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Summary

# The relationship between child death and child maltreatment

A research study on the attribution of cause of death in hospital settings

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## Introduction

Each year over 6,000 children will die. The most common cause of death varies according to the age of the child. In 1999 the largest categories of cause of death for 1–15 year olds in England and Wales were injury and poisoning (24%), neoplasms (20%), and diseases of the nervous system and sense organs (13%). For infants under 1 year old (excluding neonatal deaths), the main causes were ill-defined conditions (23%), congenital abnormalities (20%), diseases of the respiratory system (11%), and infectious and parasitic diseases.

Some types of death are expected and some unexpected. In both categories there will be deaths that could have been prevented, although there is considerable debate as to how. For example, whether their deaths are expected or unexpected, children are more likely to die if they are poor, or come from certain minority ethnic groups, or live in certain areas. Poverty and environment are just two factors that may contribute to child death, although how they do so is not clear since the majority of children who live in similar conditions do not die. Patterns and trends in child death rates indicate that some deaths are preventable: for example, if the accident death rate of children in lower social groups was equivalent to children in higher social groups, children dying from accidents would reduce.

Our current knowledge about child death is dominated by the epidemiological ‘snapshot’ approach. This type of data gives a broad overview of the causes of death and enables reflection on wider patterns and trends. It is essential to recognise, however, that statistics are underpinned by a range of decision-making practices and procedures. The specific cause must be established through a *process*, which involves observing and making sense of physical signs on and in the body, what people say in their accounts and discussions, and through the fitting of information so obtained into available categories. Causes of death do not come ready labelled; they are defined through social processes. A central question underlying this study was that of how *explanations for child deaths* were sought and achieved.

Sometimes it appears to be relatively easy to arrive at a cause of death. The first such type of case is where a child may have been suffering from a long-term chronic illness and has been expected to die. In cases where the cause of death is clear and the child has been under the supervision of a doctor, the doctor can certify the cause of death. However, even in these apparently clear-cut cases there is room for ambiguity. Within the main report, we consider the case of disabled children who die in hospital, who may have been expected to die at some point but who die unexpectedly and for whom the cause of death is not clear. In these cases it would seem that the cause of death may be attributed to the child’s disability or illness, even though there is no clearly defined cause. A second type of case where the cause of death may be apparently easy to determine is that of accidents. For example, in our data we encountered the case of two children who died as a result of a fire, caused by candles left in a plastic bath. Questions of neglect were raised about this case but ultimately the deaths were categorised as accidental. One of the interests which emerged from this research project was to find out more about how this questioning over the cause of death arises, how certainty and uncertainty about the cause of death of a child is achieved, how natural and unnatural causes are ultimately decided, and what society accepts or defines as ‘accidental’.

Where deaths are unexpected or unexplained there is a legal requirement that they are referred to the coroner. Most of the deaths that we came across in our field data were deaths referred to coroners, many of which could be described as sudden and unexpected.

The criteria of unexplained or unexpected must also be negotiated and arrived at on each separate occasion. There is a list of criteria that covers grounds for referral to the coroner, but just as a cause of death has to be arrived at through a process so do these categories for referral. Some explanations can be accepted and others not.

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## **Information on the link between child death and child maltreatment**

Mortality statistics give very little information about any possible link between child maltreatment and death and show nothing of the way in which decisions are reached about appropriate categorisation. There is agreement among paediatricians and child maltreatment researchers in many countries across the world on two points. Firstly, child maltreatment is under-represented in mortality statistics and there are links that are not represented or accounted for. Secondly, there are impediments to improving awareness of the relationship between child maltreatment and death and to official recognition and recording. These are two areas requiring further research.

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## **Aims**

The aims of the present study were to:

- identify the differences between child deaths that are attributed to child maltreatment and those that are not
- report on the method and extent to which child maltreatment is a consideration when a child dies.

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## **Methods**

The study adopted a multi-method approach in order to generate both qualitative and quantitative data that would address its aims. A review of the research and literature on preventable child death was conducted prior to fieldwork. A national survey on information processes in unexpected child death was conducted in July 2000, based on a random sample of paediatricians. Non-participant observation was conducted in an accident and emergency (A & E) department between November 2000 and February 2001. In-depth interviews focusing on staff experiences relating to child death were conducted with 28 staff from the A & E and paediatric departments of two hospitals between March 2001 and August 2001. Data was also collected through documentary analysis of one hospital's records for child deaths in A & E covering the period 1998–2000.

