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‘MMR talk’ and vaccination choices: An ethnographic study in Brighton

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Abstract

In the context of the high-profile controversy that has unfolded in the UK around the measles, mumps and rubella (MMR) vaccine and its possible adverse effects, this paper explores how parents in Brighton, southern England, are thinking about MMR for their own children. Research focusing on parents’ engagement with MMR has been dominated by analysis of the proximate influences on their choices, and in particular scientific and media information, which have led health policy to focus on information and education campaigns. This paper reports ethnographic work including narratives by mothers in Brighton. Our work questions such reasoning in showing how wider personal and social issues shape parents’ immunisation actions. The narratives by mothers show how practices around MMR are shaped by personal histories, by birth experiences and related feelings of control, by family health histories, by their readings of their child’s health and particular strengths and vulnerabilities, by particular engagements with health services, by processes building or undermining confidence, and by friendships and conversations with others, which are themselves shaped by wider social differences and transformations. Although many see vaccination as a personal decision which must respond to the particularities of a child’s immune system, ‘MMR talk’, which affirms these conceptualisations, has become a social phenomenon in itself. These perspectives suggest ways in which people’s engagements with MMR reflect wider changes in their relations with science and the state.

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Introduction

In the UK, the number of parents presenting their children for the combined measles, mumps and rubella (MMR) vaccination has declined significantly during the

last 7 years. The MMR issue has become a high-profile example of emergent problems in public engagement with science and technology, frequently dominating media headlines and editorials.¹

Amidst the controversy, this paper explores how mothers in Brighton are thinking and deciding about MMR for their infants. Certain parents came to attribute autism-like symptoms in their children to

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¹For an example of the wide range of media debate around the vaccine, see: http://news.bbc.co.uk/1/hi/in_depth/health/2002/mmr_debate/default.stm.

MMR vaccination in the early 1990s (Mills, 2002). Arguably, their views gained credence from clinical studies (Wakefield et al., 1998; Uhlmann et al., 2002). Subsequent studies considering the incidence of autism in relation to MMR among larger populations claim not to show an association (e.g., Taylor et al., 1999; DeWilde, Carey, Richards, Hilton, & Cook, 2001; Fombonne, 2001; see Miller, 2002, and Jefferson, Price, Demicheli, & Bianco, 2003, for reviews). The debate turns, in part, on the significance attributed to epidemiological as opposed to clinical evidence, and on the status attributed to parents' own observations. Indeed some parents and scientists argue that while most epidemiological studies focus on autism in general, these children have a particular, distinct disease (e.g., Thrower, 2003). Support networks for parents concerned about MMR-damage (eg., Jabs, ARCH) have, through the internet, become focal points for information sharing and comparative parental experience, forging a 'citizen science' that has engaged with similarly interested clinical scientists in the UK and elsewhere.

As medical, popular and media debate have unfolded, parental engagement with the MMR vaccination has altered. Despite assurances of MMR safety in the scientific literature and by the British Department of Health (DH), and information campaigns aimed at parents, uptake continues to decline in many areas, and by early 2004, for children aged 24 months, stood at 79.8% for the UK and 71% for the city of Brighton and Hove (HPA, 2004). As some parents opted to have the MMR components separately, a second debate emerged concerning whether these should be provided through the NHS, privately, or not at all.

In interpreting parents' reactions, a predominant view is that they misunderstand the science involved, and thus misperceive the supposed autism risk (e.g., Elliman & Bedford, 2001). Non-vaccination thus reflects misinformation or ignorance which needs correction by the provision of scientific information—the cornerstone of the DH strategy (Department of Health, 2001; NHS, 2004).

Other studies focus on the role of pressure groups in 'misinforming' the public. Thus André (2003), for example, suggests that 'a small group of the so-called educated in developed countries', who constitute an 'anti-vaccination movement' has been misclassifying health events after vaccination as vaccine reactions. Fitzpatrick (2004) makes this argument in relation to MMR. Baker emphasises the key role of pressure groups amidst divided medical opinion during the British pertussis vaccine controversy in the 1980s (Baker, 2003). The literature on anti-vaccination movements emphasises not only their long history, but also their articulation of wider social and political concerns. Durbach (2000), for example, links dissent to smallpox vaccine in the 1880s with working class movements, although Porter and Porter (1988) emphasise greater

social diversity in movement concerns even at this time. While some argue that a UK anti-vaccination movement has gradually developed over the last century (Baker, 2003), others point to significant changes in social and political context and agendas (Fitzpatrick, 2004).

Associated arguments hold that mass-media coverage miscommunicates and amplifies risks to public. Amidst increasing journalistic coverage of vaccine issues and 'scares' in the 1990s (Cookson, 2002), it is argued that public anxiety about MMR has been fueled by—even created by—media bias and styles (e.g., Ramsay, Yarwood, Lewis, Campbell, & White, 2002; Hargreaves, Lewis, & Spears, 2002; Science Media Centre, 2002).

Studies addressing the 'knowledge, attitudes and beliefs' of parents have focused particularly on perceptions of the benefits and risks of immunisations, and sources of information about these. For example, the DH commissions regular attitudinal surveys in random locations across England. From these, Ramsay et al. (2002) indicate that 67% of mothers perceive the MMR as safe or to carry only slight risk; variations over preceding years were understood as linked to media coverage. They conclude that

...the fall in MMR coverage has been relatively small, mothers' attitudes to MMR remain positive, and most continue to seek advice on immunisation from health professionals. As the vast majority of mothers are willing to have future children fully immunised, we believe that health professionals should be able to use the available scientific evidence to help to maintain MMR coverage. (Ramsay et al., 2002, p. 912).

