

**Understanding Parent's Information
Needs and Experiences Where
Professional Concerns Regarding
Non-accidental Injury Were Not
Substantiated**

RESEARCH REPORT

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Science and Research Department**

CONTENTS

Acknowledgements	6
Executive summary	7
1. Introduction	11
2. Background to the study	12
3. Project aims and objectives	14
4. Literature review	15
4.1 Medical investigations into NAI.....	15
4.2 Communicating medical concerns.....	16
4.3 Parents' experiences of child protection proceedings	17
5. Research methodology	18
5.1 Phase 1: Preparatory phase	18
5.2 Study title and inclusion criteria	19
5.3 Eventual inclusion criteria	20
5.4 Ethical approval	21
5.5 Rationale for sampling	22
5.6 Interview method	22
5.7 Data analysis process.....	24
6. Results	25
6.1 Demographics.....	25
6.2 Interview findings	25
6.2.1 Health professionals' communication style and content	26
6.2.2 Information needs	28
6.2.3 Response to communication of concern.....	30
6.2.4 Concerns regarding the child's medical care	32
7. Discussion	34
7.1 The research process	34
7.2 Communication.....	35
7.3 Contexts.....	36
7.4 Other concerns and follow-up support.....	36

8. Conclusions	37
9 Principles to inform practice	39
References	40
Appendix 1: Membership of the Project Steering Group	44
Appendix 2: Interview schedule.....	45

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Executive summary

Current difficulties facing paediatricians working in child protection are well documented. One of the areas that can be particularly difficult for health professionals is determining whether or not a presenting sign is a non-accidental injury (NAI). Some accidental injuries may at first appear to be deliberately inflicted, and there a number of medical disorders that can masquerade as child abuse (Hall, 2003). Situations of this kind are distressing for all concerned.

In recent years, the RCPCH has had a strategy to support paediatricians in this area, which has included development of evidence-based guidelines and child protection training materials, incorporating communication skills training. There has also been a parallel research agenda. A survey of RCPCH members in 2004 established that the number of complaints about child protection was rising (RCPCH, 2004). The survey was followed by qualitative research which explored the circumstances around complaints against paediatricians in relation to child protection (Haines and Turton, 2008; Turton and Haines, 2007). This study established that communication was an area that triggered complaints and highlighted the need to explore the parental perspective in subsequent research. A qualitative project was therefore undertaken with parents and carers, exploring communication when concerns about a possible NAI are first raised. This report presents the findings of this research.

The research was carried out over 20 months. Ten pilot interviews and 12 formal interviews were conducted with consenting parents/carers in 2007 and early 2008. Participants were recruited through a number of parents' support groups and 21 NHS Trusts across the UK. A narrative interview method was adopted for this sensitive topic to allow participants to express themselves in their own words, with additional probing to address particular paediatric training in communication and public information needs. Interviews were recorded, transcribed, anonymised and analysed with NVIVO software.

The study identified a range of communication-specific and other concerns that parents/carers have in these situations. The report presents verbatim quotes (from the interviews) to illustrate these concerns and locates participants' accounts in wider contexts.

Reflections on the research process illustrate the complex and contextual nature of child protection practice. Indeed the study required professionals and participants to trust the study aims and participants to relive a distressing occasion. It is suggested that further work is therefore required to establish a constructive dialogue between paediatricians and parents/carers in relation to child protection. In addition, the messages emerging from the research may be relevant for all members of child protection teams and applicable to situations whether or not concerns of NAI are substantiated.

Findings

Circumstances where professional concerns of non-accidental injury (NAI) may be raised

Concerns of NAI may be raised in a variety of circumstances. The interviews included situations where concerns were first raised by professionals at hospitals (mainly in A&E departments) or schools. In most cases the concerns were articulated to parents/carers by consultant paediatricians. The cases featured unusual/multiple fractures, bruising, a burn and concerns of possible fabricated or induced illness (FII).

Communication style and content

Most participants preferred open and honest face-to-face communication regarding what was going to happen as a result of the child protection enquiries and particularly about the child's medical care. Many reported feeling they had been treated less courteously as soon as concerns of NAI were raised: the *'interaction changed'* and participants felt they were *'getting the looks'* from hospital staff. Participants were dissatisfied when their concerns and explanations were not listened to or when not enough time was allowed for communication. Participants were particularly dissatisfied where concerns of NAI were raised in a public place.

Information needs

Participants wanted to know which agencies are involved in the investigations, the timescale of events and who else (such as the child's school or other family members) would be involved. Thorough explanations of what child protection medicals involve were preferred. The findings were not conclusive about the value of written information leaflets. The majority of participants, however, stressed the importance of spoken information early on in the process.

Participants also expected clear communication, preferably in writing, that their case was closed. Some parents were still anxious at the time of the interviews (in some cases years after the event) as they were uncertain whether or not they were *'still being monitored'*.

Response to communication of concern

Many participants stated that being subject to child protection investigations - no matter for how short period of time – left them distressed and had a long-lasting effect on the whole family. Feelings of disappointment with the 'system' were expressed, as well as anxieties about future contacts with health professionals.

By the time the interviews took place, participants had had an opportunity to reflect upon the events with the benefit of the hindsight. Many participants expressed an awareness of media reports of child protection cases where it had '*gone wrong*', which contributed to their anxieties at the time of the incident.

Recommendations

The study identified a number of key principles that may help health professionals communicate sensitively with parents when there are child protection concerns:

- Many parents who find themselves in this situation will have brought their child to see a health professional because they are concerned about their child's well-being. It is important that parents are kept informed about the child's medical care throughout any investigations as these concerns and worries remain.
- Parents prefer honest, clear and early communication on what a child protection enquiry means; what referral to social services or the police means; whether emergency proceedings are taking place; what the child protection medical examination involves; how long the child has to stay in the hospital; what different tests involve; whether further tests are needed; and how long it will take to receive test results.
- It is important that parents are treated in a non-judgemental way by all members of the professional team while the investigations are ongoing. Parents in these circumstances can feel vulnerable and particularly sensitive to the way things are phrased and how they perceive individual staff reactions.
- Parents understand the professional duty to investigate further if there are concerns. Sensitively explaining to parents that there is a protocol the professional has to follow and clearly outlining the process may help parents to accept and understand the situation.
- For many parents the realisation that there are concerns their child's injuries may have been deliberately caused comes as a shock. It is important to understand the range of emotions that may or may not surface, listen to parents' concerns, answer their questions and give them time.
- Where possible confidential discussions with the family about child protection investigations should be held in private, bearing in mind the potential impact on other members of the family, including siblings.
- It is important that parents have understood what is being explained to them, especially when using terminology they may not be familiar with, such as NAI.
- When all investigations are complete, parents need to be informed about the outcome and whether or not there is a permanent record of the concerns.

1. Introduction

The responsibilities of paediatricians in relation to the recognition of child abuse have been clearly outlined in the UK Government guidance “Working Together to Safeguard Children” published in 2006. The document acknowledges that these responsibilities place paediatricians in difficult diagnostic situations and highlights the need for a sensitive approach:

“Consultant paediatricians in particular may be involved in difficult diagnostic situations, differentiating those where abnormalities may have been caused by abuse from those which have a medical cause. In their contact with children and families they should be sensitive to clues suggesting the need for additional support or inquiries” (Working Together to Safeguard Children, 2006, p.25).

This report presents the findings of a research project, which explores how health professionals communicated their concerns to parents when in such a difficult diagnostic situation. It draws on a small-scale exploratory qualitative study with parents who had been in this situation and aims to inform how health professionals communicate with families when there are concerns about possible non-accidental injury (NAI). Building on existing research and knowledge, the parents’ accounts of their experiences are analysed in light of current child protection policy, with some key principles for how communication may be improved identified.

2. Background to the study

The idea for the project emerged directly from the findings of a previous qualitative study with consultant paediatricians who had been the subject of a complaint in relation to a child protection issue (Haines and Turton, 2008, Turton and Haines, 2007). This research suggested that difficulties arising from the ambiguity of medical evidence and communicating concerns to families were specific areas likely to trigger parents/carers to make a complaint against the paediatrician.

The impetus for the new project was to understand how parents receive communication of concerns about possible NAI, how they would like concerns to be relayed, and how this could help to inform doctors training and ultimately reduce the number of complaints. The study was therefore designed to explore what it is like to be at the receiving end of professional decisions and actions (Baistow & Hetherington, 1998), and what information needs parents may have regarding child protection proceedings taking place in health settings.

