal problems (Wakefield et al., 1998). This was reported in the popular media as a possible link between the MMR vaccine and autism, initiating an impassioned debate about the vaccine’s safety, although subsequent studies were unable to confirm such risk from the MMR vaccine (e.g., Honda, Shimizu, & Rutter, 2005; Madsen et al., 2002). The prospect of autism is extremely frightening to parents, as are the diseases prevented by MMR. At a press conference following the 1998 *Lancet* publication, the article’s lead author Andrew Wakefield suggested that it

might be safer to provide a series of three separate vaccinations for measles, mumps and rubella, temporally spaced so as to give children time to respond to each immunisation before exposing them to the others (Laurance, 1998). However, no published work has documented the relative safety of the triple versus serial single vaccines, and health officials have expressed concern about the safety, efficacy and practicability of this regimen (Duckworth, 2001; Miller, 2001).

In the UK, vaccines are provided free of charge by the National Health Service (NHS) to all children, according to the immunisation schedule recommended by an independent expert advisory committee. MMR is given to children aged 12–15 months, and again as a preschool ‘booster’. The NHS provides only the combined MMR vaccine, not single-antigen vaccines for measles, mumps and rubella, but a number of private clinics offered single vaccines as an alternative, typically for around £80 per injection. Although vaccination is not compulsory, various measures are employed to encourage uptake. These include promotional leaflets, visits by specialist nurses (‘health visitors’) and a target payment scheme whereby GPs are rewarded for achieving certain levels of immunisation among their patients (Brownlie & Howson, 2006; Rogers & Pilgrim, 1995). In addition, the media played a significant role in informing parental decision-making about the MMR vaccine. Newspaper and television reports featured stories of healthy children who suddenly became unresponsive within days of MMR vaccination (e.g., Henderson, 2003; Laurance, 1998), but also carried stories of threatened measles epidemics across the UK if vaccination rates did not increase (e.g., Carrell, 2002; Derbyshire, 2004).

Research on parental decision-making

The important political and public health implications of the MMR controversy have prompted a number of studies of parents’ attitudes to and decisions about the vaccine. A Department of Health-commissioned focus group study demonstrated that parents are not passive recipients of risk messages from the media, but actively seek information from health professionals, and interpret it in light of their own understanding and social networks (Petts & Niemeyer, 2004). Unfortunately, the in-depth analysis provided by this study was limited by not including any parents refusing the MMR

vaccine. Evans et al. (2001) found that even parents who had accepted the MMR found the decision to be stressful, and were unhappy with pressure experienced from health professionals. An anthropological study in Brighton (Poltorak et al., 2005) concluded that parents' decision-making incorporated and was shaped by personal and family histories, birth experiences and related feelings of control, personal assessments of their children's health and vulnerabilities, engagement with health services and conversations within social networks. The authors argue that official engagement with such issues is 'essential in developing an effective discourse around vaccination that parents and professionals could share, and that might help to rebuild trust relations around this controversial issue' (Poltorak et al., 2005, p. 10). Likewise, Brownlie and Howson (2005) argue 'that leaps of faith cannot be understood outside interactions and relationships nor isolated from the systems or institutions within which these unfold' (Brownlie & Howson, 2005, p. 225).

Hobson-West (2003) examined government MMR promotion materials, which adopted a 'language of risk' and were designed to help parents to correct their 'miscalculations' of individual risks through statistics about the likelihood of adverse events resulting from the vaccine and from the diseases. She argues that such a strategy may be inconsistent with parents' conceptions of health and disease, in which uncertainty and necessity may be more salient categories than the risk/benefit framework of the health promotion materials. Here, uncertainty refers to the 'unknowable unknowns' that cannot be factored into conventional risk assessments (Hobson-West, 2003, p. 279). Yet, all of the empirical studies of parents' decision-making described above *do* show parents according central importance to evaluations of 'risk', albeit construed differently from the probabilistic framework of epidemiological risk. Epidemiologists and parents talk with different 'languages of risk' (Kaufert & O'Neil, 1993), or across an 'expert-lay divide' (Wynne, 1996). Within the professional framework of risk analysis, 'risk' refers to the quantifiable probability of an outcome, whereas 'uncertainty' refers to that which cannot be quantified (Gigerenzer, 2002). 'Lay' conceptions of risk take such probabilities into account, but tend to focus more on the personalised, lived experience of harm and uncertainty about whether one will experience harm or illness (Gifford, 1986).