Pareek and Pattinson (2000) surveyed attitudes and beliefs with similar findings and conclusions. Both these studies also linked attitudes with social variables such as age, education, marital status, ethnicity, and class, associating (at least early) concern over MMR with those from higher socio-economic grades.

Other studies go beyond individual beliefs and social status to consider how culture, and social and political processes, shape parents' immunisation dilemmas and practices. Thus, Streefland, Chowdhury, and Ramos-Jimenez (1999) relate vaccination uptake to (a) how vaccination engages with local knowledge, aetiologies and perceptions of disease, and (b) specific socio-cultural contexts and experiences of interaction between people and health care providers, which together constitute 'local vaccination cultures' (Streefland et al., 1999, p. 1707). Studies of this genre have associated vaccination refusal with particular social groups having 'alternative' lifestyles and philosophical outlooks (e.g., Rogers & Pilgrim, 1995).

Some such works address political dimensions to cultural experience, including people's confidence and

trust in engaging with health institutions. In medicine (Williams & Calnan, 1996; Gabe, Kelleher, & Williams, 1994), as around other scientific issues (e.g., Beck, 1992; Irwin & Wynne, 1996), it is suggested the public increasingly treat ‘official’ views with skepticism, questioning the institutional positions, funding and wider political or social control agendas of those promoting technologies. Such critique is visible in some strands of the anti-vaccination literature (Scheibner, 1993; McTaggart, 2000; Coulter, 1990). Low confidence and trust in vaccine information sources have been linked with vaccination refusal in the case of both Pertussis (Meszaros et al., 1996) and MMR (Evans et al., 2001). Some parents’ skepticism over claims of MMR safety have been linked to their perception that GPs are ‘paid to immunise’, or that supportive scientific research is biased by pharmaceutical company funding (Evans et al., 2001). Nevertheless, other evidence suggests that doctors are trusted more than any other group.²

These cultural, social and political perspectives suggest that parental reflection on MMR may fail to match the narrow, risk-based framings dominant in public health. Especially where disagreements amongst experts prevail, they may frame the issue in terms not of risk (involving calculable probabilities among known outcomes) but of uncertainty (see Hobson-West, 2003).

In Evans et al.’s (2001) focus group study, all participants found the MMR decision difficult and stressful, while immunisers and non-immunisers shared many views, questioning the strong analytical distinction that other studies have drawn between them. This study, like Petts and Niemeyer’s (2003), goes further, however, to suggest that parental engagement with MMR is part of a wider social world, in which issues of respect, authority and social relations shape decisions, although their group-based methodologies constrain full exploration of these.

To set parental engagement with MMR within the wider social world of which it has become a part, our research examined parents’ personal experiences and reflections within the unfolding social processes and relationships in which they are involved. The research combined detailed narratives that enabled mothers to speak widely around the issue and reflect what they regarded as most important (see Mattingly & Garro, 2002, on narrative approaches), with participant observation and short, informal discussions. The latter considered how people talk about MMR amongst themselves, and how such talk is shaped by, and shapes, social context. Our approach also focused on the interactions between particular health professionals

and parents, allowing exploration of the social and political relations underlying categories such as ‘trust’, and of how they broker more personal concerns with professional directives.

Study methodology

The city of Brighton and Hove, on England’s south coast, was chosen for the study due to its particularly sharp decline in MMR coverage, its locality to the researchers and the interest shown by local public health professionals. This university town in the UK’s relatively affluent south east has become increasingly popular as both a tourist destination and by commuters moving from London. The last census (2001) reveals a relatively youthful and mobile population (ONS, 2001; CEPT, 2004). Of the total population of 247,817, 42% are aged 20–44 (compared to the England and Wales average of 35%) and 18% are defined as migrants. The 60% of adults defined as employed work predominantly in public services (26.5%), financial and business services (23%) and retail (14.4%). The local unemployment rate, 3.6%, is a fraction higher than the national average of 3.4%. The average household size, 2.09, is the smallest in the South East and the fifth smallest in England and Wales (CEPT, 2004).

Two areas of the city, Whitehawk and Fiveways/Preston Park, were deliberately identified as apparently conforming to the stereotypes of ‘deprived’ and ‘middle class’ areas highlighted by some public debate over MMR. The ‘Overall index of Multiple Deprivation for 2000’ ranks the 1998 administrative wards of Marine (covering Whitehawk) and Preston (covering Fiveways/Preston Park) at 439 and 5164, respectively (of 8414 wards in England; 1 being the most deprived) (DETR, 2000). ‘Deprived’ Whitehawk covers some rather better-off pockets, however, while ‘middle class’ Fiveways/Preston Park is not without poverty. Many Whitehawk residents feel their area is unjustifiably stigmatised, expressing satisfaction in living there because of its sense of community. Some parents there are old-time Whitehawks, others have moved due to affordability, while others have been housed there from estates elsewhere (Netley, 2002). Brighton’s Fiveways and Preston Park neighbourhoods are characterised by commuters, families who have moved in for their good schools, and Sussex-based professionals including university academics.

In collaboration with local public health specialists we identified a focal GP practice in each study area that served a significant proportion of residents, had more than one GP and welcomed the research. Neither practice either self-identifies or is known in local health care circles as having any particular ‘take’ on MMR. In each practice, we interviewed all GPs (eight in total) and

²Doctors win overwhelming vote of confidence from public’, MORI opinion poll conducted for the British Medical Association, March 2001. <http://www.mori.com/polls/2001/bma2001.shtml>.

practice nurses (three in total). In parallel, we contacted the health visitors' base serving each study area and interviewed six of the nine health visitors, going on to carry out follow-up interviews and work-shadowing with three.