Previous research in parental evaluations of child protection proceedings has predominantly focused on the role of social work and on families where there have been ongoing concerns for the welfare of children. This is the first study to our knowledge which explores parents' views of communication of concerns about NAI by health professionals.

The project focused on situations where professional concerns of NAI were unsubstantiated as this may have serious consequences for children and families as well as for paediatricians. There are a number of circumstances in which injuries may appear suspicious to health professionals and child protection enquiries initiated. These include: bruising in anatomical areas rarely bruised accidentally at any age, certain fractures (multiple, rib, femoral, spinal, metaphyseal and skull) particularly in the young child or burns and scalds (Royal College of Paediatrics and Child Health, 2006). There are also rare conditions, for example, osteogenesis imperfecta or Ehlers-Danlos syndrome, which can masquerade as NAI. Although child maltreatment due to abuse and neglect is considered pervasive within our society (Royal College of General Practitioners, 2003), it is estimated that approximately 7% of children whose signs indicate abuse actually have an underlying medical condition causing their injuries (Wardinsky et al, 1995).

The project was funded by the Department for Children, Schools and Families and the Department of Health as part of their Safeguarding Children 2005 Research Initiative. It forms part of an ongoing programme of work at the Royal College of Paediatrics and Child Health (RCPCH) in the area of child protection. This includes: developing training materials (Shabde, 2006); good practice guidance (Royal College of Paediatrics and Child Health, 2003); guidance on radiological

investigations when child abuse is suspected (Royal College of Radiologists / RCPCH, 2008); and, funding systematic reviews of evidence of physical signs of child abuse.

A broad definition of 'communication' was adopted for the study to include face-to-face encounters between health professionals and parents as well as the availability of information (written or oral) for parents about child protection processes. Although the focus of the project was on health settings, the findings are expected to provide insights for all members of multi-disciplinary teams working in child protection.

3. Project aims and objectives

The aims of the project, which was undertaken in 2006-2008 over 20 months, were to:

- explore parents experiences of situations where concerns of non-accidental injury were raised, with a particular focus on communication processes;
- generate data on parents' experiences and set these in context regarding, for example, professional duties and public discourses on child protection;
- identify any information that participants wished to receive;
- describe how participants remembered and reflected on their experiences;
- increase the awareness of paediatricians and other health professionals of what is perceived as helpful and less helpful practice from the parents' perspective; and,
- make suggestions for paediatric training to improve communication.

4. Literature review

At the start of the project a review of the literature was undertaken in order to set the project in context and to inform the study methodology. The review aimed to establish what was already known about communicating professional concerns of abuse, parent/patient information needs when NAI concerns were raised and parents' perceptions of child protection proceedings focussing on the role of the medical professional. The review was informed by:

- a literature search on Pubmed including the following terms as key words: Child protection, child abuse, non-accidental injury, physical injuries in children, clinical communication; and
- a search of the reference lists of key papers (such as Cleaver & Freeman, 1995) within the social science and medical literature on parents' views on child protection proceedings, communication in health settings and qualitative research (in particular narrative and sensitive research).

The key points arising from the review are discussed below under broad headings. These were informed by information gathered in the preparatory phase of the project.

4.1 Medical investigations into NAI

It was important to understand how and where cases of possible NAI present to health professionals, and the role of the health professional when a concern is raised. It is clear that child welfare professionals have a legal and moral duty to investigate any case that causes them concern. Section 47 of the Children Act 1989 in England and Wales; Children (Scotland) Act, 1995 and Children (Northern Ireland) Order, 1995) requires that if there are suspicions of harm the local authority makes enquiries to enable it to decide whether action should be taken.

Guidance in *Working Together* (2006) specifies that the enquiries:

- should always be carried out in such a way as to minimise distress to the child, and to ensure that families are treated sensitively and with respect;
- should be conducted in a way that allows for future constructive working relationships with families; and,
- when child protection enquiries involve a case conference, the purpose of a conference, who will attend, and the way in which it will operate should always be explained to a child of sufficient age and understanding, and to the parents and involved family members beforehand (pp 93-98).

Barber and Sibert (2000) emphasise that the purpose of the child protection medical examination is to make a diagnosis of definite or possible abuse. Decisions about further action are jointly made with social services, the courts and the police.

4.2 Communicating medical concerns

Research shows that communicating any medical concerns can be challenging. Tensions may arise for both parents and doctors if greater sharing of knowledge is accompanied by difficulties in tolerating and sharing uncertainty. For example, although parents may complain that they receive too little or conflicting information, doctors may be wary of giving information that may cause anxiety. Studies on communicating with parents whose children are acutely ill or where a disability has been diagnosed have shown that people differ in their style of coping, and some may wish to be informed more than others (Kai, 1996; Fallowfield & Jenkins, 2004).

McLaughlin (2005) has suggested that health service user dissatisfaction regarding diagnoses have a number of causes which include lack of information and guidance about the diagnosis. A number of research studies on parents' information needs suggest that greater recognition of parents' difficulties when their child has a diagnosis of acute illness may help to reduce potential disharmony between parents and doctors (Kai, 1996). In the context of giving bad, sad and difficult news (Fallowfield & Jenkins, 2004), it has been suggested that doctors frequently censor information they give to patients about outlook on the grounds that what someone does not know cannot harm them. Nevertheless such traditional paternalistic attitudes may be at odds with contemporary demands for increased autonomy and empowerment for patients (Barnett, 2002; Sharp et al, 1992).

Communicating concerns of NAI poses additional challenges to paediatricians (Haines & Turton, 2008). In a recent article about the difficulties of child protection work in the current climate, Payne (2008) expressed the view that, however calmly and impartially concerns are expressed to parents, with great care and attention paid to the choice of words, the parents' response is inevitably that they are accused of abusing their child. Comments of one paediatrician received during the preparatory phase of the study also illustrate how the assessment process can make it difficult to know how and when to communicate concerns to parents:

Children are usually seen by Junior Doctors (not in paediatrics), e.g. A&E, Orthopaedics or General Practice. Whilst it is good practice to keep parent informed of the doctors' thoughts, usually these [cases] are referred to the paediatric team for further tests. My experience is that these doctors don't mention possible diagnosis of NAI. The pretext on arrival therefore can be variable 'tests for bruises', 'needs more tests'. "The Registrar would see all NAI that are referred with that possible diagnosis [...] Depending on level

of experience or confidence the registrar would inform parent of diagnosis at that point or discuss with the Consultant. The consultant may then come and review and confirm thought of NAI at that point. Communication is an issue at this point. Parents have seen possibly 3 doctors who have said nothing re NAI and now a consultant suggests possible diagnosis. However a number of consultants don't feel confident and may wait for further more confirmatory tests before telling the parents (paraphrased from e-mail).

4.3 Parents' experiences of child protection proceedings

The literature review identified relatively few studies on the experiences of parents who have been subject to child protection interventions. What research there has been has tended to focus on the role of social work and liaison with other child protection agencies where professional concerns of child abuse have been substantiated (Baginsky, 2007; Dale et al, 2005; Cleaver & Freeman, 1995). However, some of the findings of this research may also be relevant to the health care settings.

Dale et al (2005) suggest that there is a strong tendency for parents to be highly critical of the process and outcomes of child protection interventions. Two consistent complaints are: 1) the child protection system is arbitrary and opaque; and, 2) families feel that they are treated unfairly. In the context of social work, they found that participants valued professionals who were supportive, listened carefully and effectively, had skills in promoting cooperation, were 'matter of fact', and human. Research (Cleaver et al 1998) on social services roles in child protection also highlighted that professionals presume that when they have explained something as clearly as they can, the other person will have understood it. In their study of parental perspectives in cases of suspected child abuse, Cleaver & Freeman (1995) highlighted the crucial nature of communication:

It is not so much the type of abuse that affects congruence between parental perspectives and those of professionals, but more the context in which suspicion is aroused, who makes the accusation, who handles subsequent investigations and how professionals manage their role (p.138.)

In conclusion, the literature review suggests that breaking difficult news in both general and child protection-specific contexts is challenging. It also reflects the complexity of child protection practice.