In vaccination decisions, notions of risk and uncertainty are encompassed, as Poltorak et al. noted, in the fundamental question of "'safety"—not in general, but "for my child"' (2005, p. 717).

Thus, to make sense of parents' decision-making and conceptions of health and disease, rather than abandoning the notion of risk, we need to widen its scope, incorporating social contexts and concerns. The ways in which parents in this and other vaccination debates evaluate and balance alternate risks, their decision-making responsibilities on behalf of children, and their potentially competing responsibilities as parents of individual children and as community members, provide important avenues for developing a theory of risk for children's health.

The social construction of risk: overview

This overview describes three influential streams of thought in contemporary risk research (cultural theory, the risk society, and the psychometric model) with particular bearing on the analysis of the MMR controversy. In addition, trust is an increasingly important dimension of risk debates and is discussed here in relation to the risk society.

Cultural theory of risk

Risk and Culture (Douglas & Wildavsky, 1982) is a seminal work for risk theory, arguing that all risks are socially constructed: identifying a risk requires a particular configuration of ideas about what outcomes would be undesirable and what conditions put us in danger of experiencing those outcomes. The identification of risks has to do primarily with a cultural predisposition toward a particular kind of social outlook. Douglas and Wildavsky (1982) identified two divergent cultural predispositions (egalitarianism, or 'the border', and individualism, or 'the centre'), and other authors have expanded the scheme to include other types as well (e.g., Adams, 1995).

This theory builds on Douglas's earlier work on purity laws and danger (Douglas, 1966), linking 'primitive' taboos against 'pollution' with modern Western fears through the notion of 'risk'. Risks pose a threat not only to individual well-being, but also to the prevailing social order. Risk is invoked to hold individuals, corporations, and governments accountable for harm when they do not comply with accepted ways of behaving. Risk disputes express points of tension and value conflicts in society, and

‘narratives of risk are pervaded by concepts of accountability, responsibility, liability, and blame’ (Nelkin, 2003, p. viii).

The cultural theory approach has had a large impact in the risk perception and communication fields and can be applied across diverse cultural settings, but it has been criticised for having insufficient empirical support (Sjoberg, 1997). Despite some apparent success in testing the hypothesis that risk concerns are predicted by cultural biases (Dake, 1991), such studies are methodologically problematic, because assigning people to ‘cultural’ groups is tautologically predicated on assessing their beliefs and concerns (Adams, 1995, p. 64). The theory does little to account for how different cultural biases emerge within a single society. For instance, Douglas and Wildavsky (1982) liken the ‘egalitarian’ predisposition to ‘primitive’ societies, but do not explain why some people in industrial societies would identify with such a ‘culture’ and others with a different one.

The risk society

Beck (1992) described a ‘risk society’ in which new consequences of modernity—particularly risks brought about by industrialisation—have emerged into the public consciousness, such that people ‘choose new and unexpected forms of the social and the political’ (Beck, 1999, p. 1, *emphasis in original*) and ‘reflexively’ interact with the structures of modernity. Modernisation’s benefits have been accompanied by many dangers, inherent to the process of industrialisation. Thus, a central part of reflexivity is a growing awareness of risk. Important debates emerge about what threats we, as a society, are willing to accept and to identify as ‘risks’.

While this point echoes cultural theory, Beck places it in a rather different context. Whereas Douglas’s concern was with why some things are defined as risks and others not, by different groups and at different times, Beck is interested in how the definition of risk is a reflection on and critique of modernity itself. Beck contends that it is the industrial generation, not the number of deaths or injuries, that makes risk a political issue. Thus, he contrasts risk debate in late modernity against anxieties of earlier times. Only in late modernity is risk debate about accountability and responsibility, because in the risk society threats come about as the result of people’s economic decisions (Beck, 1999, p. 50). This is in stark contrast to Mary Douglas’s

work demonstrating underlying similarities in attributions of blame for misfortune between tribal and modern societies. Although both models emphasise that different population sectors have different concerns and ways of talking about risk, Beck distinguishes between a monolithic ‘public’ and an opposing sector of scientific experts. The ‘risk society’ is of limited generalisability across cultures and in fact may only apply to a very particular section of modern industrial society (Adams, 1995; Oaks & Hawthorn, 2003).