MP and ML interviewed health professionals together and made initial contacts with five different carer and toddler groups during March–May 2003. These groups ranged from those organised by health professionals and community workers, to informal drop-in sessions co-ordinated by the National Childbirth Trust and a social-services supported community centre, to an organised physical activity/music class. Three were used as the base for group discussions (one led by ML, three by MP) convened amongst four to seven mothers who happened to be present on a particular day; no advance attempt was made to unite those sharing any particular view. Group discussions and in-depth interviews were transcribed in full.

Many short, informal discussions and much participant observation of 'MMR talk' amongst parents also took place during our visits to these groups, and during the anthropologists' presence in the study areas. Of the research team, three are parents of young children who have made decisions over MMR, and regularly participate in the social dimensions of the issue. Forty-eight of these conversations were recorded and transcribed in full, and 23—evenly distributed between the two study areas—developed into in-depth, narrative interviews of 1–2 h in length conducted by MP. This sample was opportunistic and was not intended to be statistically representative. The only selection criterion was having a child under three and willingness to be interviewed, either at the time or by later arrangement at home or another mutually agreed location. Mothers were contacted at the five different carer/toddler groups or introduced by one of six different health professionals. We spoke to only two mothers recommended to us on the basis of their vaccination decision (one by a doctor as an interesting case of non-vaccination; the other by a mother as someone who vaccinated despite having an autistic child). The mothers interviewed had a variety of social, demographic, educational and occupational backgrounds, and had made a variety of vaccination decisions for their children, summarised in Table 1.

Analysis

Initial interviews suggested that a biographical format would elicit the required basic information and encourage parents to speak widely around the subject. Thus interviews sought a processual appreciation of vaccination decisions through starting with the question, 'When do you remember first thinking about MMR for your child?', and then seeking elucidation and expansion on the specifics that parents raised. In giving their own

Table 1
Vaccination decisions made by interviewed mothers

Vaccination category	Number
MMR, all children, on time	7
MMR, all children, but delayed	2
MMR for one child but not all	2
Single vaccines, all children, on time	0
Single vaccines, all children, but delayed	2
No MMR, but intention to vaccinate	3
No MMR, undecided	4
No MMR, intention to have single vaccine for mumps alone	1
No MMR, single measles vaccine alone	1
No MMR (nor DTP or other vaccines), all children	1
Total mothers	23
Total (have had MMR or intention to go ahead)	12
Total Whitehawk residents	11
Total Preston Park/Fiveways residents	12

explanations, mothers also theorised other mothers' decisions in relation to their social worlds. MP transcribed and then summarised all the in-depth interviews into 23 parent profiles with associated key narrative themes and vaccination biographies. All researchers examined these and discussed their significance in two meetings. These themes were then expanded, adapted and grouped in a working paper that was shared, discussed and modified in consultation with the study's stakeholder advisory panel.

Findings

When relating their engagement with the MMR, mothers' narratives ranged widely, frequently touching on personal histories, birth events, the social life of motherhood and engagements with health professionals, as much as on understandings of vaccination. Here we illustrate and discuss these emergent issues, and reflect on the finality or otherwise of mother's vaccination decisions.

Personal histories

Narratives reveal how mothers bring to parenthood diverse experiences, knowledge, ways of validating and engaging with information, and expectations of health professionals which set the stage for thinking and talking about MMR.

In getting to grips with MMR, many described drawing on the history of vaccination decisions and disease experiences in their own and other families. A few had been brought up in families with a longstanding

rejection of all vaccination, while in others, vaccination was very much valued. Most, however, had a family history in which vaccination played a minor role. Several parents were familiar with children who had been brought up unvaccinated with, they perceived, little ill effect:

My mum thinks that in the past when there was no midwives and health visitors they just got on with it. Mum thought she didn't think it would work for us, she thought if we were ill we would be ill. (Mother).

Experiences of oneself or others catching childhood diseases with few serious effects, or less frequently, with complications, also feed into people's perspectives on vaccination. Some parents in deliberating MMR actively pursued such histories, questioning relatives or friends to discover whether they themselves were vaccinated for the diseases concerned.

Mothers also drew on other familial, professional, personal, philosophical and travel experiences when they started to engage with vaccination. In particular, the narratives suggest that previous medical experiences or contact with medical professionals influenced trust in or suspicion of biomedical recommendations to vaccinate. Among the mothers were several health professionals; they did not all accept vaccination unquestioningly, but also narrated their increased awareness of iatrogenic disorders, medical mistakes and possibilities of error. Equally, the narratives show how longstanding sickness or inherited conditions led some parents to gain more insight into the practicalities, politics and pitfalls of healthcare than the theories supporting medical treatment.

Some mothers claimed political or philosophical attitudes that make them suspicious of or offended by what they experience as heavy-handed or patronising denials of their ability to choose for themselves. Some are suspicious of drug companies' involvement in vaccination programmes. Inversely others come from families with a history of compliance born of economic need that makes them ill prepared either to research or to feel confident to criticise. Several parents acknowledged particular personality quirks or phobias that made them apprehensive of biomedical intervention, however mild.

Only four of the 23 mothers expressed total confidence in the MMR, saying that they always knew their children would be vaccinated. Notably, all four also distinguished themselves from other mothers on the basis of their personal histories. Only one linked her unworried perspective to a claimed scientific knowledge of the issue. She had a PhD in a biological science and both her parents had worked in the health service. This mother had also been the subject of measles vaccine research in the 1970s, and had extensive work experience

of communicating scientific research to funding bodies. The other three mothers distinguished themselves in (inter alia) their (a) trust of professionalism, (b) suspicion of the media, (c) acceptance of the MMR/autism connection as one risk among many (captured in the statement 'There's a fine line to tread. It's what you want for your children, whether you can cope with a bit of autism or blind and deafness, it's pot luck then at the end of the day'), (d) travel experience in poor countries, and (e) resistance to 'reading into things'.