5. Research methodology

The research was overseen by a multi-disciplinary steering group consisting of child protection professionals, project funders and parents' representatives (Appendix 1 for membership). The group met regularly throughout the project and provided a forum for discussion of progress and project issues as they emerged.

The project was rolled out in three overlapping phases over a 20 month period from August 2006 to April 2008. The three phases were:

Preparatory phase including a literature review

Data collection (interviews)

Analysis and write up

5.1 Phase 1: Preparatory phase

From the outset it was recognised that contacting parents would be a challenge; in the RCPCH study into child protection complaints, the researchers had also wanted to include parental views. Clinical directors (or the chief executives) of 40 NHS Trusts were asked to help contact parents who had complained about a paediatrician. Of the 16 Trusts that responded to the request, none was able or willing to help (Turton & Haines, 2007).

An extensive preparatory phase in the current project was therefore considered essential. The aim of this phase was to:

- explore options for identifying and recruiting the research participants;
- define the group of parents/carers we wanted to interview;
- establish links with relevant parent support groups with a view to potential collaboration;
- gain an in-depth understanding of the ways in which children with injuries that might be non-accidental present to health professionals;
- seek advice from Named & Designated paediatricians UK-wide;
- seek advice and possible collaboration from other relevant professional groups such as Social Services and those working in nurseries;
- refine the original research methodology; and
- gain ethical approval for the project.

During this phase the interviewer also attended a number of child protection meetings, seminars and conferences in order to gain an overview of current developments in child protection work and training in the UK, including multidisciplinary approaches and different types of abuse, to complement the literature review.

5.2 Study title and inclusion criteria

There was considerable discussion during the preparatory phase about the study title and the inclusion criteria. This was important as the title of the study needed to accurately describe the precise group of parents we wished to interview. Furthermore, the title would appear on all study documentation including that sent to parents.

Originally the intention of the project was to capture communication issues in situations featuring ‘true negatives’ and ‘false positives’ as defined by Dale et al (2005) in Table 1.

<p>True positive</p> <ul style="list-style-type: none"> • Abuse is detected • Risk is real • Child is protected 	<p>True negative</p> <ul style="list-style-type: none"> • No abuse • Risk is appropriately discounted • Enquiry is sensitive and proportionate
<p>False positive</p> <ul style="list-style-type: none"> • No abuse • Risk is overestimated • Interventions are inappropriate and disproportionate • Family is harmed by inappropriate child protection interventions 	<p>False negative</p> <ul style="list-style-type: none"> • Abuse is undetected • Risk is underestimated • Interventions are absent/ inadequate • Child is re-injured in context of inadequate child protection interventions

Table 1: Desirable and undesirable outcomes of child protection interventions (reproduced from Dale et al, 2005, p.11)

Hence the study title in the protocol originally submitted to the funders was: ‘*Understanding parents’ information needs when abuse is suspected*’. However, as a result of discussions within the project steering group, the title was lengthened to: ‘*Understanding parents’ experiences of situations where non-accidental injury was suspected but later disproved or not proved*’. Wider consultation concluded that this too was unsatisfactory as the words ‘suspected’, ‘disproved’ and ‘not proved’ were too negative. The final version agreed by the steering group, used vocabulary similar to that in ‘*Working Together*’ (2006) and was: ‘*Understanding parents’ information needs and experiences where professional concerns regarding non-accidental injury were not substantiated*’ although some felt that ‘deliberate’ or ‘unexplained’ was preferable to ‘non-accidental’.

There was also considerable discussion during this phase over what was meant by “unsubstantiated” or “not substantiated”. It was clear some health professionals challenged the concept of ‘false positives’ because of the complex and difficult nature of this area. One professional wrote:

There is a need to be clear that ‘unsubstantiated’ does not mean ‘no abuse’. Are we talking about ‘probability of abuse believed to be <50% after full Multidisciplinary investigation?’ In child protection, ‘shades of grey’ are the norm. Most child abuse cases have a raft of medical and non-medical concerns. The conclusion that abuse is likely to have occurred is supported from a variety of angles (paraphrased from an e-mail).

5.3 Eventual inclusion criteria

From the outset it was understood that focusing on parents of children with physical injuries would be likely to yield the greatest number of potential research participants. Although the true incidence of NAI is unknown, largely due to a lack of reliable prevalence studies, there is varying terminology for what constitutes ‘maltreatment’, and the overlapping of different types of abuse (Benger & McCabe, 2001; Cawson et al, 2003). After neglect, physical abuse is the most commonly recognised form of child maltreatment in the UK (Brandon et al 2008). It has been estimated that in the UK 7% of children suffer serious physical abuse by a parent or carer, and two children under 15 years of age die from abuse each week (Hamilton & Browne, 2002). Other studies suggest that each year one child in six attends emergency department because of physical maltreatment, which is equivalent to 2 million child attendances per year (Lazenbatt & Freeman, 2006) and in England and Wales, as many as 40,000 children are the subject of a case conference each year for suspected physical abuse (Barber & Sibert, 2000).

Early on in the discussions it was agreed we should not approach parents whose children had suffered life-threatening trauma, and that it was essential that parents had been made aware of the concerns at the time. We were also anxious that the research should not be seen by parents to interfere with or have any influence on any child protection proceedings. In view of all these issues it was agreed that the inclusion criteria should be participants:

- whose child/ren had sustained an injury that was at first thought to be non-accidental and who were aware of the concern;
- for whom section 47 of Children Act 1989 (and the equivalent in Scotland and Northern Ireland) enquiries had not substantiated the original concerns about the child being at risk of, or suffering, significant harm; this means that the concern about non-accidental injury was not substantiated and the child was no longer – or never was – on child protection register;
- for whom any legal proceedings were never instituted, or for whom legal or any other proceedings had been closed or resolved;
- for whom the incident had occurred in the last seven years; and
- for whom physical injury was not associated with other types of abuse.

Even once the criteria had been agreed a number of concerns were voiced:

- The numbers for cases matching the inclusion criteria in any one hospital/clinic were so low that the study was not feasible.
- Many of the children presenting directly to A&E and paediatric units had severe injuries.
- Once families were discharged from the hospital, the hospital paediatrician was not necessarily aware of the outcome of investigations.
- It would be difficult to identify cases retrospectively, because paediatricians may not recall parents' surnames, and information letters may go to wrong addresses if incident had happened some time ago.
- In the great majority of cases, the concern of inflicted injury is raised by someone else, such as a teacher, health visitor or the GP.
- The research might send out anti-child protection messages and/or lead to further complaints.

These concerns were discussed and considered by the project steering group.

During the preparatory phase, 10 pilot interviews were undertaken with volunteer participants, all of whom had heard about the project through parent support groups. The pilot interviews had two main purposes: to develop the interview themes; and, to develop practical and ethical inclusion criteria for the main study. Although the data generated in pilot interviews are not included in the findings, valuable insights were gained beyond our particular focus on communication. For example, the pilot interviews helped in understanding the range of situations where concerns of non-accidental injury may arise, as well as the complexity of diagnostic processes regarding different types of injuries and rare conditions.

5.4 Ethical approval

The study received ethical approval in April 2007 from a London Multi-Centre Research Ethics Committee (MREC) and approvals from the Research & Development (R&D) departments of each collaborating NHS Trust were obtained prior to formal interviews with participants. The key ethics concerns for the study were informed consent and avoidance of causing further distress to participants.

The approach taken in this project was based on three core principles, honesty, sympathy and respect (Hollway & Jefferson, 2000). This involved intention not to compromise the interviewees', collaborators' or children's dignity in any way. Although previous research has suggested that talking about emotive issues is difficult for participants, some participants have felt interviews were an opportunity to 'express the stress' and potentially 'therapeutic' (Hutchinson, 1994; Lowes & Gill, 2006; Murray, 2003).

The project was not about blame, complaints or taking sides; it was about listening to parents/carers' views in a non-threatening environment. A sensitive qualitative interview method was chosen to enable us to do so and it is indeed hoped that the project did not cause further distress to those who participated.

5.5 Rationale for sampling

Families were recruited through parent support groups and through local collaborators in 21 NHS Trusts. Six support groups actively advertised the project on their websites (names withheld for confidentiality reasons), and parents interested in participating were asked to contact the interviewer directly. The local collaborators were asked to identify participants who met our selection criteria and forward our information sheet and invitation letter to them. The information leaflet provided details of the study as well as contact details for support organisations. Written consent was obtained from all participants.

