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THE IMPACT OF 'HEALTH SCARES' ON PARENTS
INFORMATION NEEDS AND PREFERRED
INFORMATION SOURCES:
A CASE STUDY OF THE MMR VACCINE SCARE.

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ABSTRACT

Health scares are characterised by mass media reporting that generates panic about a particular health issue or intervention. Health scares may generate information needs for those who are involved. However, these information needs have been little researched and a greater understanding of the information needs associated with health scares is required. This paper describes a study that aimed to examine one specific health scare, the MMR (Measles, Mumps and Rubella) vaccination scare, its impact on parents of young children, and its effect on their need for information. Seventeen semi-structured interviews were carried out with parents in Sheffield, United Kingdom (UK). The interviews were analysed using a grounded theory methodology. Despite the homogenous nature of the sample, the study generated interesting results. The analyses revealed several categories including the one presented in this article, “Information and the MMR vaccine”. The analyses revealed that the health scare increased parents’ information needs in relation to their decision whether to have their child vaccinated with the MMR vaccine. Parents viewed traditional sources of information critically as they did not consider them to be trustworthy. Parents considered trustworthiness of the information source to be an important factor in assessing information supplied during, and as a result of, the health scare. Ongoing work in this area is investigating these issues further through a large-scale, quantitative study.

Keywords: MMR vaccine (1), Information (2), Parents (3), Health scare (4).

INTRODUCTION

Health scares are a relatively modern phenomenon and are characterised by mass media reporting that generates panic about a particular health issue or intervention. Recent examples in the United Kingdom (UK) have included the safety of the contraceptive pill and side effects of childhood vaccinations. Relatively little research has been undertaken examining the non-medical effects of health scares, and specifically the effect they have on information needs and information behaviour.

This paper reports on the first part of a study, the aim of which is to investigate the impact of health scares on parents, the effect of health scares on their information needs and the information resources that parents use to meet these needs. This part of the study used a qualitative methodology to identify the information needs of parents in relation to a specific health scare, that surrounding Measles, Mumps and Rubella (MMR) vaccination in young children. After outlining research that has already been undertaken in this area, the paper describes the methods used in this part of the study, before describing and discussing the results of the study in relation to one of the identified themes. The paper concludes by describing how this part of the study will inform the development of a larger scale quantitative study, and how between-methods triangulation will be used to analyse and interpret the qualitative and quantitative results.

BACKGROUND

In this section we discuss current knowledge and understanding of the information needs associated with health care, and in particular with the information requirements of parents of young children.

Information needs in the context of healthcare

The general public, patients, carers, health care professionals and health service managers all have needs for information and this has been recognised at a national level in the UK through the publication of the “Information for Health” White Paper (Burns, 1998), the information strategy for the UK National Health Service (NHS) from 1998 to 2005. The information needs of individuals vary according to their roles, and even within these roles there is great diversity. For example, among patients, extensive research has shown that information needs vary according to demographics, socio-economic status, type of illness or disease, stage and timing in the disease process and various psychological attributes (Gann, 1995; Coulter, 1998; Coulter et al., 1998; Leydon et al., 2000; Rees and Bath, 2000). Various scales and models have been developed and adapted from other disciplines to examine the importance and impact of information for patients, e.g. the Miller Behavioural Style Scale (Miller, 1995), Dervin’s Sense Making Methodology (Dervin, 1992), and Dixon-Woods’ models of patient education and empowerment in the context of patient information leaflets (Dixon-Woods, 2000).

In addition to patients' requiring information in relation to their illness or disease, the general public have information needs relating to healthy living, nutrition, health promotion and disease prevention, and health services (Burns, 1998). An additional group of consumers involved in health care, i.e., carers, have requirements for information above and beyond those of patients, and beyond that of being members of the general public. The research described in this paper examines the health information needs of a specific type of carer, parents of children under the age of five years old. There has been little research on the health information needs of parents of children, despite this being one of the commonest information needs within this group (Nicholas and Marden, 1998). In this paper, we examine information needs of parents in relation to childhood vaccination, and in particular the MMR vaccination scare.

Childhood vaccination in the UK

Immunisation against infectious diseases has been an important part of health promotion in the UK in the latter part of the twentieth century and the twenty-first century.