Birth events

The narratives suggest several connections between mothers' engagement with birth and vaccination. Decisions around pregnancy and birth, for the first child at least, first make parental choice a major issue. Birth is a key point when parents balance choice and trust in a medical institutional setting, experiences of their own autonomy in relation to medical authority, and wider social desires. The extent of active choice, and the kind of birth that a mother chooses emerged as a marker of the extent of her research and experience of dealing with often sceptical health professionals.

Several mothers who later rejected MMR had sought 'natural' or active birth. While in such cases, both birth and MMR decision might have been shaped by a prior worldview emphasising a particular notion of 'the natural', the narratives also suggest that birth experiences can guide thinking about vaccination, whether by reinforcing or undermining a previously held view. In one contrasting example, the previous experience of an interventionist birth undermined a mother's faith in the medical profession and reinforced her belief in 'nature' and natural ways of doing things. Another mother's experience of interventions associated with premature delivery made her feel denied of choice, increasing her sense that the MMR decision should be her choice.

Didn't have the choice of breastfeeding, she was so early she had to be droplet fed. Eye dropper thing because she didn't suck the bottle properly. So that choice was taken from her basically, didn't really want a caesarean, wanted to just have gas and air, didn't want an epidural, heard horror stories, didn't really have the choice for that, that kind of choice was taken away from me. So in a way it made it easier? (Young single mother).

Active research and interest in birth and in vaccination can also go together. Four mothers who invested much time in research around birth and who started thinking about vaccination at least 4 months before birth went on to have single vaccines or not to vaccinate at all. It also appears from our narratives that informed

rejection of the Vitamin K injection at birth may be a good predictor of future concern with MMR.

Becoming a mother with other mothers

MP: What information have you had apart from the newspapers?

(Mother A) You probably get more information from talking like this, as a group, if (my friend) comes around we talk about different things, maybe I'll try that with (my daughter), ... you get more of an idea.

(Mother B) You feel that you can ask, you can't actually go to the doctor and say, look I've got a real big problem, life is really hard, I cannot cope, but you can say to your friends 'she's a nightmare, have you got anything I can try'.

(Mother A) Everyone's been through exactly the same. (Focus group in Whitehawk)

It is the rare mother who has not been drawn into a particular way of discussing MMR along with other issues of concern (sleeping, feeding, behaviour...) in the many groups most mothers participate in with their children, from organised carer/toddler sessions to informal gatherings at home or in the park. Such conversations appear to be framed by an informal, egalitarian and friendly ethos which obviates any implicit hierarchy of knowing more than others, by having done more research or by having older children. The narratives and participant observation suggest that parents rarely seek or give advice but rather learn from hearing and sharing experiences and tips, generally valuing forms of information sharing grounded in the unique relationship and responsibility that each has for their child. Our ethnographic work has not revealed anything resembling peer pressure to vaccinate or not; what does emerge is a sense of taking other parents' concerns seriously.

My friend asked me what she should do and I say whatever is right for you. I don't say, oh 'don't do that', I'd tell them how I feel but 'you may have other reasons to feel how you feel' and she did have the MMR done. I didn't say 'oh you stupid' whatever, it was like 'Ok is the baby fine? Good'. You can't put your highly opinions on them, otherwise if they did what you did and they did catch something they could blame you, couldn't they? (Mother of two girls /single vaccines).

Indeed, for many mothers, the wish for a common camaraderie is linked to a way of discussing MMR that rejects any denial of parental right to choose. However scientifically informed a mother is, the powerful association between talking about MMR and fomenting relationship with other mothers means that the failure to

question assurances of MMR safety threatens newly established and valued relationships. Equally, strong identification as a mother makes it difficult not to relate sympathetically to the accounts of mothers (first-hand, or through social networks, internet or media) who noticed a dramatic change in their children's behaviour after vaccination. In short, to ignore concerns about MMR, one has to distinguish oneself as a mother from other mothers.

Through such groups parents are also exposed to a variety of other techniques, therapies and support groups (for example in cranial osteopathy, homeopathy, baby massage) that may help build confidence in embracing or rejecting alternative strategies for their child's health. Not all parents who use alternative therapies refuse to vaccinate, and nor do all non-vaccinators embrace alternative therapeutic ideas. Several mothers suggested, however, that more experience of alternative medicine might encourage rejection of the MMR.

Such aspects of MMR talk are common amongst both Whitehawk and Fiveways mothers. In Whitehawk, however, mothers within older Whitehawk families, with strong community relations, contrasted with newly settled mothers whose parenting relations were structured more through their engagement with health and social services. In this vein, four newly settled single mothers expressed how their sense of isolation from peers overwhelmed their ability to make what they regarded as an informed choice for the DTP.

Had all of the baby jabs done. Because being on my own, as I said my mum wasn't down here and I hadn't established a group of friends down here, I felt really vulnerable. The responsibility of looking after him was extremely overwhelming. (Single mother).

On this account, vulnerability was a reason for vaccination, or at least for handing over judgement about it to health professionals.

The encouragement to research (or 'to look into it') and then make up your own mind is a pervasive theme in the narratives. Indeed, they suggest that vaccination has become a subset of expected personal research into parenting options and advice of all kinds, encompassing health, diet, sleep, behaviour and other issues. That some parents are implicitly defensive of not looking into vaccination in more detail is evidence of this.