Participation of any parent/carer who met the inclusion criteria was welcomed. For ethical reasons, the voluntary and possibly anonymous participation of participants was prioritised over any statistical representativeness, for example, in terms of social class, age, ethnicity or gender. Due to the small number of cases, any comparisons of this kind would not be feasible. Instead, the emphasis was placed on the generation of insights through long in-depth interviews: the insights gained from a small study can be generalised on a theoretical rather than on a numeric level.

This small scale exploratory study has aimed to provide insights into the subjective, lived experiences of parents. The data analysis was informed by phenomenology:

“Although diverse samples might provide a broader range from which to distil the essence of the phenomenon [such as experience of child protection proceedings], data from only a few individuals who have experienced the phenomenon – and who can provide a detailed account of their experience – might suffice to uncover its core elements” (Starks & Brown Trinidad, 2007, p.1375).

5.6 Interview method

Interviews explored issues that participants wished to bring forward about situations when they were made aware that there were concerns about NAI:

- Was it the way this was communicated to them? If yes, what modes of communication do participants prefer/recommend?
- Was it something else? What?
- How did this situation fit in the wider context of what was going on in the family's/child's life?
- Was there any information that participants would have needed at the time but did not receive?
- How did participants remember and reflect on what happened?

Qualitative semi-structured interviews were carried out with participants on a one-to-one basis, unless they wished to be interviewed with a partner or relative. When participants first contacted the researcher they were given detailed information about the study and the interview procedure. This information was repeated at the beginning of the interview. Preliminary discussions with participants also involved a thorough explanation of the limits to confidentiality regarding possible disclosure of child abuse and what action would be taken in such a situation. A convenient location was identified for face-to-face interviews. Participants decided whether they wished to have a face-to-face or telephone interview and were also given the option to call anonymously. After the interviews all participants were contacted by phone or e-mail to check that the interviews had not caused distress.

The interviews were recorded with participant's consent and were carried out in a sensitive manner. Interviews were not used as either interrogation, confession or as a counselling session (Corbin & Morse, 2003). At the end of the interview participants were offered information about support organisations and were offered an opportunity to read and amend the interview transcripts.

Health services user perspectives can be mapped out by a variety of methods ranging from surveys to in-depth life story interviews. In this project, accounts were sought about 'disruptive events' (Andrews et al, 2004) in families' lives. An adapted biographic narrative interview method (Wengraf, 2001) was chosen for the project as it allowed for:

- the interviewee to speak in their own words, without the interviewer 'destroying' the narrative following their own concerns;
- the interviewer to gently address issues about communication with probing questions after the interviewee has had the opportunity to tell 'their story' (Hollway & Jefferson, 2000; Rosenthal, 2004); and,
- the gathering of both base line and in-depth information.

The rationale for adopting this type of interview method stemmed from methodology previously widely used for sensitive topics in social and applied health research. For example, in health services research, the rationale for listening to patients' 'illness stories' (where diagnosis of illness has been the disruptive event) has been to improve service provision (Bury, 1982).

More generally, narrative research often attempts to investigate the lives of 'hidden populations' that are subject to stigma, isolation, vulnerability to stress and depression (Liamputtong, 2007). A central concern for qualitative interviewing in research of this kind is that interviewers should not dominate the interview (Rubin & Rubin, 1995). The emphasis is on 'active listening', rather than 'active questioning'. Interviews conducted in this manner allow for detailed accounts to emerge. Throughout the interview, the emotional well-being of the interviewee is given a priority.

5.7 Data analysis process

The interview recordings were transcribed by the lead researcher/interviewer and NVIVO qualitative software was used to enable systematic thematic analysis that was informed by phenomenological considerations.

For the analysis, the situation where the concern of possible NAI was communicated to participants is characterised as an 'event'. The data were analysed by:

- literal reading of how parents experienced the 'event' and its aftermath;
- joint interpretive reading of anonymised participants' accounts by chief and principal investigators;
- cross-sectional reading of all the interviews as a set; and,
- holistic reading of each interview (Mason, 1996).

Data analysis was set in context by the preceding literature review and by the extensive consultations during the preparatory phase. The interpretation of qualitative data – as in discourse analysis - also recognises that participants tell their own unique stories by adapting and combining other stories and intersubjective meanings that are available in the society (Denzin, 1989; Elliott, 2005) – for example, from friends, families and/or in the media. It was acknowledged that participants interpret past events from the perspective of the present and with the future in mind (Frank, 1995).

Because the purpose of the study was to generate recommendations for good practice regarding communication, the data analysis required focussing on what was relevant in this specific sense. Therefore, the data analysis did not look at individual stories as testimonies as such. Furthermore, due to the small number of interviews, a 'case study' type of approach to analysis would have potentially compromised the confidentiality of the participants. Instead, a thematic approach was adopted so as to highlight key messages parents wished to bring to the fore and how these resonated with previous research and other participants' experiences. At the same time, this approach in no way minimised the sense of personal and individual difficulties experienced by participants.

6. Results

6.1 Demographics

Over 100 letters were sent to potential participants by the local collaborators in 21 NHS Trusts. Six support groups advertised the project in newsletters or on their websites. These two approaches resulted in 12 interviews (two of which were joint interviews with both parents) from an initial target number of 25. The ratio between parents recruited through support groups and those identified by Trusts was 1:3. Two of the 12 interviews were separate interviews about the same case, which were treated as individual interviews for the data analysis but as a single case for the demographic breakdown presented below; 10 mothers, three fathers and one carer participated. Nine of the 12 were face-to-face interviews, and three were telephone interviews. No children were interviewed.

In the 11 cases, NAI concerns were raised because of fractures (6: ranging from pre-mobile children to toddlers), bruising (3: toddlers), burn (1: 8-year-old) and possible FII (1: teenager). In eight cases concerns were first raised in A&E or a hospital clinic, whereas in three cases schools (not paediatricians) had initiated concern. Out of the 11 cases with a presenting injury: in four the participants reported that they had observed the accident that caused the injury; in one case the injury was not observed but the child explained how it had happened; in two cases the parents had no explanation for the initial injury; and, in another bruises were noticed at a hospital visit for a routine test. In one case a rare disorder was subsequently diagnosed. The median time between the incidents and the interviews was 24 months (range three months to seven years).

In all but two families the concerns were resolved without the need for care proceedings. Of these two cases, in one case the children had been removed but later returned to their parents care after further investigations, whereas in the other the child had already been placed in permanent foster care before the parents' appeal was resolved. There was a range of ages, ethnicities, personal circumstances and geographical locations. All interviewees were fluent in English.

6.2 Interview findings

The findings are presented under the following subheadings: 1) participants' accounts of health professionals' communication style and content; 2) participants' information needs; 3) participants' response to the communication of NAI; and, 4) participants' concerns regarding the child's medical care during the child protection proceedings. To safeguard confidentiality, all doctors in interview extracts are referred to as 'she' and children as 'child' or 'he'. Names of people and places,

dates and times have been omitted and pseudonyms are used for interview excerpts. Personal and identifiable details have been omitted without compromising the depth of the account. The researcher's words are in bold.

At the end of the interviews, many parents thanked the interviewer for the opportunity to talk, or expressed the feeling that it had not been as difficult as they had thought it would be. It is noted, however, that interviews of this kind can be very emotional for the parents. A number of parents asked the interviewer for information about their children's diagnosis or legal matters, which the researcher could not provide help with. It was therefore important to clarify the role of the researcher at the outset of the interview and provide participants with information about support organisations.

6.2.1 Health professionals' communication style and content

Although the specific circumstances in which the concerns were raised varied from case to case, all of the most common scenarios were represented in the interviews. There were three cases where concerns were raised in a school setting and the child was referred to a paediatrician for a child protection medical. In one case the parent took their child to hospital for a routine test when bruises and subsequently multiple fractures were spotted. In all other cases parents took their child to hospital because of the presenting injury. In eight cases the concern was in relation to an isolated injury whereas in three cases hospital investigations revealed further signs of concern. None of the children was on a child protection register at the time of the incident.

The first extract is an example of where a parent felt the health professional communicated concerns in a clear and informative way:

Yeah, they took us into a little side bit, we were on the ward. The main thing was that they said it was consistent with a non-accidental injury and it was the procedure in those cases therefore to inform social services and also to do a full skeletal x-ray in those cases (ID: Jane).