Children in the UK undertake a schedule of vaccines that include diseases such as diphtheria, tetanus and tuberculosis. Three of the diseases that are prioritised in the UK immunisation schedule are measles, mumps and rubella (MMR).

Vaccination components, which protect against measles, mumps and rubella, are combined in a live vaccine, which has been part of the vaccine schedule for children in the UK since 1988. Prior to this date, the measles vaccine was given as a separate vaccine, and mumps and rubella vaccinations were targeted at groups who were particularly at risk. However, the individual components were combined in a triple vaccine to ensure that as many people as possible were protected from the diseases, by

having a critical mass (95%) of the population immune to the diseases (herd immunity) set by the UK Department of Health (2002). In the National Health Service (NHS) in the UK, health care professionals (HCPs), usually General Practitioners (GPs), Practice Nurses or Health Visitors administer vaccinations to children and play an important role in offering advice and information to parents. The importance of their role as providers of information has been emphasised by the Department of Health targets for vaccination and concerns about the safety of the triple vaccine.

The MMR vaccine scare

The safety of the MMR vaccine was first called into question when Wakefield et al (1998) published research that suggested a possible link between the measles component of the MMR vaccine and deterioration in the health of children, which occurred shortly after vaccination with MMR. A link was made between the measles component and an autistic condition with associated bowel disorders. This research was widely reported by both the print and broadcast media. Since 1998, this alleged link has been widely researched and findings reported in the academic press. There has also been sporadic reporting by the media. Despite reassurances from official bodies in the UK such as the Medical Research Council (MRC) and the Department of Health (DOH), many parents have rejected the vaccine on safety grounds and have failed to have their children immunised. As a consequence MMR vaccination rates have shown a steady decline from 91% in 1998, to 87% in 2000/2001 and to 84% in 2001/2002 (Department of Health, 2002).

In January 2002, the MMR vaccine made headlines again as a result of suspected measles outbreaks in London and Newcastle, which were attributed to the fall in MMR vaccination rates. The reporting of these outbreaks led to a re-emergence of the debate about the safety of the MMR vaccine. It was at this point that the study was carried out.

The relatively recent nature of the MMR vaccine scare means that little research has been published on the scare generally and almost none on the impact of the scare on parent's relationship with information. Jewell (2001) examined the reasons for the reporting of medical research evolving into a health scare and found that previous scares, such as the scare that surrounded eating British beef infected with Bovine Spongiform Encephalopathy (BSE) had led to a mistrust of official information and an increased reliance on the media for information.

Pareek and Pattinson (2000) in their study of mothers of children under the age of five, found that while the mothers that they interviewed were highly influenced by the media, they did consult a wide variety of information sources with reference to the MMR vaccine. While the HCP was the most important source for information about the MMR vaccine, the media were the most important source for information about side effects of the MMR vaccine. Evans et al (2001) looked at parent's views about MMR vaccination in light of the health scare and mentioned information as a source of concern. While parents were aware that media reporting was sensationalised, official information was viewed as being insufficient to meet parents' information needs, in terms of the breadth and depth of information available. While a variety of information sources were referred to, parents reported being heavily influenced by the media, especially in situations

where they felt that there were no other information sources available. Johnson and Joynes (2001) also found that the media were the main source of information for parents as a result of distrust in official sources fostered through a number of health scares in the past. These studies suggest that there is a need for a greater understanding of the information needs of parents in relation to MMR vaccination, so that their information needs might be met more successfully. Meeting these information needs may then help parents to make informed decisions concerning whether to have their children vaccinated. The aim of this study was to identify the information needs of parents of children under the age of five in relation to MMR vaccination.

METHODOLOGY

The overall study, including the interview study is framed within a post-positivist methodology. Post-positivism seeks explanation of phenomena in order to add to knowledge. (Lincoln and Guba, 1994). Post-positivism argues that observable phenomena can be tested but they have to be supplemented with an understanding of those phenomena that cannot be measured. Post-positivism adopts a more sympathetic approach to qualitative research, arguing that it should be treated similarly to quantitative research as both seek valid truths. (Clark, 1998)

This study took an inductive approach to data analysis, in which data were collected and analysed, and then observations and theories were developed. This is in contrast to the deductive approach, in which hypotheses are developed and tested through the collection and analysis of data. Adopting an inductive approach will allow the themes

and observations from the interview study (to be discussed) to be utilised in additional research as part of the larger scale study.