Personal research is encouraged by other parents, as well as by health professionals. It involves searching for recommended books, contacting parents' groups for advice, and surfing the internet, balancing the dramatic claims of individual mothers, the perspectives of anti-vaccination campaigners, serious work on history of science and public health, and relatively inaccessible texts on immunology. The research process is rarely

satisfactorily concluded by any vaccination choice, but rather accentuates a sense of doubt; only those mothers who researched to support a previously felt position ended up taking a decision they felt clear about.

Engaging with health professionals and government

Most of the GPs we interviewed feel little involved in most parents' MMR decisions: few consult them, and most of those who do have already made up their minds, seeking support rather than advice. Many mothers confirmed that they did not raise their questions with GPs, seeing them as time-constrained and probably partial in their advice (not least because of their financial gain from meeting vaccination targets) and because of a sense of unequal power relations, invoking worry about appearing ignorant.

Health visitors generally appreciate parents' dilemmas, and do not wish to compromise carefully built trust relationships through anything that might be perceived as heavy-handed advocacy to vaccinate. Moreover, vaccination is not the immediate priority for health professionals working with parents who are perceived as deprived, with many related health and social problems. As one professional described her work in Whitehawk,

I think your role is much more, damage limitation, sometimes they have so many illnesses and so many risk factors, that you take the worst one and try to deal with that.

While an established relationship of trust between parents and health professionals may already have been built through mutually dealing with other childhood sicknesses and concerns, this does not necessarily affect parents' vaccination decisions. Only in one dramatic intervention of a GP saving the life of a child with meningitis was a previous familial rejection of vaccination reversed.

Narratives indicate how some mothers actively choose between health professionals, seeking out those who will support their particular perspective on vaccination. Such an egalitarian engagement premised on common concerns is often highly valued. For some, having a supportive health professional lends momentum to the process of research and of acquiring confidence in one's judgement. In contrast, other parents act passively. Some feel patronised or intimidated in engagement with health professionals, and thus do not ask questions; this can be read, mistakenly, as passive acceptance (compliance). Thus, to quote one GP

I think the majority of Whitehawk are not having to make those decisions, because they are allowing us to make those decisions, because they are quite happy to hand that over, that responsibility over, they don't want to have to think about that, hopefully because

they trust what you are doing or don't have the space to put thought into it, I don't know.

However, the same GP, in relating one particular case, appeared highly aware of how such institutional relations influence their encounters. For example,

She won't even come back and talk to me. She is not as educated, she finds it really threatening to talk about the details, and that [information] pack is very technical, which is one of the reasons that I wanted to see her again.

Observation by social services may also make engagement with health professionals problematic, if mothers feel that they are being judged for their particular vaccination decision.

In our interviews, few parents mentioned the controversies over BSE and genetically modified foods in the UK as influencing their lack of trust over MMR, and a few actively denied any link:

Have you been worried by any of the scandals about food that were reported in the papers? No, no (affirmatively), BSE! I was told that I was a mad cow anyway. It doesn't bother me. (Mother. One child vaccinated with MMR).

Indeed, trust in government appeared in the narratives as less relevant than mothers' personal confidence in their decision process. Thus, some mothers' celebration of informed choice appears predicated on a form of personal responsibility that implicitly takes governmental fallibility into account, reflecting an established lack of trust. This acceptance of personal responsibility is manifest in the recurring statement 'I couldn't forgive myself if [my child became autistic; my child developed complications from measles]' explaining both non-vaccination and vaccination. Some mothers certainly seem to be less anxious and to express less responsibility for their children while attributing public institutions with greater knowledge and right to intervene.

Understandings of vaccination and contra-indications

The narratives reveal various ways that mothers conceptualise vaccine contraindications and risks that are logical to them within the framings of their personal histories and experiences. Most of those concerned about the MMR suggested that three vaccines were too many for the immune system to cope with and could 'knock back' a child. Others invoked ideas that can be broadly summarised as (1) increased susceptibility reflected by the presence of some disorder within the child or family, (2) the value of natural immunity and of supporting it with nutrition, and (3) the particularity of individual immunity, sometimes linked to hereditary factors. Three mothers strongly argued that conditions

such as eczema, asthma, allergies and learning disorders—of parent or child—predispose a child to suffer serious effects from the MMR vaccine.

This field of reflection and discussion leads some parents to regard the MMR as appropriate for most people, but not for their own child because of a particular weakness or susceptibility. Fear of an unknown weakness may be reason enough to avoid the MMR. Here, the possibility of risk—in other words, uncertainty—shapes rejection of vaccination.

Several mothers who chose to avoid or postpone vaccination described the effects of measles infection in similarly particularistic terms. They saw their child's vulnerability to serious effects as depending on the strength of their immunity as acquired through nutrition and appropriate nurturing. They backed up such thinking with the idea of valuable, acquired natural immunity, and by appreciation of historical or geographic associations between measles morbidity and nutrition.

Many mothers express the particularity of each child through their different personalities and the history of their weaknesses and strengths, and conceptualise each person's immune system as particular. Parent-child links and responsibility are affirmed through ideas that parental illness susceptibilities can be passed on to children. Even the tuberculosis suffered by a child's grandparents may be conceptualised as manifest in their constitution. This sense of particularity is another reason why many mothers see their own vaccination decisions as not relevant to other parents.

Confidence in decision

I don't feel we have enough information. I sway one way then the other. Single vaccinations concern me too. Confusion really. When I do do it, and I probably will, it will be closing my eyes, running and jumping. (Mother of three-month-old baby).

Many of the parents we talked to participated in the agonising of other parents, heard stories of 'vaccine damaged' children, talked conspiracy, and expressed belief in many of the DH's list of 'MMR myths', yet still went on to vaccinate. While this could be attributed to 'trust', several mothers emphasised lack of confidence or lack of knowledge as explaining decisions to vaccinate.