However, another parent felt the communication was insensitive:

She [paediatrician] took us into her room and I'm like 'what's happened', we've been sitting here for four hours etc etc and she just says 'look we want to admit child' and I said 'I want to take him home' and she said 'we're admitting child and if you try to leave hospital with him, we will phone the police'. Exactly like that and I will never forget the way she said that and that's what I've had a problem with, you know what I mean (ID: Sally).

In the latter account, the parent expresses frustration not only with the long wait and lack of information, but also with the communication style, which has had a long-lasting impact. In a similar vein, the next extract describes communication about investigations into potentially life-threatening injury:

When we were at the hospital, the staff there weren't very helpful, they told that, one of the doctors actually told me in the middle of the ward that child had a fractured skull as well and just walked off, she just said 'fractured skull' and walked away and I just burst into tears because I thought 'my god my baby has got fractured skull'. And they never told us that that wasn't actually true. It was only when I asked again later about the fracture and they said 'oh that was an error'. But they didn't actually come back to tell us that she didn't actually have fractured skull. They thought child had been shaken so they did the tests and checked the back of her eyes and everything and it was all clear (ID: Kate).

With hindsight, many parents expressed the feeling of being treated less courteously by health professionals, when concerns of NAI were raised, even when parents were not aware of the concerns at the time:

At that point kind of the interaction of staff slightly changed, I perceived it that way I would say, because it had been slightly, let's say friendly, there was this concern before and then it changed into, you kind of thought you were put under suspicion, whereas nobody actually explained to us at that point about what was happening, apart from the fact that child had a fracture (ID: Tom).

One parent suggested the doctor could have 'phrased it a bit better':

Like 'look, I've got a problem because this kind of break is associated with abuse, we need to investigate it further'. It may have been a bit more palatable for us than 'your story is not feasible'. Because she doesn't know how it happened, she doesn't know the circumstances of the family; she doesn't know anything, so we felt that it didn't sit with us very well to be honest (ID: Peter).

Another parent felt that the health professional had disbelieved her account and manipulated her words:

She [health professional], if anyone, was the worst one I'd come across, she was twisting your words, it was so obvious that even the nurse noticed. Like she said 'you heard a crack', and I said 'no, I never'. I said 'my other child heard that'. I think the thing they need to look at when they train paediatricians is the way they speak to people (ID: Lucy).

In terms of child protection medicals, parents found it helpful when the doctor explained exactly what the examination involved and reassured them that the child would be all right:

And she took a look at it [injury] and said 'well, as far as I can see that sort of tallies with what you said to me'. And she said 'I would be perfectly happy to say that as far as, you know, it looks to me very much like he'd banged that off hard surface just in the way you've described'. And she asked me then to undress child and to remove all of his clothes. She was kind to me and kind to child, and she examined him from head to toe. You know, I think he had, I remember he had a bruise on his knee and of course I immediately thought, I saw this bruise and I thought 'oh no, not another bruise'. But she said straight away 'oh bruises on knees, little boys always have bruises on knees'. And that sort of put me at ease as well. And she sort of checked around his genitals and she explained to me that she had to do that, it was part of the examination but I wasn't to worry (ID: Alison).

6.2.2 Information needs

Participants generally pointed out a lack of information regarding child protection proceedings. One parent described a situation where the family was waiting for test results in a side room unaware that social services had been involved:

Somebody just appeared in the room, we were put in a room, most of the time we were just in this room with some toys and things. We were wondering why we were just in this room. People just kept coming in and going out all the time and then this chap came in, he was all smiley and looked very smiley and we were thinking 'who was he' because he wasn't dressed as a doctor and then he said 'I am a social worker' (ID: Louise).

When professionals do communicate concerns, it is important that the language is clear and unambiguous:

At the time, I remember when I first heard somebody said 'NAI' I thought it was a medical condition. I'd never heard of it before (ID: Jane).

Parents generally appreciated a thorough explanation of what tests were being undertaken and what they involved, including an explanation that a genital examination is a routine part of a child protection medical:

So this social worker came out, this child protection officer come in our house and said that we had to go and see a paediatrician, he was able to fit us in. After we went to this place where the doctor is based, she's lovely. She checked him all over when we went in, asked what had been going on. She checked his little bum (ID: Mary, mother).

I was sitting there so I was thinking he was checking if I was sexually abusing my own child in front of us in this room full of people (ID: Jack, father).

One parent felt it had been difficult to ask questions due to the lack of privacy where the investigations took place:

And that was it and you are kind of sitting there, and it's a fairly open place, you've got a lot of people around, doctors and nurses, and you don't necessarily want to start to enquiring 'what do you actually mean by that?' (ID: Tom)

Another parent was upset that concerns about possible NAI had been discussed in front of the child's siblings:

It was destroyed literally, my kids could not enjoy Christmas, they thought they could never see their sibling again because the social services said in front of them that 'child' has to go to foster care'[...]The kids cannot understand what's happening, they should not be involved in it further' (ID: Lucy).

As well as wanting clearer information about the child protection process, very few parents had been informed when the case had been closed and the investigations completed. This uncertainty contributed to considerable long-term anxiety about what would happen if and when they needed to take their child to hospital again, and the possible impact on the family:

But every time he has a runny nose you are thinking if this gonna be something that I've got to take him to the doctors for or is it gonna come up on the screen that there was a child protection investigation (ID: Alison).

Lack of communication during the child protection investigation also caused considerable anxiety:

And all the emotional distress as well, you know ten days is a long time to be thinking that there's something happening (ID: Tom).

In the interviews, parents were asked if they had been given a written information leaflet about child protection proceedings, at the time of the incident, and if not, whether such information would have been helpful. Participants were ambivalent about the value of a written information leaflet, emphasising instead the need for something in writing when the investigations had been completed:

I mean even like the doctor had said that he was going to write out a written report and obviously send it to the social services, the GP, and he said that he would send the same copy to us, and we've not received anything. So we didn't even get a written report about it, so I think something like that (ID: Mary, mother).

Just a letter just to say 'satisfied, nothing went on'. Just some type of closure (ID: Jack, father).

One parent reflected upon the potential impact of an information leaflet about child protection proceedings:

Yeah, you might find out that some parents, if you gave that out routinely you might frighten parents (ID: Peter).

Finally, the interviews indicated the need for support and humane communication during and after the investigations:

Now when you were in the hospital, looking back to this, what kind of information do you think you would have needed at the time? (Interviewer)

Just, I don't know what information they could have provided because we didn't even know what services were available. It just would have been nice for someone to sit down and talk to you like you're a human, not just like you're a monster (ID: Kate).

6.2.3 Response to communication of concern

In several of the interviews participants reflected on how they had felt when they realised that the authorities were considering a non-accidental cause for the child's injuries. Participants described it as the moment when it 'started to dawn on them' that they were 'under suspicion'. Shock was a common reaction:

And then she [doctor] said 'right well, I do not have any other option but refer child to social services and I need to do a full skeletal survey now'. So I said 'what does that mean, full skeletal survey?' It sounded strange and I was very shocked at that, I was quite shaken (ID: Helen).

Anger was another common theme:

It's early hours of the morning, we're sitting there with a x month old baby, who's not happy anyway and then they hit us with this, so of course my immediate reaction was anger. You know what I mean, when it started to dawn on to me what they were assuming, that it was down to us (ID: Sally).

Many indicated that reports in the media in contributed to their anxiety:

It was as if someone had smacked us in the face - we were now under suspicion. [...] And you may say that having extra knowledge was detrimental to us in that but at the same time, when you read stories in the press about child protection investigations you immediately think that you are under suspicion yourself and you are naturally thinking of a worst case scenario (ID: Tom).

During the interviews, some reflected on how their own communication could have influenced the course of events. One parent wondered whether her own comments had affected the course of events:

So all it was, it was really just a question, I just said 'does he need to have the x-ray?' and that made me suspicious that they began to think that 'oh, there is something suspicious about this, she does not want her child to be x-rayed'. And because I was distressed about child's distress, I would have been quite willing to do it if it had been needed; I just wanted a bit more understanding from them. But because you were very pressurised there at the hospital, there were these long waits and doctors are busy and she wouldn't co-operate, if you feel a pressure from that then obviously...(ID: Louise).