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## **Ethics**

The project was reviewed and agreed by the University of Central Lancashire's Faculty of Health Ethics Committee. In addition, NHS Local Research Ethics Committees were approached in two NHS trusts in the North of England with a request to allow observations and interviews in A & E departments. One hospital agreed but in the other permission was only granted to interview staff working in paediatrics.<sup>1</sup>

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<sup>1</sup> This added an additional dimension to our data in that many children who enter hospital do so through A & E but other children may go straight to paediatric wards or are transferred on to the paediatric ward by A&E.

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## Findings

The data demonstrates, from every aspect of the study (observation, interviews, literature review and questionnaire), that systems are not in place to collect information relevant to furthering understanding of the relationship between child death and child maltreatment. Child maltreatment deaths are only enquired into once they have been so categorised. This study found that a categorisation of child maltreatment was only achieved if firm evidence was in place, such as clear indications of injury and a confession by a parent or carer. We came across cases in our data where suspicions had been raised but, because the evidence was not what might be considered ‘beyond all reasonable doubt’, the cause of death ultimately remained uncertain. It is discouraging to find, as this study does:

- that children die and there is little collective learning from their deaths, either within the hospital or outside it
- that child deaths are not systematically enquired into to rule out (as well as rule in) maltreatment as a cause
- that those children who survive become equivalent in information terms (records, further enquiry) to children who do not experience life threatening situations
- that social information is not given equivalent status to medical information as a matter of routine.

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## Summary of findings in the current literature

The literature review gave a considerable amount of information on different types of child death. However, the review found that there was only a limited amount of previous research relevant to our central aims. The current literature has focused on the relationship between child maltreatment and child death in terms of: the association of variables, the misclassification of a cause of death, the distinction between homicide and maltreatment, and the need for better information.

**Association of variables:** Child deaths by accident are associated with variables that are similar to those associated with maltreatment, including: poverty, family stress, lack of supervision, and poor housing. Similarly, child homicide has been associated with: parental mental illness, chaotic and violent home background, marital violence, financial and housing problems. Sudden Infant Death Syndrome (SIDS) has been associated with poverty. Thus, some children who are vulnerable to maltreatment will also be vulnerable to other causes of death, such as accident and SIDS.

**Misclassification of cause:** It has been suggested that attribution of the SIDS label can mask cases which are actually the result of deliberate child harm (Creighton, 1999; Hobbs & Wynne, 1996; Hobbs *et al.*, 1995; Southall *et al.*, 1997). Some authors suggest that SIDS can be used as a label to avoid asking awkward questions about the circumstances of a child’s death where maltreatment is suspected (Meadow, 1999; Nam *et al.*, 1989). Less is known about the misclassification of accidents or other causes of death.

**Distinguishing between homicide and maltreatment:** The defining characteristics of a death due to child maltreatment are not addressed in the literature. Hagell (1998) in reviewing the literature concludes that ‘the current state of the information is not such that we can be conclusive about the distinctions between homicide and abuse ... both are bound to be rather complicated and, at the minimum, overlapping to some degree’.

**Improving information about the cause of death:** Obtaining a case investigation, death-scene examination, information on the circumstances of the death, and the clinical and/or social history have all been recommended (Berry *et al.*, 2000; Meadow, 1999;

Reder & Duncan, 1999; Willinger et al., 1991), and are accepted by the major SIDS organisations such as the SIDS Network (US) and the Foundation for the Study of Infant Deaths (FSID) (UK). Such information is not currently collected for all child deaths, only for some of those referred to the coroner and subject to an inquest or a Serious Case Review by the ACPC.

**In summary, the literature suggests that there may be an overlap between child maltreatment and other types of death though there is no clear understanding of the nature of the overlap or of the defining features of a child maltreatment death. There is also some consensus that better information concerning child death is required.**

The present study was therefore addressing new ground, enquiring into how decisions were reached about child maltreatment deaths in a hospital setting. In focusing on information processes it also provides data on how these might be improved in order to better understand child deaths and their prevention.

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## Summary of findings in research data

**Differences between child deaths that are attributed to child maltreatment and those that are not:** Child deaths that are not attributed or considered in the context of child maltreatment are those that do not raise suspicion. These include:

- deaths that can be anticipated, for example where a child is on a life-support machine or has a life-threatening illness
- deaths of children where there is an existing condition such as a chronic disability or illness. These deaths may be unexpected and unexplained but in practice they become linked to the child's previous medical history
- deaths that can be explained in a public context, for example road accidents or falls in public places
- deaths that occur in the home which are presented as accidents where a clear explanation is offered that fits with the injuries and symptoms presented in the child.