I'd have to be a lot more knowledgeable not to have it. (Mother of 6-month-old child/unsure about MMR).

I'm not confident enough to go down the non-vaccination route. (Mother of 6-month year old child/ intends to have single vaccines)

Some mothers who mentioned contraindications in their narratives postponed vaccination until they felt

their child's constitution had strengthened, or a period of particular susceptibility had passed. A greater susceptibility to measles may also be the final impetus to undecided mothers. A reported measles outbreak in the area—not confirmed by microbiological testing—was sufficient for some mothers to go and seek MMR.

Even amongst parents with longstanding, research-based, informed concerns in favour of vaccination, the final decision to vaccinate may be postponed for logistical or familial reasons. Several mothers only consented to vaccination once the child's father finally agreed to take the children, claiming that they could not bear to see their children suffer. However, they were perhaps implying the need for combined parental responsibility on the issue.

Thus, a decision to vaccinate does not necessarily reflect resolution or acceptance of the safety of the MMR. It may on occasion be a simple realisation of being unable to afford single vaccines, or a spontaneous or professionally encouraged decision on the spur of the moment, when in the surgery for other business. The narratives suggest that one can still vaccinate voicing both exaggerated risks of autism, and serious dangers from measles. The difficulty in deciding and dealing with the wide variety of social and economic factors, pressures, uncertainties and implications for parental responsibility are captured well in the narrative of a 21-year-old single mother from Whitehawk who has postponed the MMR vaccination for about 6 months.

Do you ever get to the point when you can decide?
She's going to have it. I've been told. Her dad's told me he wants her to have it and it's a strong thing that he wants her to have it, so he's going to take her to have it, and I'm ok with that. I don't want to take her to have it, really.

Do you feel because it's his decision because he took the responsibility, takes the pressure off you a bit?

A bit yeah. I do feel like it's a lot of pressure and I do think she should have it, really, realistically. I just cannot pay for single ones. If I could afford it, I would have single ones. Why should your child's development maybe suffer, we don't know yet, because you can't afford it... That's not really fair is it?

How come your partner is so sure that it's right?

Well, ...hmm.. she needs to have something done. I'm weighing up the pros and the cons of it, for her to have it, she could become autistic then that's the chance you are going to take. If she doesn't have it, she could get very ill, she could die. Then realistically I'd rather she be autistic. It sounds really silly, maybe, I'd rather take that option, if she's still here with us, and I would still love her, she is still my child, rather than thinking to myself I'm putting her

through all that illness, for nothing, you know, when really I could vaccinate against that. It's probably less chance of her becoming autistic than there is of her actually getting ill. Even if she didn't get really poorly she'd still get ill, she'd still get it, she's having it now, (laughing....) I'm not quite sure but she's having it.

Whatever the choice, the process of learning about MMR continues and plays a role in future vaccination decisions for future children. While non-vaccination or single vaccination requires a continued engagement to affirm the position taken, even parents who opt for MMR continue to learn and say they remain open despite having taken a decision that is irreversible.

You've got to hope and pray that the decision that you made was the right decision, yours and your own. (Mother, one child vaccinated).

In the immediate weeks after vaccination, parents may be aware of possible side effects and express relief that nothing serious happened. Even long after vaccination, when reflecting on problematic aspects of their child's development, the unnerving worry remains that the MMR might be responsible. Future children may not be vaccinated with the MMR even if previous children were.

In remembering and communicating their decision to other parents in MMR talk, some issues, such as the importance of choice, become a safe idiom through which to verbalise more ambiguous experiences.

Do you think you think about it differently now post event than the way you were thinking about it then?

Possibly, I think, I don't think I would change my mind and have the MMR but I don't necessarily think the MMR is a bad vaccine, that there is a problem with the vaccine. I just think there should be a choice for parent to, you know, so that you can make the decision yourself. Unless something comes out that there is absolutely no link with autism, it is completely safe, I think the choice element should be there and that's how I felt at the time that I wanted to make that choice and that's what I chose for my children. But I just think the choice should be there for all parents (Nurse and mother of two children both vaccinated with single vaccines).

Discussion

Our ethnographic and biographical approach has shown how parental engagement with MMR is part of an unfolding of experiences in relation to child health and institutions, and is shaped by other aspects of these experiences. In focusing on mothers' narratives, we have

neither attempted to address the gender dynamics around MMR choice nor sought to relate MMR talk and practice systematically to social categories such as class, gender and education. Both these dimensions are addressed in the survey component of our wider research programme.

Our ethnographic work raises several issues for policy and public debate around MMR. Mothers in this study tend to conceptualise their child's health and immune system as shaped by a specific pathway extending back into family health history, birth, illnesses and other events, and incorporating concerns about sleep, allergies, eczema, asthma, dietary tolerances, character and behaviour. This personalised framing extends into ideas about a child's particular vulnerabilities to disease or vaccination effects, so parents reflect on MMR 'risks' or 'safety' not in general, but 'for my child'. The perspective of personalised pathways of vulnerability (or invulnerability) leads some to seek a personalised approach to vaccination: which vaccines, their timing, and 'choice' of single vaccines.