METHODS

It was decided that the most appropriate study method would be semi-structured interviewing (Britten, 1995). This method was adopted in order to be able to be flexible in the approach to interviewing parents, allowing parents the freedom to expand upon their answers while adhering to a structure that allowed all the identified areas of interest to be addressed. The study commenced in February 2002 during the MMR vaccination scare that had arisen again as a result of suspected measles outbreaks in London and Newcastle mentioned previously. The empirical part of the study was commenced at this time in order to collect data while the MMR vaccination scare was in progress and many of the issues surrounding the scare were currently attracting attention among parents of young children.

A purposive sampling strategy was used to recruit parents of children under the age of five years old via community based childcare organisations (nursery schools and toddler groups) that provide childcare for children in this age group. This approach was used to ensure that the sample included parents whose children were due to be vaccinated or who had been vaccinated recently. Details of childcare organisations were obtained from the Sheffield Children's Information Service (a local service dedicated to providing parents with information regarding their children's health, welfare and upbringing) and leaders of the organisations were contacted to gain permission to attend their group. Parents in the group were given a letter and information sheet and asked to

contact the researcher if they required any additional information. Arrangements for the interviews were made either when the researcher attended the group or when the participant subsequently made contact by telephone.

Prior to the first interview in the study, pilot interviews were undertaken with two parents and the interview questions were refined following the feedback provided.

At the time of the interview, parents were asked to complete a consent form and demographic questionnaire, the data from which were analysed using Statistical Package for the Social Sciences version 10.0.

The interview data were recorded using an audio cassette recorder and were transcribed. The transcribed data were imported into ATLAS.ti, a computer program designed to facilitate qualitative data analysis using a grounded theory approach. (Strauss, 1987). The data were analysed using a code and retrieve method to develop codes and categories. These were then assembled and analysed to create the core category.

Subsequent to the interviews, parents were contacted and requested to complete an evaluation of the results of the interviews in order to check the validity of the results.

RESULTS AND DISCUSSION

The results of the study and the discussion of these results are presented in two sections. The first section examines the demographics of the study participants; the second

section presents the results of the study and sets them in context (both in terms of the available literature and in terms of the overall study).

Demographics

Seventeen parents agreed to be interviewed and the interviews lasted between 30 minutes and one and a half hours.

- **Participants**

Of the 17 participants, 16 were female (94.1%) and one was male (5.9%). All 17 of the participants (100%) were married or living with their partner. Sixteen (94.1%) of the 17 parents classed themselves as White and one (5.9%) as Other. Two (11.8%) of the participants were working full time, three (17.6%) were working part time, two (11.8%) were on maternity leave and ten (58.8%) were not currently employed. Of the 17 spouses of the people interviewed, and of the 13 for whom data were available, all (100%) were working full time. Data were not available for four of the participant's spouses.

- **Children**

The 17 parents interviewed had 29 children. In terms of age, the modal age category was 25-36 months. The mean age in months was 35.5 and the range was from six to 156 months. In relation to the MMR vaccination status of the children of the participants, 19 (65.5%) of the 29 children had been (or were going to be) vaccinated with the MMR vaccine and 10 (34.5%) of the children had not been (or were not going to be) vaccinated with the MMR vaccine.

Interviews

The analysis of the interview data generated one core category, Information and the Truth, and a number of main categories, one of which was “Information and the MMR vaccine”. The other main categories are described elsewhere (Guillaume). The category “Information and the MMR vaccine” had four sub-categories:

- Information needs of parents.
- Information sources for parents.
- Parents views about MMR vaccination and the MMR scare.
- Parents decision about MMR vaccination.

This paper presents the results for this category and the sub-categories. The results describe the information that parents needed as a result of the MMR scare, and the sources that they used to gain this information. The impact of information on parent’s decision-making is also examined.

- Information needs of parents

When faced with the MMR vaccination scare, parents expressed a desire for general information, and suggested that a large amount of information was required and that this information should be presented clearly.