It is possible that each of these categories could contain deaths caused by maltreatment, particularly fabricated or fictitious illness, neglect or filicide. For example, a father may deliberately crash a car with his children inside. If all the people in the car are killed, it would be difficult to distinguish this from an accident. Disabled children may be the victims of maltreatment, which may not be detected because parents have built up relationships with hospital staff and staff anticipate the child will be ill.

A number of accidents encountered in our data could have been linked to neglect, for example a three year old who strangled himself during the day on a bunk bed while both parents were in the house and who was not detected for some time, or the children who died in a fire started after candles had been put into a plastic bath because the electricity had been cut off.

**Extent to which child maltreatment is a consideration when a child dies:** Observations were made of the extent to which child maltreatment is a consideration when a child dies in Hospital A. Some of these will apply to other hospitals and some will not. For example, not all hospitals will have a dedicated health visitor in A & E or an information protocol in the event of a child death, as were the case in Hospital A. However, all hospitals have hierarchies, staff must interpret signs and symptoms and will rely on similar mechanisms to do so.

### **Observation findings specific to Hospital A (A & E):**

- Hospital A was able to call on the services of the health visitor in cases of child death. In particular, the health visitor noted all child deaths and made sure that these were discussed at regular child protection case meetings with the Hospital A community paediatricians and the senior nurse (child protection).
- The A & E dept had an information protocol, to be completed when a child died. It was designed, in part, to give staff who may have had suspicions about potential child maltreatment, or simply that 'something wasn't right', encouragement to record such views.
- Before maltreatment became a consideration, signs and symptoms had to be interpreted by staff, which, in some cases, might lead to dispute or disagreement. This interpretation did not rely upon the physical evidence alone, but occurred within a context in which parents gave, or were asked to give, accounts for events. Staff used what they saw as abnormalities in such accounts to designate a case as more concerning.
- Suspicions could be raised by the behaviour of parents. The expectations of how mothers and fathers should behave were also clearly linked to assumptions about gender and class.
- The lack of an explanation for events can also raise suspicions.
- A post-mortem may raise questions about maltreatment that had not arisen previously. For example, in one case a six-month-old baby girl had died after her breathing stopped. There was no obvious explanation for her death, but a post-mortem raised the question of maltreatment when a bruise was found beneath the skin of the head.
- Questions about maltreatment were more likely to be raised when there were key staff, such as a paediatrician, who took a keen interest in child maltreatment and continually raised the question for consideration. This sometimes meant that other staff regarded such a stance as 'over-zealous', that is looking for maltreatment rather than seeking to raise the question.
- Consideration of maltreatment can depend on whether staff agree that child protection concerns are relevant. Potential child maltreatment is not always agreed among staff and, therefore, some cases which may involve maltreatment are not referred any further.

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### **Summary of findings on information processes**

This section relates to all data from observations, interviews and the national survey. In the hospitals concerned there was no system in place to routinely and systematically collect relevant information related to child maltreatment when a child dies under any circumstances. The following findings focus on information processes that occur when a child dies. They are considered in terms of their relevance to diagnosing maltreatment and show where weaknesses in diagnosis may occur in the absence of systematic enquiry. Many aspects of information gathering can militate against a systematic enquiry into child maltreatment.