All of the participants interviewed expressed awareness that child protection was the duty of doctors and other professionals (including nurses, teachers, health visitors or social workers):

I know and I do understand their point of view as well, there must be some really horrible cases and where people have actually done it, they must all note it and take the child and keep them away from the parent, that's how I would feel if you know that it's actually happening (ID: Kate).

Nevertheless, being put under an investigation, even if for a short while, was experienced as a personal threat to one's parenting capacity:

And [parenting] it's a thing that you think should be natural and you shouldn't need help with it. And if someone starts sort of trying to suggest ways that you could be a better parent, it brings out very odd emotions. And I think I understand how even the most placid people get very angry and defensive when that happens, if someone tries to suggest ways in which you could improve your parenting or ways in which you could do things better. You know I've always known the health visitors and doctors and things, they are only doing their jobs but if they say to you that you know you could try different ways of bringing up your child, you immediately think 'well, are you trying to tell me I'm not a fit mother?(ID: Alison).

In two cases in which the paediatrician had not been the first to raise the concern, the intervention of the paediatrician was seen to be helpful. In one case, the child's school had contacted social services and a paediatrician undertook a child protection medical:

Child got examined by the paediatrician doctor and she said in the presence of the social worker 'Child has been exceptionally well cared for'. I quote her words: 'He is in pristine condition and that's what I will put in my report'. And the social worker stood there and heard and he left and he said to me that the findings of the doctor is the most important issue here and that I shouldn't worry (ID: Julia).

Several interviews suggested that parents found it more acceptable when the paediatrician explained investigations into NAI in terms of having to follow a protocol. For instance:

So first of all I was seen by, I think she was some sort of nurse and she just basically asked me about what had happened and said that because of the Victoria Climbié case they had to ask a lot of questions (ID: Helen).

Most parents felt that the initiation of child protection investigations was an over-reaction in their case. Some participants reflected that they would have understood the need for child protection investigations better had they been on the child protection register or had the child's injury not been a one-off incident. Nevertheless most expressed an awareness of and support for child welfare professionals' legal duties to protect children:

[...] our sort of more considerate view is that they have got a very difficult job to do. But like in any profession you get a few rogues out there but by and by they've got a hard job to do (ID: Peter).

6.2.4 Concerns regarding the child's medical care

For most participants, it was not the quality of the child's medical care but the ambiguities about the cause of the injury and differences in opinion by different child welfare professionals that was problematic. However, a number of interviews also suggested that the parents felt the child's well-being became secondary when child protection concerns were raised. There were concerns about an apparent lack of follow-up once child protection enquiries were initiated:

And actually I don't know, I don't even think the x-rays were sent to Dr X, they were only sent to other people. But no other person saw child medically after that day, after he was in the hospital, nobody else. He wasn't even sent back [...] if you have all these fractures, he wasn't even made a follow up appointment to see if the fractures were healing or anything (ID: Jane).

Most participants had taken their child to hospital because they wanted to know 'what was wrong' with the child:

"Don't get me wrong, if I, after everything we've been through, I don't regret taking the child into the hospital. Because, at the end of the day, I was worried about him" (ID: Jane).

Parents may also require general information about child's medical care, whilst in hospital:

I don't know it was all a bit vague to be honest because we didn't know what was going on, we were sent up to this other ward and that time he got a plaster on but we weren't told, they just said 'give him some Calpol' or something. And I was like 'how much should I give him, when do I give it to him'. Then they said 'give him this', there were two things, and I had to really keep going back and they were not giving information (ID: Louise).

In addition, several interviews suggested that parents would have wanted professionals to listen to their concerns about the child's well-being and comfort whilst medical tests and x-rays were undertaken.

7. Discussion

This small-scale exploratory study arose from the findings of previous research that communication between professionals and parents when there are concerns of NAI is an area which triggers complaints. The research approach was in line with the ethos of patient and public involvement, which is about empowering patients and the public to have a say¹.

The study, although small, has identified issues relating to communication as well as additional concerns that participants wished to bring to the fore. The fact that the research explored parents' experiences some time after the incident rather than being a first-hand observation of the doctor-parent communication could be regarded as a study limitation. Criticisms of this kind are not uncommon in health service user focused narrative research. Bury (2001) argues that patient narratives are sometimes treated as if they represented the authentic voice of the patient 'underdog' as opposed to the voice of dominant medicine. Cleaver & Freeman (1995) also discuss the intentions and meanings of parents interviewed about child protection proceedings:

As anyone who has faced a crisis will testify, life glimpsed darkly from the perspective of two o'clock in the morning is very different from that viewed at midday, but both versions are convincing and, moreover, seem reasonable at the time (p.124).

This study did not seek to prove or disprove the allegations of NAI, nor did it investigate whether parents' accounts were 'true' or 'false' as we wished to value participants' stories as they unfolded. In qualitative research of this kind the interpretation of data recognises that participants tell their own unique stories by adapting and combining other stories that are available in the society (Denzin, 1989). Bury (2001) suggests that the desire to represent the interviewee's viewpoint does not mean that an evaluative and contextual approach to patient narratives is not required. We have adopted this approach making links between participants' accounts and previous research in relevant areas.

7.1 The research process

The recruitment of parents took longer and the response rate was lower than initially anticipated. This may well reflect the complexity of child protection practice as well as the challenges of undertaking research in this field. It may also be a result of the recent high profile media coverage of child protection cases, particularly those cases where professionals 'got it wrong'. Feedback from a number of parents and carers also suggest that the response was low because parents did not wish to relive a distressing experience.

¹ <http://www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/PatientAndPublicInvolvement/InvolvingPatientsPublicHealthcare/fs/en>

Difficulties in undertaking research that involves hard-to-reach groups and/or deals with areas that are private, stressful or sacred are well documented in social science and health services research (Lee, 1993; Sturges & Hanrahan, 2004). Low response rates may be a result of participants own motives as well as institutional barriers (Thompson & Phillips, 2007; Groger et al, 1999; Dale et al, 2005). Few researchers have systematically assessed how patients or their families felt immediately after having received bad news, due to worries about burdening already distressed people (Fallowfield & Jenkins, 2004). It may be that our invitation letters further upset those parents not wishing to take part, and feedback from a small number of non-participating parents indicated that the invitation letter raised concerns that the family's names remained on medical child protection records. It was certainly not our intention to exacerbate the situation.

Considerable efforts were made to maximise avenues for recruitment. This involved talking to individual paediatricians, presenting the study to child protection special interest groups, using the RCPCH newsletter and bulletins to publicise the study aims, and sending individual letters to designated and named child protection paediatricians and RCPCH Officers. It is important to note that from the outset a small number of experienced child protection paediatricians took the initiative to contact the researchers to offer their support, advice and encouragement. This was invaluable to the researchers and the project as a whole.

7.2 Communication

Parents' and carers' accounts in this research resonate with previous literature on communication and information needs in health settings. In their review of the literature, Fallowfield and Jenkins (2004) concluded:

- Parents most appreciate doctors who are confident, show concern, and are caring, but who also allow patients/parents plenty of time to talk and ask questions.
- Patients/parents are critical about the way in which the bad news was broken, citing a lack of privacy.
- There is a need for clear verbal and written information to parents, including the provision of copies of letters to family physicians about patients' own or their children's care, and for clear communication between doctors and parents and between multidisciplinary team members (Fallowfield & Jenkins, 2004, p.315; McLaughlin, 2005).

The idea that communication is an essential aspect of medicine is not new, and in recent years communication skills in teaching and assessment have become more visible in medical education (Ihler, 2003). Informal conversations with professionals in the course of this study have highlighted the difficulty of '*getting the balance right*' – of being honest but at the same time supportive to parents during child protection investigations, in the face of uncertainty regarding

diagnosis. The ideal timing of communication in the investigation process poses another challenge for professionals who are to express concerns.

Current recommendations for practice also require case-by-case decision making as to whether to share concerns with parents:

Working Together to Safeguard Children [...] makes it clear that the only bases on which concerns should not be discussed with the family prior to making a referral to social services is where such discussion would place the child at increased risk of significant harm or where evidence might be lost. If agreement is withheld, but it is thought a child is at risk of significant harm if the referral/consultation does not take place, then the referral/consultation should go ahead (Baginsky, 2007, p. 76; paraphrased).