... we wanted every last piece of information that they could give to us (Annie)

You can no longer tell people ‘its good for you so do it’ because people want to know, well why is it good for you? (Alison)

It would be nice to have a leaflet with clear information (Naomi)

They also expressed a need for information about very specific information about the MMR vaccine:

... why do you have to have it in a triple form ... I think that is the information that I require (Kate)

I would like to know the ingredients of the MMR jab (Susan)

Parents expressed a need for balanced information as they felt that this was difficult to obtain:

It would be nice to see a straightforward report on it rather than all this arguing (Jane)

It is confusing and conflicting. In order for it to be informative you have to sift through the information (Naomi)

Parents' desire for balanced information has been reported in a number of other studies. Brazy et al (2001) found that parents who were placed under stress by conflicting information found it harder to make decisions. Bond et al (1998) argued that a lack of balanced information was the main barrier to parents getting their children immunised. This study supports these findings and emphasises the need for an appropriate amount of balanced information that would help parental decision-making, a process which was

particularly complicated for MMR vaccination, and which was made more difficult through conflicting advice and information.

Interestingly, the study found that parents expressed a desire for information in the form of medical research:

We would like to see ... a medical study into the kind of children more likely to develop bowel problems and autism as a result of the MMR triple vaccine (Annie)

... employ a non-government body to research it and look into every single avenue and not be influenced by the government in any way (Helen)

This high level of understanding and awareness may reflect the educational and socio-economic background of the respondents in this study, but also indicates a desire for information that was independent and could be trusted.

- Information sources for parents

Parents continually came into contact with information throughout the MMR vaccine scare. Parents cited the mass media as their initial source of information about the scare. They also used information when they were making the decision about whether to proceed with vaccination and were also aware of their exposure to the ongoing media coverage of the controversy surrounding the vaccine. Exposure to media information about the MMR vaccine scare can have a real impact on parents, with consequences for vaccination rates. Mason and Donnelly (2000) found that a negative media campaign

against the MMR vaccine by a local newspaper in the UK was associated with a fall in vaccine rates of 13.6% ($p=0.05$).

In terms of parents initial source of information about the MMR vaccine scare, the mass media were frequently cited as a source of information and were considered favourably:

I think that they have got a very important role in exposing these issues (Kate)

I felt that it was great for the initial information (Jean)

Television was an information source that parents appreciated. The UK mass media produced a number of television programmes during the MMR vaccination scare in 2002 which parents found helpful:

TV is always good; I thought that debate on Trevor McDonald was really useful (Annie)

I found the Panorama programme quite good because it wasn't biased (Jean)

However, they were aware of the shortcomings of television, particularly in that presentations of the issues could be one-sided or portrayed in a particular way:

I think by its nature you are watching a programme that someone else has designed to give you that side (Helen)

... you can get information from some news programmes but it is sensational (Carol)

Newspapers were a mass media source that were also used by the parents in this study as an information source:

If I really want to start off getting a bit of background, I'd probably get a paper, a good paper and read the newspaper and get a good idea of where to go from there (Becky)

I think newspapers have quite a high influence because with newspapers I will cut the article out, read it and go back again in a couple of days and read it again (Helen)

I can take in the statistics a bit more rather than just hearing them on the TV and not being able to remember them half an hour later (Helen)

However, they were reluctant to trust information that did not come from broadsheet newspapers (which are traditionally considered to offer less biased, more factual information than the tabloid press). In this case, parents considered that broadsheet newspapers offered a more balanced coverage of the MMR vaccine scare than the tabloid press:

I think that the broadsheets would be better in that they would give a more balanced view (Rosie)

The tabloids tend to hype things up a little bit (Jane)

There is a difference between the broadsheets and the tabloids because the tabloids sensationalise the story and seem to lose the truth in it (Alison)

However, on the whole, parents were unwilling to trust the information supplied by the media, as they were considered to be untrustworthy:

I just use it as a background. I don't take it as a consensus view on anything (Becky)

The media wants to make money and therefore the stories are sensationalised (Naomi)

Evans et al (2001) also found that parents considered the media to be untrustworthy. However parents felt coerced into using the media as an information source because other sources were seen to be equally untrustworthy.