Clearly, the role of risk in late modernity is related to the erosion of trust in governments and science. As societies become more complex, we increasingly rely on trust—in systems and in strangers—in order to perform all the tasks required to manage everyday life (Giddens, 1994). Risk and trust are closely linked, because we are reliant on others, and must trust them, to protect us from risks. When trust between experts and the public is damaged, many players work hard to restore it, but this is widely regarded as a very difficult process. The collapse of trust has been said to be governed by an ‘asymmetry principle’ (Slovic, 1993) summarised by the aphorism: ‘Trust comes on foot but leaves on horseback’ (Calman, 2002). In particular, public trust in health care systems appears to be in a state of crisis (Calnan & Sanford, 2004). Social trust is based on shared cultural values and communication using a common ‘language of good and evil’ (Fukuyama, 1995, p. 270). Communication of shared values within social groups is generally widespread and fairly well understood. Communication and trust *across* social boundaries are harder to achieve. Earle and Cvetkovitch (1995) argue that the imaginative use of narrative to develop emerging meanings from events and facts can foster communication and trust across group divisions. Such rhetorical use of narrative, as opposed to mere reliance on statistics, might address the risk communication problems highlighted by both the cultural theory and risk society models.

Psychometric models of public risk perception

Psychometric models provide a different approach to the study of risk by seeking to explain why lay public perceptions of risk are often at odds with ‘expert’ calculations of risk probabilities through quantitative measures of people’s perceptions of risks and benefits. This theoretical framework

‘assumes risk is subjectively defined by individuals who may be influenced by a wide array of psychological, social, institutional and cultural factors’ that can be quantified and modeled (Slovic, 2000, p. xxii). Some risks are feared more than others because of key features like voluntariness of exposure and ‘dread’ (which takes into account a risk’s potential for causing catastrophic damage, as well as its origins in poorly understood or mistrusted technologies).

However, some risks are also deemed more ‘acceptable’ than others and may be undertaken in anticipation of some benefit. A number of factors, including familiarity, control, catastrophic potential, equality and level of knowledge, seem to determine the level of risk that people are willing to accept (Fischhoff, Slovic, & Lichtenstein, 2000; Starr, 1969). But this notion is problematic, because the approach takes ‘the public’ as its unit of analysis, while failing to take account of the inequitable distribution of risks among the public, even within a single population. Although individuals may accept certain levels of risk when they anticipate benefits from doing so, extending this analysis to society means that its more powerful members will determine the acceptable level of risk for others. The theory of ‘acceptable risk’ does not address how determinations of acceptability can be made on behalf of potentially vulnerable others, a point which is particularly salient in dealing with children’s risks.

The psychometric approach has been praised by risk analysts seeking to understand why public opinion is often at odds with their claims (Royal Society Study Group, 1992). However, Douglas forcefully criticised this approach, complaining that it does not shed any light on ‘big decisions’ or *why* people take the risks they do and fails to take into account interactions among people, culture and politics (Douglas, 1997). Like the risk society theory, this model’s usefulness is probably limited to the Western, industrialised population from which it emerged.

Both the risk society and the psychometric approach assess risk debates in terms of ‘the public’ versus ‘the experts’. But it is vital to look for competing risk notions and interests among members of the public themselves. And in cases like the MMR debate, where the very existence of particular risks are called into question, we must consider the heterogeneity that exists not only in terms of what risks people are willing to accept, but also in terms

of how risks are defined and what sort of evidence about risk people accept.

Study methods

This paper draws on the results of a study on risk conceptualisation, trust and decision-making in MMR vaccination (Casiday, 2005). Eighty-seven parents of young children (77 mothers and 10 fathers), in and around Cambridge and Durham, UK, participated in focus groups ($N = 16$) and individual interviews ($N = 71$) between November 2002 and October 2004. Both research sites are university cities, with relatively affluent and well educated populations, although both have pockets of socioeconomic deprivation, and Durham is surrounded by some of the poorest areas in England. Both Cambridge and Durham had nearby private clinics offering single-antigen vaccines as an alternative to MMR vaccination, and at the time of the study had official MMR uptake rates of 83% and 88%, respectively (compared with a national average uptake of 82% and a government target of 95%) (Department of Health, 2004). No significant differences in parents’ interview responses were noted between the two cities.