7.3 Contexts

The hospital paediatrician will not always be the first to raise concerns of possible NAI. In many circumstances paediatricians will be carrying out child protection medicals after a referral from social workers. This means that the communication with families differs from those circumstances where the paediatrician is the first to raise the concern. The interviews support the idea that the perceived quality of communication is linked to the role of the professional and concurs with previous research with paediatricians (Turton & Haines 2007):

I think the person who initiates the inquiry of...abuse, it doesn't matter what sort of abuse, gets an awful lot of criticism (p. 35).

The present study is also located in a wider context of how child protection is represented in the media. Parents' accounts suggest that reports in the media may fuel anxieties and might even have contributed to the low participation rate in the study. Discussions with health professionals in the preparatory phase suggest that child welfare professionals may be affected by media discourses in a similar way.

7.4 Other concerns and follow-up support

In the interviews, parents reflected on the impact of this 'disruptive event' in their lives. Parents felt that the investigations were initiated very quickly but once over, they and their children were left without any follow-up support. In addition, a number of participants felt that their child's ongoing well-being became secondary to professionals as soon as child protection investigations were concluded. Some participants also felt anxiety about what would happen when they took their child to see a doctor again. On the other hand, there were some parents who felt '*strong enough*' to cope with the child protection proceedings and capable of '*putting things behind them*'. These parents no longer – or never had – required support such as counselling.

8. Conclusions

This research set out to explore how parents experienced professional communication regarding concerns of NAI. The following answers were found to our research questions.

a) How were concerns of NAI communicated to participants and what modes of communication do participants prefer/recommend?

Participants generally felt there was a lack of communication while investigations into NAI were initiated. Clear, courteous and honest explanations were expected regarding the child's medical care and what was involved in child protection proceedings. These findings on communication are consistent with previous literature on parents' experiences on child protection proceedings (e.g. Cleaver & Freeman, 1995; Dale et al, 2005), as well as with studies on communication in health settings more generally (Fallowfield & Jenkins, 2004).

b) What other concerns did participants have?

A number of parents had concerns about the child's care or treatment either in the hospital or afterwards particularly in the cases where there had been no conclusive medical diagnosis. It was important for the parents that they were reassured about their child's well-being during and after child protection investigations. A number of participants also expressed anxiety about having to take their child to a doctor if accidents happened in the future. The need for a formal closure letter was another common theme.

c) How did this situation fit in the wider context of what was going on in the family's/child's life?

We did not investigate all the mitigating factors but did listen to what messages participants wished to pass on. The findings suggest that being put under child protection investigations was a highly unexpected and 'disruptive event' for families with potentially far-reaching consequences.

d) Was there any information that participants would have needed at the time but did not receive?

Participants generally wanted thorough explanations of what was happening and the prospects about the child's well-being and child protection investigations. Participants wanted someone to sit down with them and explain what was happening and in language they could understand. The findings were less conclusive about the value of written information. The majority of participants, however, stressed the importance of spoken information early on in the process and many wished to have had a closure letter in writing.

e) How did participants remember and reflect on what happened?

Previous literature on parents' experiences of child protection proceedings suggests that parents'

evaluations were highly critical (Dale et al, 2005). This project, however, suggests that parents reflect on their experiences (when given an opportunity to do so) and evaluate their situations from a number of angles. This was done, for example, in light of information available in the media or conversations with family and friends. Participants would assess the course of events in light of the present, stating things such as '*looking back in light of what I know now*', and also reflect on their own behaviour at the time in terms of how it might have affected the investigation process.

No matter how much time had passed since the disruptive event, participants remembered their anxiety at the time; many expressed feelings of bitterness at the time of the interview. On the other hand, time appeared to be a healer for a number of participants. Many wished to put the experience behind them and were also looking into positive aspects in their lives and what they had gained from the experience. One participant stated this experience and surviving it had made her more confident as a parent.

9. Principles to inform practice

The study identified a number of key principles which may help health professionals communicate sensitively with parents when there are child protection concerns:

- Many parents who find themselves in this situation will have brought their child to see a health professional because they are concerned about their child's well-being. It is important that parents are kept informed about the child's medical care throughout any investigations as these concerns and worries remain.
- Parents prefer honest, clear and early communication on what a child protection enquiry means; what referral to social services or the police means; whether emergency proceedings are taking place; what the child protection medical examination involves; how long the child has to stay in the hospital; what different tests involve; whether further tests are needed and how long it will take to receive test results.
- It is important that parents are treated in a non-judgemental way by all members of the professional team while the investigations are ongoing. Parents in these circumstances can feel vulnerable and particularly sensitive to the way things are phrased and how they perceive individual staff reactions.
- Parents understand the professional duty to investigate further if there are concerns. Sensitively explaining to parents that there is a protocol the professional has to follow and clearly outlining the process may help parents to accept and understand.
- For many parents the realisation that there are concerns their child's injuries may have been deliberately caused comes as a shock. It is important to understanding the range of emotions that may or may not surface, listen to parents' concerns, answer their questions and give them time.
- Where possible confidential discussions with the family about child protection investigations should be held in private, bearing in mind the potential impact on other members of the family, including siblings.
- It is important that parents have understood the situation, especially when using terminology such as NAI.
- When all investigations are completed, parents need to be informed about the outcome and whether or not there is a permanent record.

References

- Andrews M, Day Sclater S, Squire C & Tamboukou M (2004) Narrative research in Seale C, Gobo G, Gubrium J F & Silverman D *Qualitative research in Practice* London: Sage
- Baginsky M (2007) *Schools, social services and safeguarding children: Past practice and future challenges* London: NSPCC
- Baistow K & Hetherington R (1998) Participants' experiences of child welfare interventions: an Anglo-French comparison in *Children & Society* 12: 113-124
- Barber M A & Sibert J R (2000) Diagnosing physical child abuse: the way forward in *Postgraduate Medical Journal* 76: 743-749
- Barnett M M (2002) Effect of breaking bad news on patients' perceptions of doctors in *Journal of the Royal Society of Medicine* 95: 343-347
- Benger J R & McCabe S E (2001) Burns and scalds in pre-school children attending accident and emergency: accident or abuse? in *Journal of Emergency Medicine* 18: 172-174
- Brandon, M et al (2008) Analysing child deaths and serious injury through abuse and neglect: what can we learn? A biennial analysis of serious case reviews 2003-2005, *Department for Children, Schools and Families*
- Bury M (1982) Chronic illness as biographical disruption *Sociology of Health and Illness* 4(2):167-182
- Bury M (2001) Illness narratives: fact or fiction? *Sociology of Health and Illness* 23(3): 263-285
- Cawson et al. (2000) *Child Maltreatment in the UK: A Study of the Prevalence of Child Abuse and Neglect* London: NSPCC
- Chamberlayne P (2004) Emotional retreat and social exclusion: towards biographical methods in professional training in *Journal of Social Work Practice* 18(3): 337-350
- Children Act 1989, Chapter 41 http://www.opsi.gov.uk/acts/acts1989/Ukpga_19890041_en_1.htm
- Children (Scotland) Act 1995, Chapter 36, http://www.opsi.gov.uk/ACTS/acts1995/ukpga_19950036_en_1
- 14.Cleaver H & Freeman P (1995) *Parental perspectives in cases of suspected child abuse* London: HMSO
- Cleaver H, Wattam C, Cawson P and Gordon R (1998) *Children living at home: the initial child protection inquiry. Ten pitfalls and how to avoid them. What research tells us* London: NSPCC
- Corbin, J., Morse, J.M. (2003), The unstructured interactive interview: issues of reciprocity and risks when dealing with sensitive topics in *Qualitative Inquiry* 9(3): 335-554
- Dale P, Green R, Fellows R (2005) *Child protection assessment following serious injuries to infants; fine judgments* Chichester: John Wiley & Sons Ltd