Despite this lack of trust in the media, parents felt that they were able to judge the media information and choose which information they accepted and that which they rejected:

... to be perfectly honest, the scare mongering in the press, I don't take any notice, or far less than the statistics (Heather)

I will assess the source before I would incorporate any information that I am given into my body of information (Lisa)

I think that I would probably judge it on whether it is sensational or a publicised scientific article (Heather)

Therefore, although the parents in this study regarded and used the media as a source of information, they appeared to be aware of the media's limitations; they were particularly sceptical about certain media types and developed their own criteria for judging the suitability of the information. When following up the initial media information that they received, parents turned to more traditional health information sources, namely the leaflet and the health care professional.

Numerous leaflets have been produced for parents about the MMR vaccine by official UK bodies, such as the Health Education Authority (HEA) and the Department of Health (DoH). However, parents viewed the leaflets that they received as being insufficient to meet their information needs:

... they gave us a leaflet, the gen that the Health Education Authority wants you to know which doesn't really tell you a great deal (Carol)

... it was a little leaflet and it didn't tell me anything that I needed to know (Sally)

Lieu et al (1994) found that parents did not consider Vaccine Information Pamphlets (VIPs) useful and a proportion of the parents interviewed actually found that VIPs increased their worries about vaccination. Parents in this study frequently mentioned the lack of useful information in VIPs.

Parents had a complex relationship with HCPs and therefore had complex views of HCPs as information providers. Some parents were supplied with useful information by their HCPs:

... the GP made available, he has like a file of recent publications and medical journals that he allowed us to take away and read (Alison)

The health visitor and the people in the hospital either gave me leaflets or (I) talked about particular issues with the doctor (Carol)

These results also suggest that different health care professionals were used as an information source, although other parents found the HCP an insufficient information provider:

...a lot of health professionals don't have any information (Becky)

It would be very nice if the health visitors were up to speed because I don't think that a lot of them are (Heather)

Parents found the HCP important in terms of the support role that they fulfilled:

The doctor gave it to her and she had for her own children and she was quite adamant that it was quite important (Susan)

I think we could have made the decision either way and it wouldn't have affected the relationship (Alison)

The doctor is fantastic; I am really lucky that we have got a good doctor (Mary)

For the parents interviewed in this study, the key issue was not whether they were supplied with information that they needed, but whether they believed the information that was supplied to them and whether they trusted the source of that information:

Health care professionals do what they are told to. They spew out the standard line and are not free thinking (Naomi)

Parents were unwilling to trust HCPs for the following reasons: that HCPs were pro-MMR vaccination and unwilling to discuss alternatives with parents and also that HCPs were also viewed as being unduly influenced by the government:

All the information that you get from the surgery and from the health visitors is quite biased because they support the MMR (Jean)

... they weren't even willing to discuss an alternative point of view and they just said, 'no it is perfectly safe' (Mary)

I just feel like their hands are tied and they cant say anything to you because they are supposed to give the standard line so they cant really tell you what they feel if they've got doubts (Becky)

I think that they should be able to make their own decision (Helen)

This mistrust of HCPs as an information source was also reflected in parents' mistrust of the government. Parents felt that the government were hiding the truth from them, either deliberately or through not providing in depth information:

I haven't seen any government programme saying this is what we have actually done, which to me means that they have got something to hide if they are not willing to tell everybody what they have done (Helen)

I am very sceptical about what the government say, mainly because they talk about why it is good but I haven't heard any of them talk in depth about the sincerely held concerns that these people really do believe that their children have been harmed by it (Carol)

Parents attributed the UK government's support of the MMR vaccine as being associated with the fact that it is cheaper for the government to combine the measles, mumps and rubella vaccine than to give the components as single vaccines of measles, mumps and rubella:

I think that it is because it is cheaper and you only have to give it to individuals once (Kate)

Because it saves them money. They are just economic reasons and are related to drugs companies (Naomi)

I think because in the long run it costs them less money (Mary)

Parents were sceptical of the government as a result of the scare that surrounded eating beef that had been infected with Bovine Spongiform Encephalopathy (BSE). The UK government's handling of this health issue had alarmed parents:

I think that it has been quite influential in me being cynical about certain government ministers saying this [MMR] is fine (Carol)

It been similar for things like BSE, they've said a particular thing and you know over a five to ten year period its come out that there are problems and perhaps their advice hasn't been the best thing so that's made me sceptical (Becky)

... you would have though that mad cow disease, railway disasters would teach us better (Mike)

Jewell (2001) proposed that previous health scares surrounding BSE and the contraceptive pill were a major cause of the MMR vaccination scare in terms of how they reflected upon the perceived trustworthiness of the government.