While this contrasts with uniform vaccination programming linked to service efficiency and public health outcomes, it conforms with wider NHS agendas for 'patient choice' and active citizenship (NHS executive, 1995, 1996; Ford, Schofield, & Hope, 2003, p. 590), and in parenting, with arguments promoting active, child-centred, personalised approaches for improved child health and developmental outcomes. A new equation has come to be drawn between the good parent and the parent who, as the best expert on their own child, seeks to negotiate parenting advice with the child's individual particularities; a shift from acceptance of more authoritative and generalised childcare regimes visible (but by no means total) in, for example, the tenor of childcare advice books from the 1970s (e.g., Spock, 1976) to the present (e.g., Leach, 2003). Thus, public health framings which reject an individual-choice ethic for MMR and other vaccines, because individual decisions have implications for other children, have little resonance with the paradigm that our narratives suggest now guides parental reflection on their children's health. Moreover, the narratives suggest how wider societal trends, including older parentage, greater choice at birth, and wider access to parental support groups and information underlie parents' desire for choice, and their confidence to pursue it.

Arguably, current personalised framing of a child's health and vaccine-response trajectory has been accentuated by popular appreciation of the new genetics of disease, and the cultural resonance of immunological metaphors in wider society (Martin, 1994). Moreover, the narratives suggest links between personalised approaches to immunisation, and a personalisation of responsibility in the 'risk society' (Beck, 1992), where distrusting the capacity of public institutions to manage

technological risks, parents feel they have no one to blame but themselves. If these are true transformations, then the evolution of the current MMR vaccine ‘crisis’, and of possible future vaccine crises, cannot be expected to mirror past experiences (e.g., over Pertussis) and simply fade away; it is qualitatively different, unfolding as part of changing cultural paradigms and science–society relations.

While many studies have treated MMR as a single decision, this research suggests this may misconceive parental engagement. Actual outcomes depend not on a singular deliberative calculus and the information and education that informs it, but on contingent and unfolding personal and social circumstances in an evolving engagement. The MMR issue has taken on a social life, and understanding parental engagement with it requires us to understand how ‘MMR talk’ and anxieties unfold amidst relationships between parents, and with the diverse worlds of official and complementary health delivery. When parents ‘talk MMR’, they are not merely exposing their scientific reading, but also what they regard as valued parenthood, their responsibility to their child, their trust in institutions, how they place themselves amongst their friends, and so on. Neither social engagements with MMR, nor personal reflections on its implications for a particular child’s health, stop with the act of vaccination (or without it). How parents ‘read’ or react to different information sources (whether pro-MMR DH publicity or health professionals’ advice, or information from anti-MMR pressure groups) depends on when and how, in these social processes, they encounter them—questioning the central significance of information itself emphasised in other studies. Moreover, mothers’ interactions with health professionals are shaped by broader relations of power and authority, albeit modified by professionals’ diverse personal approaches. Seen in this way, seeming compliance may reflect reluctance to question more than informed realisation that MMR is ‘safe’. Whether mothers go against what they perceive as professional expectation turns on issues of confidence. Personal research, accessing alternative knowledge, and engagements with other parents in MMR talk, can help build this, while MMR talk, it seems, also promotes trust in mothers’ accounts of vaccine damage, affirming solidarity.

Generalised arguments and supportive research attributing non-vaccination to the media, ignorance and misinformation, class or predisposition tend to obscure this ambiguous, processual, and particular character of parents’ histories and vaccination engagements. They obscure too, parents’ dilemmas in interpreting information perceived as politicised, and accumulated social experiences of health-related institutions. In turn, such arguments and research lead to flawed and ineffective policy prescriptions. If policy-makers and health profes-

sionals are to engage effectively with parents, then one-way information delivery needs to be replaced by dialogue that appreciates the social processes around MMR reflection. Official engagement with detailed lay theories of child health and vulnerability such as we describe, which go well beyond medically recognised contraindications, would also appear 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.

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References

- André, F. (2003). Vaccinology: past achievements, present roadblocks and future promises. *Vaccine*, 21, 593–595.
- Baker, J. P. (2003). The pertussis vaccine controversy in Great Britain, 1974–1986. *Vaccine*, 21, 4003–4010.
- Beck, U. (1992). *Risk society: towards a new modernity*. London: Sage.
- CEPT. (2004). The Chief Executive Policy Team, Research and Consultation Unit. Brighton: Brighton and Hove City Council. Available at <www.citystats.org/cityStats/>.
- Cookson, C. (2002). Benefit and risk of vaccination as seen by the general public and the media. *Vaccine*, 20, S85–S88.
- Coulter, H. (1990). *Vaccination, social violence, and criminality: the medical assault on the American brain*. Berkeley and Washington, D.C.: North Atlantic Books.
- Department of Health. (2001). MMR Pack for Health Professionals, <http://www.immunisation.uk/dhletter.html>.
- DETR. (2000). *Measuring multiple deprivation at the small area level, the indices of deprivation 2000*. London: Department of the Environment, Transport and the Regions. Available at <<http://neighbourhood.statistics.gov.uk>>.