- Denzin N K (1989) *Interpretive biography; Qualitative research methods series 17* London: Sage
- Elliott J (2005) *Using narrative in social research: Qualitative and quantitative approaches* London: Sage
- Fallowfield L & Jenkins V (2004) Communicating sad, bad and difficult news in medicine in *Lancet* 363: 312-319
- Frank A W (1995) *The wounded storyteller; Body, illness and ethics* Chicago: The University of Chicago Press
- Groger L, Mayberry P S, Straker J K (1999) What we didn't learn because of who would not talk to us in *Qualitative Health Research* 9(6): 829-835
- Gubrium J & Holstein J (1997) *The new language of qualitative method* New York: Oxford University Press
- Haines L & Turton J (2008) Complaints in child protection in *Archives of Disease in Childhood* 93: 4-6
- Hall D (2003) Protecting children, supporting professionals in *Archives of Disease in Childhood* 88: 557-559
- Hamilton C & Browne K (2002) Predicting physical maltreatment in Browne K D; Hanks H; Stratton P & Hamilton C (Eds) *Early prediction and prevention of child abuse: A handbook* Chichester: John Wiley & Sons Ltd
- Hollway W & Jefferson T (2000) *Doing qualitative research differently; Free association narrative and the interview method* London: Sage.
- <http://www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicyPatientAndPublicInvolvement/InvolvingPatientsPublicHealthcare/fs/en>.
- Retrieved on 30.11.2006
- <http://www.palsglos.org.uk/pals9081.html>
- Retrieved on 14.09.2006
- Hutchinson H A, Wilson M E & Wilson H S (1994) Benefits of participating in research interviews in *Image Journal of Nursing Scholarship* 26: 161-164
- Ihler E (2003) Patient-Physician communication; Editor's note in *JAMA* 289(1): 92
- Kai J (1996) Parents' difficulties and information needs in coping with acute illness in preschool children: a qualitative study in *British Medical Journal* 313: 987-990
- Lazenbatt A & Freeman R (2006) Recognising and reporting child physical abuse: a survey of primary healthcare professionals in *Journal of Advanced Nursing* vol. 56(3): 227-236
- Lee R M (1993) *Doing research on sensitive topics* London: Sage
- Liamputtong P (2007) *Researching the vulnerable: A guide to sensitive research methods* London: Sage
- Lowes L & Gill P (2006) Participants' experiences of being interviewed about an emotive topic in *Journal of Advanced Nursing* 55(5): 587-595

- Maguire S, Mann M K, Sibert J, Kemp A (2005) Are there patterns of bruising in childhood which are diagnostic or suggestive of abuse? *Archives of Disease in Childhood* 90(2): 182-186
- Mason J (1996) *Qualitative researching* London: Sage
- Maynard D W (1992) On clinicians co-implication: recipients' perspective in the delivery of diagnostic news in Drew P & Heritage J (eds) *Talk at work. Interaction in institutional settings* Cambridge: Cambridge University Press.
- McLaughlin, J (2005) Exploring diagnostic processes: social science perspectives in *Archives of Disease in Childhood* 90: 284-287
- Murray B (2003) Qualitative research interviews: Therapeutic benefits for the participants in *Journal of Psychiatric and Mental Health Nursing* 10: 231-238
- NHS Information Centre for Health and Social Care (2005) *Data on Written Complaints in the NHS 2004-2005*
- Payne, H (2008) The jigsaw of child protection On-Medica Tuesday, 15 January 2008 <http://www.onmedica.com/ViewsArticle.aspx?id=b5c56478-552c-4cd0-a11b-38c9c743d751>; Retrieved on 19.03.2008
- Prosser I, Maguire S, Harrison S, Mann M, Sibert J, Kemp A (2005) How old is this fracture? Radiological dating of fractures in children: a systematic review in *American Journal of Roentgenol* 184(4): 1282-286
- Rosenthal G (2004) Biographical research in Seale C, Gobo G, Gubrium J F & Silverman D *Qualitative research in Practice* London: Sage.
- Royal College of General Practitioners (2003) *The Role of Primary Care in the Protection of Children from Abuse and Neglect* London: RCGP
- Royal College of Paediatrics and Child Health (2006) *Child Protection Companion* London: RCPCH
- Royal College of Paediatrics and Child Health (2004) *Child Protection Survey* London: RCPCH
- Rubin H J & Rubin I S (1995) *Qualitative Interviewing: The Art of Hearing Data* London: Sage
- Shabde N (2006) Child protection training for paediatricians *Archives of Disease in Childhood* 91: 639-641
- Sharp M C, Strauss R P, Lorch S C (1992) Communicating medical bad news: parents' experiences and preferences *Journal of Pediatrics* 121: 539-546
- Starks H & Brown Trinidad S (2007) Choose your method: A comparison of phenomenology, discourse analysis and grounded theory *Qualitative Health Research* 17: 1372-1380
- Sturges J E & Hanrahan K J (2004) Comparing telephone and face-to-face qualitative interviewing: a research note *Qualitative Research* 4(1): 107-118
- The Children (Northern Ireland) Order 1995
- The Royal College of Radiologists and Royal College of Paediatrics and Child Health (2008) *Standards for Radiological Investigations of Suspected Non-Accidental Injury* London: RCPCH

- Thompson S & Phillips D (2007) Reaching and engaging hard-to-reach populations with a high proportion of non-associative members in *Qualitative Health Research* 17: 1292-1303
- Turton J & Haines L (2007) *An investigation into the nature and impact of complaints made against paediatricians involved in child protection procedures* London: RCPCH
- Wardinsky T D, Vizcarrondo F E & Cruz B K (1995) The mistaken diagnosis of child abuse: A three-year USAF medical center analysis and literature review *Military Medicine* 160: 15-20
- Wengraf T (2001) *Qualitative research interviewing; Biographic narrative and semi-structured methods* London: Sage
- Working Together to Safeguard Children* 2006 London: HMSO

Appendix 1: Membership of the Project Steering Group

Denise Bartlett	Eaton Foundation
Dr Carolyn Davies	Research Advisor Institute of Education Department for Children, Schools and Families
Sue Dunstall	Policy Advisor for Health & Family Support NSPCC
Maria Von Hildebrand	Freelance Consultant in Patient and Public Involvement
Dr Jacqueline Mok	Consultant Paediatrician Community Child Health Department, Lothian
Rosemary Neary	Eaton Foundation
Dr Neela Shabde	Consultant Paediatrician Community Child Health Department, Northumbria Healthcare
Prof Terence Stephenson	President RCPCH
Dr Jacqueline Turton	Lecturer Department of Sociology, Essex

Appendix 2: Interview schedule

1. Opening statements

- a. Thank you for taking part
- b. This interview will take about an hour
- c. You can ask for a break anytime. You can stop this interview and you don't have to give me any reasons for it if you feel like it
- d. (for those interviews where contact details are known)I would like to tape-record this interview. I will ask you to sign consent form before the interview/give verbal consent after the interview.
- e. This interview is confidential. However, if you tell me that you know a child who may be harmed by someone I will have to inform social work; but I will not tell anyone I heard this from you
- f. I do not wish to know any names of doctors/health professionals. Even if you told me these, I will not disclose them to anyone else.

2. Recap the purpose of interview

I would like to understand your experience when suspicion of non-accidental injury was expressed to you. We would like to learn from your experience – we hope this will contribute to the training of paediatricians. We are very interested in how this news was communicated to you. However, if there are any other issues you would like to point out about your experience please let me know.

3. Free association narrative

- a. What would you like to tell me? In your own words, in your own time
- b. We can start with what happened on the day you took your child to see the doctor – you can tell me details of the injury if you wish but you don't have to
- c. Make notes of key events – then probe the following as necessary:

4. Probes

The circumstances of clinic/A& E visit including, reason for attendance, diagnosis and outcomes and who attended with the child.

- Child's previous attendances at clinic/A&E and reasons/diagnosis/treatment – events leading to the key visit
- How they felt when it was explained to them that NAI (use participant's terminology) was being considered as part of a differential diagnosis
- How the paediatrician/clinician communicated this and who else was present
- Which other members of the hospital team they had spoken to and the content of the conversation
- Who else had spoken to them before, during or after the event (e.g. social work, teacher, health visitor)
- Their understanding of the child protection process and the explanation given
- Whether any oral/written information was made available to them following the consultation: This might include specific medical conditions, accident prevention leaflets, information about the child protection process and complaints procedures
- What information they would like to have been given and by whom?
- Is there any information/support parents need now? Have parents taken any initiative in finding more information/support?
- What in your opinion was good about the way this situation was dealt with?
- What advice - if any – would you like to give to doctors (others) to improve services?
- What kind of help would you like to be provided with?

5. Recap

Summarise the 'whole story' and key messages from parents.

6. Closing

- Thank you for taking part
- You can get a copy of the transcript if you wish (if address known)
- Are you still happy with your participation in this research?
- You may call me again if you feel that you need to

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