Parents were recruited at toddler groups, community centres, and nurseries through personal visits and flyers, which asked for ‘parents of young children who would be willing to discuss their views and experiences about the MMR vaccine.’ Snowball sampling was also used to access additional parents refusing the MMR vaccine. Participants were purposively selected to include a broad range of educational qualifications, socioeconomic backgrounds and immunisation decisions. Although refusal to participate was not quantified, recruitment was generally straightforward, with lack of time cited as the main reason for refusal. Two parents declined to interview because they were in strong disagreement on the issue with their domestic partners. Parents were given written information about the study and an opportunity to ask questions, and provided written consent to participate. Of the 87 participants, 56 had vaccinated their children with the MMR at the time of interview, 16 had (or were planning to have) separate (single-antigen) vaccines, 10 did not vaccinate their children against measles, mumps, and rubella, and 5 were still undecided.

The focus groups and interviews followed a semi-structured format, asking parents to describe their

experiences of deciding whether to give the MMR vaccine to their children, with careful attention given to avoid generating anxiety among parents where it did not exist before. Transcripts were carefully read several times to build an interpretive framework for qualitative analysis. The analytic approach used here involved both answering questions of *a priori* research interest (e.g., How did parents conceptualise risk from the vaccine and the diseases it protects against?) and searching for emergent themes, using techniques identified by Ryan and Bernard (2003). A list of keywords related to each theme (e.g., risk of autism, risk of disease, decision-making process) was developed and blocks of text were coded for keywords and according to the speaker's decision with respect to MMR immunisation, using AnSWR (Centers for Disease Control and Prevention, 2000). AnSWR was then used to generate a list of all passages related to each keyword. These passages were read in relation to one another to develop an outline of salient issues. Segments of text were selected to illustrate key points, following Mason (2002), with participants identified pseudonymously.

Balancing risks

To decide whether to immunise their children with MMR, parents engaged in a process of 'weighing the risks of vaccinating against the risks of not vaccinating' (*Preetha, immunised her daughter with MMR*). The balance was determined not only by assessing statistical probabilities—although parents often stated that they would like better information about those statistics—but also by evaluating *which* risks, should they come about, would be unacceptable (echoing the assertions that different types of risk carry different levels of acceptance (Fischhoff et al., 2000; Slovic, 2000)). As anticipated by cultural theory (Douglas & Wildavsky, 1982) and found in previous studies (Petts & Niemeyer, 2004; Poltorak et al., 2005), social contexts, previous experiences and strong emotions played a significant role in parents' evaluations of the risks involved. While many parents accepted the MMR despite uncertainty about the possibility of it causing autism, for others even an extremely slight risk of autism was too great. The dramatic contrast between the children's apparently normal early development and the disturbing behaviours after MMR vaccination was particularly worrying:

But then all the stories you hear were very scary and a friend of mine, a speech therapist, and she deals with two children whose parents are convinced that their child's had problems since having the MMR. Even though you can't prove it, to know someone that actually knows children who have changed quite dramatically was quite scary. (*Marsha, planning to immunise her child with MMR*)

Other health problems, such as allergies and asthma, which had not been highlighted in the media coverage, were also frequently cited as potential risks from the vaccine:

I read that they carried out a survey on children who had been breastfed for the first six months, and half of them were vaccinated and half of them hadn't, and they found that the ones who had been vaccinated were five times more likely to get asthma. Which is quite considerable really. (*Sarah, did not immunise her child with MMR*)

Many parents also mentioned concern about 'overloading the immune system' and felt it was too taxing for a child to receive three vaccines—any three vaccines—at the same time:

Since giving her the single [measles vaccine] we've spoken to a geneticist who says that there is quite a strong link between overloading the system with vaccines and, not autism, but actually overloading your system leading on to other problems. (*Brenda, immunised her daughter with separate vaccines, not MMR*)

Such concern is related to a holistic notion of the immune system, like that described by Martin (2000), in which the immune system is viewed as central to the body's overall health, but is itself intricate and delicately balanced; it must be maintained so that it can flexibly and effectively cope with a multitude of challenges from the environment. Disrupting the immune system, in this view, can cause a wide range of problems, which may or may not be recognised as related by scientists looking only at infection or immediate side effects from vaccination. On these grounds, parents also queried the multiple immunisations routinely given to younger infants, but were more inclined to accept those vaccines because there was less media attention challenging their safety and because the diseases being immunised against, especially polio and meningitis, were particularly frightening.