Parent's scepticism of the government was enhanced by the refusal of the UK Prime Minister, Tony Blair, to disclose to the public whether his young son, Leo (who was born in 2000), had been given the MMR vaccine:

I think that Tony Blair should have come out and said whether or not his little boy had had the jab. I think that it is important because what the public needed was a show of confidence (Rosie)

... people really do need to know, if he is telling us that it is safe, he means that it is safe for his children as well (Alison)

If he is going to stand up there and say that 'this is what I think' then I think that he should back it up with proper evidence and he should say yes or no (Mary)

These results show how parents look to leaders and politicians not only as an example, but also with expectations that they should share personal and confidential information to support government policy.

- Parents views about MMR vaccination and the MMR scare

Most of the parents in this study supported the MMR vaccine and made the decision to proceed with the vaccine. This support was for a variety of reasons. A number of the parents interviewed had accessed the research undertaken by Wakefield et al (1998) that cast doubt on the safety of the vaccine and based their support for the vaccine on their rejection of the validity of the Wakefield et al (1998) study:

... there were one or two reported studies, one team I think which reported a potential link with autism and Crohn's disease, that wasn't substantiated by any other studies. (Becky)

I have read that research paper. I don't think that it was a particularly good piece of research, tiny sample, relatively low incidence... (Kate)

...it came from one study that wasn't a statistically good study because it was looking after the event and it wasn't a controlled study (Heather)

This again reflects the relatively high intelligence and knowledge demonstrated by the sample interviewed for the study. Support for the vaccine was influenced by information that parents had received from other sources that supported the vaccine. Support was also based on the length of time that the vaccine had been used worldwide:

I know it's used worldwide with very few problems (Becky)

... it is used in many many countries and it has been for many many years (Alison)

Parents also accepted the argument in favour of the vaccine as proposed by supporters of the vaccine, i.e., that the development of autism and vaccination with the MMR could not be linked causally, but was coincidental:

I cant help thinking that some of it is because of the fact that autism develops at the time that they have the vaccine (Jane)

... autism becomes evident at the time you get the MMR so to say that it is causal is pretty poor (Lisa)

Some parents are associating it with autism, but autism coincides with the timing of the MMR (Naomi)

Opposition to the MMR vaccine was more complex and encompassed a variety of views, not all of which were influenced by information. The negative publicity that the MMR vaccine received had clearly influenced parents, but parents' views on the severity of the conditions of measles, mumps and rubella also shaped their response to the vaccine.

Parents were wary of the vaccine because of the length of time that it had been used in England, as discussed previously:

I just don't think that it is long enough and withstanding enough for everyone to say that it is safe (Annie)

...while with whooping cough, diphtheria and tetanus they have been time tested, it doesn't seem like the MMR has been time tested (Sally)

Parents also felt that the research that had been undertaken by Wakefield et al (1998) required greater consideration:

... everyone was just writing stuff that discredited Dr Wakefield rather than investigating what he said (Annie)

I know that the research that Andrew Wakefield has done and his findings. I know that it is not categorically proven but to me there is enough evidence to be questioned (Helen)

Parents also had a number of more specific concerns about the MMR vaccine, some of which were unmet information needs:

... it is a triple vaccine so it's quite powerful and quite a lot for a child to deal with (Susan)

... why should you have them all together, what is the benefit of having them all together?

(Kate)

Given that information leaflets on MMR vaccination are made available to parents, and that HCPs act as information providers to parents, it is perhaps surprising that not all information needs are being met. A possible explanation for this might be that these information sources may be being provided to try and change the behaviour of parents, i.e., to encourage non-immunisers to have their children vaccinated, rather than because they have been prepared with the intention of meeting the parents' information needs and answering their concerns, and therefore avoiding particular issues. Dixon Woods (2001) discussed the problems of presenting information in order to achieve patient compliance in the patient education model, and proposed that information should instead be used to empower patients and help them make informed decisions.