- DeWilde, S., Carey, I., Richards, N., Hilton, S., & Cook, D. (2001). Do children who become autistic consult more often after MMR vaccination? *British Journal of General Practice*, 51, 226–227.
- Durbach, N. (2000). 'They might as well brand us': working-class resistance to compulsory vaccination in Victorian England. *Social History of Medicine*, 13, 45–62.
- Elliman, D., & Bedford, H. (2001). MMR vaccine-worries are not justified. *Archives of Disease in Children*, 85, 271–274.
- Evans, M., Stoddart, H., Condon, L., Freeman, E., Grizzell, M., & Mullen, R. (2001). Parent's perspectives on the MMR immunisation: a focus group study. *British Journal of General Practice*, 51, 904–910.
- Fitzpatrick, M. (2004). *MMR and autism: what parents need to know*. London: Routledge.
- Fombonne, E. (2001). Is there an epidemic of autism? *Pediatrics*, 107, 411–413.
- Ford, S., Schofield, T., & Hope, T. (2003). What are the ingredients for a successful evidence-based patient choice consultation? A qualitative study. *Social Science & Medicine*, 56, 589–602.
- Gabe, J., Kelleher, D., & Williams, G. (Eds.). (1994). *Challenging Medicine*. London: Routledge.
- Hargreaves, I., Lewis, J., & Spears, T. (2002). *Towards a better map: science, the public and the media*. Swindon: ESRC.
- Hobson-West, P. (2003). Understanding vaccination resistance: moving beyond risk. *Health, Risk and Society*, 5(3), 273–283.
- HPA. (2004). COVER programme: October to September 2003. Community Disease Reports CDR Weekly [Serial online] 2004 [cited 25 March]; 14(13): immunisation. Available at <<http://www.hpa.org.uk/cdr/PDFfiles/2004/cdr1304.pdf>>.
- Irwin, A., & Wynne, B. (1996). *Misunderstanding science?*. Cambridge: Cambridge University Press.
- Jefferson, T., Price, D., Demicheli, V., & Bianco, E. (2003). Unintended events following immunization with MMR: a systematic review. *Vaccine*, 21, 3954–3960.
- Leach, P. (2003). *Your baby and child*. London: Dorling Kindersley.
- Martin, E. (1994). *Flexible bodies: tracking immunity in American culture from the days of polio to the age of AIDS*. Boston: Beacon Press.
- Mattingly, C., & Garro, L. C. (Eds.). (2002). *Narrative and the cultural construction of illness and healing*. Berkeley: University of California Press.
- McTaggart, L. (Ed.). (2000). *The Vaccination Bible: the real risks they don't tell you about all the major vaccines*. London: What Doctors don't tell you Limited.
- Meszaros, J. R., Asch, D. A., Baron, J., Hershey, J. C., Kunreuther, H., & Schwartz-Buzaglo, J. (1996). Cognitive processes and the decisions of some parents to forego pertussis vaccination for their children. *Journal of Clinical Epidemiology*, 49, 697–703.
- Mills, H. M. (2002). MMR: the story so far. *Private Eye Special Report* May 2002.
- Miller, E. (2002). MMR vaccine: review of benefits and risks. *Journal of Infection*, 44, 1–6.
- Netley, F. (2002). *Holy oak: a history of Whitehawk and Manor farm 1934–1974*. Brighton: Phoenix News, Wellsbourne Centre.
- NHS. (2004). MMR: the facts. Immunisation information website, Immunisation Information, Department of Health. Available at: <<http://www.mmrthefacts.nhs.uk>>.
- NHS Executive. (1995). *Priorities and planning guidance for the NHS: 1996/97*. Leeds: NHS Executive.
- NHS Executive. (1996). *Patient partnership: building a collaborative strategy*. Leeds: NHS Executive.
- ONS. (2001). Census 2001. London: Office of National Statistics. Available at <<http://neighbourhood.statistics.gov.uk>>.
- Pareek, M., & Pattinson, H. (2000). The two-dose measles, mumps and rubella (MMR) immunisation schedule: factors affecting maternal intention to vaccinate. *British Journal of General Practice*, 50, 969–971.
- Petts, J., & Niemeyer, S. (2003). Health risk communication and amplification: learning from the MMR vaccine controversy. *Health, Risk and Society*, 6(1), 7–22.
- Porter, D., & Porter, R. (1988). The politics of prevention: anti-vaccinationism and public health in nineteenth century England. *Medical History*, 32, 231–252.
- Ramsay, M., Yarwood, J., Lewis, D., Campbell, H., & White, J. (2002). Parental confidence in measles, mumps and rubella vaccine: evidence from vaccine coverage and attitudinal surveys. *British Journal of General Practice*, 52, 912–916.
- Rogers, A., & Pilgrim, D. (1995). The risk of resistance: perspectives on the mass childhood immunisation programme. In J. Gabe (Ed.), *Medicine, health and risk: sociological approaches*. Oxford: Blackwell.
- Scheibner, V. (1993). *Vaccination: 100 years of orthodox research shows that vaccines represent a medical assault on the immune system*. London: Minerva Books.
- Science Media Centre. (2002). *MMR learning lessons*. A report on the meeting hosted by the Science Media Centre on 2nd May 2002.
- Spock, B. (1976). *Baby and child care*. New York: Pocket Books.
- Streefland, P., Chowdhury, A. M. R., & Ramos-Jimenez, P. (1999). Patterns of vaccination acceptance. *Social Science & Medicine*, 49, 1705–1716.
- Taylor, B., Miller, E., Farrington, C. P., Petropoulos, M., Favot-Mayaud, I., Li, J., et al. (1999). Autism and measles, mumps and rubella vaccine: no epidemiological evidence for a causal association. *Lancet*, 353, 2026–2029.
- Thrower, D. (2003). MMR and acquired autism (Autistic Enterocolitis)—a briefing note, Warrington. Available at: www.whale.to/a/pdf/thrower.html.
- Uhlmann, V., Martin, C.M., Shiels, O., Pilkington, L., Silva, I., Killalea, A., et al. (2002). Potential viral pathogenic mechanism for new variant inflammatory bowel disease. *Molecular Pathology*, 55(2), 84–90.
- Williams, S. J., & Calnan, M. (1996). The 'limits' of medicalization? Modern medicine and the lay populace in 'late' modernity. *Social Science & Medicine*, 42, 1609–1620.
- Wakefield, A. J., Murch, S. H., Anthony, A., Linnell, J., Casson, D. M., Malik, M., et al. (1998). Ileal-lymphoid-nodular hyperplasia, non-specific colitis and pervasive developmental disorder in children. *Lancet*, 351, 637–641.