Different risks, including potential exposure to infectious diseases and social risks, attended the decision not to immunise one's children with the MMR. Most parents cited the potential fatality of measles as grounds for serious concern. Many knew or had heard of people who suffered blindness or other complications of measles. Even parents who did not plan to immunise their children said that they might reconsider their decision if measles emerged locally. On the other hand, some parents' memories of measles being a common childhood illness made this prospect less frightening.

Things like mumps and measles I had them when I was little, and so I was fine. (*Susan, did not immunise her children for measles, mumps or rubella*)

A different, but very important, type of risk that parents perceived from not allowing their children to be vaccinated was the social risk of being seen as a bad or irresponsible parent. As in the study by [Evans et al. \(2001\)](#), parents discussed negative reactions from health professionals as stressful experiences associated with this decision.

When [the GP] found out that I wasn't going to have Sara immunised... she really put this huge guilt trip on me... So, I felt quite dejected when I came out and felt I was a bad parent. (*Kathryn, did not immunise her children for measles, mumps or rubella*)

Despite her initial feelings of guilt, this mother did not change her decision, but rather came to view the doctor's advice and opinions with suspicion. However, for parents who were unsure about their decision or placed a high value on being respected by health workers, feeling that they would be viewed as bad parents did make them more likely to comply with medical advice. Being removed from GP patient lists (to boost the percentage of immunised patients and thus secure the GP's target payment) was an extreme consequence of this social risk that some parents feared.

Decision-making on behalf of children

The choice that parents were making would have important consequences for their children, unable to decide for themselves. So getting this decision 'right' came to symbolise what it means to be a good parent (cf. [Alderson, 1990](#)). Children were vulnerable, passive recipients of their parents' and health

workers' actions, but would ultimately bear the full consequences of those actions:

Who do you love more than your children? You want to know am I putting him at unnecessary risk? So that's the other thing that makes it hard, is that you're not just deciding it for yourself, you're deciding it, with your best intentions for somebody else. (*Katie, immunised her children with MMR*)

The process of weighing these biological and social risks was made difficult for parents by uncertainty about whether any given child would suffer one of the anticipated adverse outcomes. One means of coping with this uncertainty, and thus guiding the parents' decisions, was to seek explanations for why some children seem to be more vulnerable to adverse outcomes than others. MMR was clearly safe for most children but a tiny minority, such as the children featured in the [Wakefield et al. \(1998\)](#) paper, seemed predisposed to adverse consequences. The difficulty was determining whether a given child would be a part of that minority or of the majority who would benefit from the vaccine.

Several characteristics of children or their families were repeatedly identified as contributing to this vulnerability. These included allergies, digestive disorders, premature birth, and family history of allergies or autism. Parents also believed that some children were more vulnerable to measles, mumps and rubella than others. Children attending nursery or school were more likely to be exposed to infectious diseases, but some parents expected their children to cope well with such an exposure, because their environment, diet and overall health were very good. [Poltorak et al.](#) also found evidence for parents considering the 'particularity of each child' ([Poltorak et al., 2005, p. 716](#)) but these particularities must also be set within the context of parental responsibility for children unable to evaluate uncertainty and choose for themselves. The ideas about vulnerability that parents expressed served to distinguish one's own child from an otherwise impossible array of contradictory information and uncertainty. They might serve as a precaution that a child was especially likely to be harmed by the vaccine (or by not having it), or as a reassurance that the child was unlikely to suffer damage as a result of the parent's decision.

Trust and public vs. private good

Although parents were the focal point for this study, parental roles must be viewed in the wider context of contemporary British society, in which many private and state-appointed actors (e.g., nurseries, the National Health Service and local government councils) have a responsibility to protect children's health. In addition to the vulnerabilities of individual children (the chief concern of parents), population-level risk forms a crucial part of any debate about vaccination safety. There may be a tension between the public health mandate to protect all children from infectious diseases and the parental responsibility of protecting one's own children. This tension has been described elsewhere (Davison, Davey Smith, & Frankel, 1991; Rogers & Pilgrim, 1995): as immunisation becomes more successful and widespread, then vaccine-preventable diseases become rarer and the risks posed by immunisation become more important relative to the risks of not immunising. Public health concern over the low rates of MMR uptake stems from the need to achieve high levels of immunity in the population in order to prevent outbreaks of measles, mumps and rubella. This consideration was widely highlighted in media reporting of drops in MMR vaccination rates. Well over a third of the informants spontaneously mentioned contributing to the 'herd immunity' of the population by vaccinating one's own children, as a parent's responsibility to the community. However, parents also said that their own children's health and safety was a more important concern than the small contribution to the health of the population that they could offer by vaccinating their children—even when they generally supported immunisation to protect the wider population.