- Parents' decision about MMR vaccination

In terms of the decision about whether to proceed with the MMR vaccination, some parents had had their child vaccinated, some parents had not or did not intend to proceed with having their child vaccinated, and some parents had had one child but not all of their children vaccinated. Parents who made the decision to proceed with the MMR

vaccine were not certain that they had made the correct decision, although they did not express a need for more information to confirm their decision:

... although I am doing MMR I am not 100% convinced because the scare has affected you

(Lisa)

I think I probably went along with slightly more head than heart thinking I suppose that is ok

(Kate)

Comments made by parents in the study may reflect monitoring and blunting behaviour as described by Miller (1995), in which individuals actively seek information (monitoring) or avoid it (blunting). When faced with the decision about MMR vaccination some parents sought as much information as possible (in some cases delaying the decision until all information had been reviewed) whereas others made a choice and then tried to limit the extent to which they were subsequently influenced by information. These two behaviours could be attributed to monitoring and blunting although further research would need to be undertaken to examine this further within this population.

The parents who decided not to proceed with MMR vaccine showed evidence of having been influenced by the media coverage of the MMR vaccine scare:

It was a programme ... saying that the research that they have done so far said that the links to the MMR and bowel disease and autism were higher in children that had a family history of arthritis, diabetes,[and] children who are on long term antibiotics (Helen)

... we decided that we wouldn't give it to our son ... because of his allergies (Annie)

Some parents stated that information was integral to their decision:

You can make informed decisions about the MMR (Mike)

I went on the Internet... it was an educated decision rather than off the top of our head (Sharon)

My daughter had it later because it took me two months to decide you know, two months to read and make a decision (Becky)

...when I read that research I thought 'fine'. There is no causal link between autism and Crohn's disease (Lisa)

The GP made available, he has like a file of recent publications and medical journals that he allowed us to take away (Alison)

This also suggests that the parents used a variety of sources for information and did not rely solely on HCPs. In contrast, other parents did not use information as much when they were making their decision:

I didn't do a lot to seek out information although it is something terribly important (Carol)

I think that before we started it we were on the side of not having it really. So I suppose information didn't make us change our mind (Mary)

I had decided before they gave me the information about it (Sally)

These responses suggest that information from HCPs and from information leaflets may be little valued by some parents, particularly non-immunisers. This may be due to parents' reluctance to change their minds, but again may reflect the quality of the information provided and the motives behind the development of this information as discussed earlier.

VALIDITY AND LIMITATIONS OF THE STUDY

Validity

Of the 17 participants in the study, nine returned the evaluation sheet distributed to them, giving a response rate of 53%. All nine of the respondents thought that the results contained elements of the interview that they had participated in and that the results were an accurate representation of the interview. Participant's comments regarding the study (which have been anonymised) are as follows:

... it makes for interesting reading, notably that parents felt influenced by the BSE scare.

This issue seems to have fallen off the agenda at the moment. However, I don't feel that any attempt to provide more and better information has or is being made. I hope your research will help to change this.

However, one parent felt that their GP's offer to provide them with research papers about the MMR vaccine should have been mentioned. During the interview this parent mentioned that this was a major influence on their decision to proceed with the MMR vaccine:

No reference to helpful information provided by GP, which informed our decision.

Limitations

The main limitations of this study were the relatively small sample size and the limited range of backgrounds from which the participants were drawn. Although the results of qualitative research are not intended to be generalised to the wider population, nonetheless we acknowledge that the results may reflect the background of these respondents. The majority of participants that took part in the interview study demonstrated prior knowledge about the research surrounding the MMR vaccine. Some of the participants interviewed supported the MMR vaccine on the basis that the research carried out by Wakefield et al (1998) was flawed. This high level of understanding about the issue of the MMR vaccine and the MMR scare may have influenced the results collected. It is important to understand the reasons for this high level of understanding and whether it can be related to the participants' use of information. One suggestion is that it can be related to the (high) social class and possible educational background of the participants in this study. It is possible that the participants' backgrounds affected their attitudes and responses to the questions. These issues will be further investigated in the second phase of the research.

In this study, the group of participants interviewed was relatively homogeneous. All but one of the participants was female, all were white (one participant was mixed race) and the majority lived in relatively affluent areas of Sheffield (S10 and S11). This may well have introduced a bias into the data collected. The second phase of the research will involve a large-scale quantitative study and will attempt to examine if any of these socio-demographic factors influence how parents use information in this context. The second phase of the research will utilise quantitative methods and adopt a stratified sampling method to ensure heterogeneity within the sample.