My own children's health and safety is more important than the impact on the population... I don't want you to think that I'm not putting my children first that I'm putting the population first because that's not the case. But I feel by protecting them I'm also protecting the population. But by protecting the population I'm protecting them. It's sort of two ways. (Amy, immunised her children with MMR)

On the other hand, parents who feared that the vaccine was unsafe clearly resisted the notion that their children should assume this risk in order to help protect others from infection. The ideas about

vulnerability discussed above were important here: when parents perceived their own child's vulnerability to measles, mumps and rubella to be low, or their vulnerability to harmful effects from the vaccine as particularly high, then immunising in order to protect others in the community was less appealing. Rubella was a special case in point because childhood infection is not particularly dangerous; the rationale for widespread childhood immunisation against rubella is to protect against congenital rubella syndrome caused by infection *in utero*.

I guess for me, every now and again I feel guilty because I feel, well maybe if I did have my children vaccinated then there would be a chance that this illness would not be around at all. But then, well then I think actually those statistics are probably very much connected to children who aren't necessarily you know, living in such good conditions as mine are and aren't as healthy. (Stephanie, did not immunise her children)

The government aren't worried about my child, they're actually worried about protecting pregnant women [from rubella infection]. (Brenda, immunised with separate measles, mumps and rubella vaccines)

Clearly, the MMR debate was highly politicised, and in this study many parents mentioned their perceptions of governmental mishandling or dishonesty about other issues like BSE (Caplan, 2000; Murphy-Lawless, 2003; Rowell, 2003) and the ongoing war in Iraq as undermining their confidence in governmental pronouncements that the MMR vaccine was safe. This finding is in contrast to that of Poltorak et al. (2005) but similar to the distrust in government in general found by Brownlie and Howson (2005). Government policy-makers were accused of colluding with pharmaceutical companies, pushing immunisations for the manufacturers' financial gain rather than for the health of the nation's children. Thus, parents did not accept the government's decisions until they had evaluated the relevant evidence themselves.

I think a lot of this has been on trust. But trust in an informed, knowledgeable way, not just trust for trust's sake. I don't think I'd trust any government unless there was facts and figures to back up what they were saying (Sabrena, immunised her child with separate vaccines, not MMR)

In contrast to government political agendas, medical practitioners' advice was generally trusted when they showed concern for the individual child, as opposed to merely protecting the population or their own professional reputations. Thus, personal relationships with medical professionals were extremely important. When doctors engaged in discussions about the frightening stories that parents had heard about the vaccine, and shared their own stories about making such decisions as a parent or about positive experiences of MMR vaccination, parents were reassured that their concerns had been taken seriously.

Most of the evidence for the safety of the MMR came from large-scale epidemiological studies finding no association between the vaccine and autism. However, parents were concerned that epidemiological evidence would overlook some children who might have really been harmed by the vaccine. If the reaction was real but extremely rare, then these children would not 'show up' in the statistical analyses (Casiday & Cox, 2006). Twelve parents said they wanted more research concentrating on detailed case studies of those children. These parents felt that this would enable better understanding of the risk posed by MMR to a small minority of children:

There are work [*sic*] that are picking up on the vaccine strain virus in the gut of some of these kids. More research into the actual biology probably [*is needed*]. Hands on, you know... Rather than the sort of broad things. (*Jo, did not immunise her son against measles, mumps or rubella*)

These parents took a fundamentally different epistemological approach to the problem than the epidemiological one used by the health authorities (Elliman & Bedford, 2001). They demanded a different type of evidence, focusing on the anecdotal accounts of dramatic behavioural changes that parents had observed in their own children.

And to me the clinching thing on why I wanted the single vaccines was the parents on the television that were showing their children... That these parents were so convinced that it was the MMR... They truly believed that, do you know what I mean? (*Dianne, immunised her daughter separately and with MMR*)

Dianne placed great importance on the other parents' claims because she felt parents know their

own children better than anybody else and are in a unique position to notice changes in their behaviour. The challenge for doctors and scientists is to find ways of taking seriously these experiences while interpreting other types of evidence, such as that provided by epidemiology. Parents, clinicians and epidemiologists speak different 'languages of risk' and must seek ways to communicate across this barrier (Frankenberg, 1993; Gifford, 1986; Kaufert & O'Neil, 1993).

This highlights the importance of narrative for linking and interpreting observations (Earle & Cvetkovitch, 1995). Epidemiological findings can suggest whether or not there is a statistical association between events like MMR immunisation and the occurrence of autism. But these findings in and of themselves lack the rich meaning offered by the narrative accounts found in parents' descriptions of their children changing and in the media. Some proponents of the MMR vaccine have begun to incorporate powerful narratives into their arguments. For instance, one GP described his experience overcoming feelings of guilt as the father of an autistic boy (Fitzpatrick, 2004) and newspapers have presented narrative accounts of measles-infected children (McDonald & Ungood Thomas, 2004). Many parents were indeed persuaded by these narratives. It is important to recognise the importance and the value of narrative, because simply dismissing parents' anecdotal accounts of changes they observed in their children has resulted in many parents feeling that important facts had been overlooked or, even worse, covered up by the medical establishment.

Theoretical implications

The particular findings of this study are undoubtedly related to the role of the UK government in providing vaccines and encouraging compliance with vaccination, but the range of attitudes expressed by parents is remarkably similar to the patterns of vaccination acceptance found in very different cultural settings (Nichter, 1995; Streefland et al., 1999). For parents making decisions amidst this controversy, risk encompasses more than the relative probabilities of a child falling ill from measles or suffering autism as a result of vaccination. It also encompasses other health risks (such as allergies) and social risks (such as appearing to others to be a bad parent). The interplay between individual-level and population-level risk highlights

a point of tension in society between state public health interests and the individual 'right to choose'. Parents differed in how they weighed the relative risks of immunising and not immunising. Thus, it is important not to treat all parents as a homogenous group, but rather to look for differences between parents' risks concerns. Even more importantly, we should consider how social contexts and experiences can help make sense of those differences. For example, parents seeking explanations for why particular children may be more vulnerable to the vaccine or to the diseases are choosing which risks to make their own problem and which can be dismissed. Such decisions are necessarily related to previous experiences, as well as notions of parental and governmental responsibility. Individuals are reflexively interacting with society in individualising these risks, as discussed by Beck and others (Beck, 1992, 1999; Giddens, 1994). But different groups of parents choose different risks, as anticipated by cultural theory (Douglas & Wildavsky, 1982).

This paper highlights especially the importance and difficulty that parents attributed to making risk decisions *on behalf of children*. Risks that are particular to children have not been treated explicitly in the 'classical' risk literature, although other work on childhood and children's health has described the importance of ideas about children's vulnerability to parental decisions and perceptions about the role of a 'good parent' (Frankenberg, Robinson, & Delahooke, 2000; Kelley, Hood, & Mayall, 1998; Sobo, 2005). The notions of 'voluntariness of exposure' and 'acceptable risk' take on a new level of significance when those who would potentially be most affected are unable to participate in the decision, while those making the decision are engaged in wider debates about individual choice, community health, and the relative responsibilities of various actors for protecting children's health. If risk is invoked to hold individuals and governments accountable (Douglas & Wildavsky, 1982; Nelkin, 2003), then it becomes all the more important for parents holding themselves as ultimately accountable for what befalls their own children. An appropriate theoretical framework for dealing with risks to children should take account of the ways that notions of children's vulnerability and inability to make their own medical decisions impact upon worries about risks to children's health, decision-making and allocation of responsibility between parents and other actors.

Acknowledgements

This research was undertaken for a Ph.D. thesis in anthropology at Durham University, supervised by Catherine Panter-Brick and Tricia Cresswell. I am grateful to the Wellcome Trust, who funded my Ph.D. research expenses in the form of a Public Engagement with Science research studentship, and to all of the parents who participated in this study. I also wish to thank especially Kate Hampshire, Peter Phillimore, Peter Collins and three anonymous reviewers for their feedback on this work. Ethics approval for the qualitative study presented here was given by the Durham University Ethics Advisory Committee, in July 2002 (Application number 01 EAC 87).

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