The interviews were conducted during the MMR vaccination scare that had arisen in January 2002. Although data collection was commenced deliberately at this time when the issues surrounding the scare were currently attracting attention, it may have influenced the responses of parents, and in particular their comments regarding the media. However, it was felt that the advantages gained in overcoming the common problem of recall bias when data are collected retrospectively more than compensated for this limitation.

Although the main focus of the research, i.e., the health scare, was current, the decision-making experience of parents may not have been current and therefore may have been subject to recall bias. However, the next stage of the research may overcome this by recruiting only those parents who are currently facing the decision of whether or not to vaccinate their child.

Another factor that may influence the results was the response rate to the recruitment. The overall response rates for the study were low (nursery schools 6.3% and toddler groups 21.3%). This may suggest that the parents who volunteered to participate in the study were those who felt very strongly about the MMR vaccine, or those who were interested in the issue. This can introduce bias into the results, but the larger quantitative study will allow an understanding of whether the views expressed by the participants in this study are reflected in a wider sample. Triangulation of the qualitative and quantitative results will then permit the results of this part of the study to be confirmed or otherwise. Despite the limitations of the study described previously, a number of conclusions can be drawn from this study.

CONCLUSIONS

This study was an exploratory examination of an area in which little previous research has been undertaken. While the results were exploratory, a number of interesting issues have emerged, which will be explored further in the second phase of the study.

The MMR scare and information were interwoven issues as far as parents were concerned. Initial information about the MMR vaccine scare was received from the mass media. Parents appreciated the immediacy of information from the media, but were critical of it, believing that value judgements about the trustworthiness of information needed to be made before they accepted the information. When faced with the scare, parents expressed a need for information about various different aspects of the MMR vaccine. These needs tended to be unmet. Parents on the whole rejected traditional sources of information such as HCPs. This was not due to their information

being insufficient but on the basis that their information was biased and could never be independent of the government. The parents were critical of the government, whom they viewed as supporting the MMR vaccine for economic reasons alone and whom they viewed as being dogmatic in their response to parents concerns. The BSE scare and the reluctance of Tony Blair to reveal whether his son had been vaccinated with the MMR vaccine only sought to enhance parents mistrust of the government.

Within healthcare in the UK, vaccination of children against measles, mumps and rubella is regarded as essential in reducing the incidence and prevalence of these diseases. This study has shown that information can have a part to play in encouraging parents to have their children vaccinated. However, parents need to trust the information source if they are to believe the information they are supplied with and information providers should consider the needs of parents for information, rather than developing information to change behaviour. This is the challenge that the government, health service providers and HCPs face, i.e., that information alone is not sufficient and that parents must believe that the information they are receiving is the truth.

Future research

This research has raised a number of issues that warrant further research. The next phase of the research will consist of a questionnaire that will employ stratified sampling to gain a wider socio-economic sample. The questionnaire will be based around the Health Belief Model (Rosenstock et al 1988). The model examines the individuals' motivation to undertake preventative health behaviour and is based around four

constructs (perceived severity, perceived susceptibility, perceived benefits and perceived barriers) that measure the individuals' perceptions of the disease that the preventative behaviour protects against and the individual's perceptions of the protective behaviour. The four main constructs of the model will be tested to see if there is a relationship between information, parents response to the MMR vaccination scare and parents subsequent choice about whether to proceed with vaccination. Evidence for the applicability of the HBM in this research can be seen in the following comments, which reflect perceived severity, perceived susceptibility, perceived benefits and perceived barriers respectively.

I know that it is very serious, it is spots, fever, can be fatal and can cause brain damage or other disabilities (Severity) (Sally)

If people don't let their children have it then there will be a surge in measles, mumps and rubella (Susceptibility) (Lisa)

I would rather know that my boys are safe and vaccinated and that I am not putting them and other people at risk (Benefits) (Sharon)

Part of being a parent and thinking that they are going to need vaccinations is thinking 'oh my god they are going to have needles stuck in them' (Barriers) (Mike)

Following on from the questionnaire research, the results will be triangulated with the interview study results, for confirmation and completeness, to gain a deeper understanding of this important area.

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