**Figure 1** Aspects of information gathering that affect the diagnosis of child maltreatment related deaths

Finding	Relevance to diagnosing maltreatment deaths
The taking of a patient history is key to seeking full explanations, but can be of limited quality (partly due to lack of time).	A comprehensive, detailed and thorough social history is essential for the diagnosis of death due to maltreatment.
Physical, social and circumstantial evidence must be interpreted.	Diagnosis is contingent on maltreatment routinely being considered as a possible interpretation, however unlikely.
Accounts are negotiated and arrived at through dialogue, but questions of power emerge here because some accounts may prevail over others due to hierarchical claims.	Questions of maltreatment may be dismissed through hierarchical claims related to knowledge or expertise. For example, it was reported that some consultants were less likely than others to take suspicions about maltreatment seriously.
Staff seek to match accounts with the evidence before them.	Accounts can be plausibly constructed by parents, carers and others to match the evidence and mask maltreatment.
Staff are more concerned where past episodes are known about.	Many cases involve babies where past concerns may not be known about or, if known, not recorded. Some incidents of maltreatment may be first episodes.
Lack of accessible interpreters means that some patients are unable to give their accounts, or that the parent who does speak English can impose their version of events over that of the parent who does not.	Because the diagnosis of maltreatment depends heavily on verbal accounts, cases of children from families where English is a second or other language may be missed.
Specialist medical knowledge regarding children is accessed via paediatricians and paediatric pathologists, but this does not always happen.	Specialist medical knowledge regarding maltreatment may be absent and cases will be missed.
Child deaths are dealt with on a case-by-case basis, often without continuity in members of staff involved.	There is no overview of maltreatment related deaths.
Child deaths can be upsetting and they affect staff involved, many of whom feel the need for emotional support.	The emotional impact of the death may lead staff to empathise with the parents and to want to avoid further distress to them through diagnosing maltreatment.
Staff stated that training around the issue of dealing with deaths, including child deaths, is needed on all medical and nursing courses. Some felt that pressure to meet operational targets, for example to decrease ambulance response times, was being prioritised over staff care.	Improved training could lead to better diagnosis and handling of child maltreatment deaths.
Medical staff increasingly work in a climate of litigation. Staff are reluctant to give a conclusive assessment of child maltreatment, even where they believe it is probable. Rather they pass on the information they consider relevant to others in the hope that the same assessment will be reached (for example, social services, coroner's office).	The reluctance to diagnose maltreatment on the basis of the balance of probability raises the test of proof to beyond all reasonable doubt, which is rarely possible in maltreatment cases.

**Information gathering is a process over time:** This process begins with the first contact with paramedics or nursing staff. Changes in information over time are commonly reported. These can be a consequence of:

- limited sources of information initially, including those relating to parental distress and availability;
- parents/carers changing their accounts of the circumstances that led up to admission;
- the co-ordination of information, especially where observations are made at the beginning but not necessarily mentioned or recorded until later when other information is shared by staff.

**Information that is collected as standard is done so for different purposes:**

- to identify the child in the record system (name, date of birth and address)
- to assess what treatment the child requires (the circumstances leading up to the injury, illness or death, the medical records and previous medical history of the child and family)
- to inform others who need to know and to check whether there are any concerns known to other agencies/professionals (contact details for parents, GP, health visitors, schools and school nurses, social services)
- in the context of caring for the child and his/her relatives.

**Methods of recording information varied between the hospitals:** In the A & E setting in Hospital A information is first recorded on the 'casualty card'. If a child dies, information is recorded in a special system referred to as the 'green folders'. These were specific to the hospital and were devised by a consultant who was concerned about the quality of information retained after the death of child. They included prompts for staff to check that specific information had been obtained and that the relevant people had been informed, to record any additional observations, including suspicions about cause of death or observations of parents, and to provide standard information for parents. In Hospital B, the paediatric ward, a multi-disciplinary assessment form was completed for each child admitted and details of observations, interventions and any other relevant information was kept in the child's medical notes. There was no separate system for recording information once a child had died.

**There were two distinctions between different types of information that have relevance to improving information gathering when a child dies:**

■ **Medical and social information.** Medical notes referred to diagnosis, clinical interventions, and medical history. Social information generally referred to involvement with social services, the status of the parents' relationship, their occupations, where the family lived, siblings and close relatives. There were occasional references to the child's care but no systematic information on child care or the relationship between the child and his/her carers preceding the incident.

■ **Information recorded prior to death and information recorded after death.** In Hospital A the green folder was only completed for children who died but no such system existed in Hospital B. In both hospitals information on children who survived near-death experiences was recorded on the casualty card and was generally brief. However, circumstances leading up to the life-threatening experience could be very similar to those children who died. In some cases where children are resuscitated there is little to distinguish between the child who died and the child who lived, except the outcome. When a child dies in unexpected or unexplained circumstances there is likely to be a post-mortem but there is no equivalent enquiry when a child survives a near-death experience. Thus, information may be lost about children who survive, particularly social information and details of events leading up to the reason for admission.

**Information collection was fragmented:** The quality of information collected depends on the level of skill and experience of staff. Staff could adopt many different roles in the information-gathering process and would collect information relevant to that role. There were also many parts to the information-gathering process from the paramedic's first contact, reception, admission, resuscitation, moving to the intensive care unit or neonatal unit, transfer to other hospitals, transfer to the pathology lab, and finally the coroner's office and any police involvement. When questioned, most staff thought that it would be beneficial to discuss the outcome of a case because it would offer a learning opportunity and help them identify information they may have missed.

**Crucial background information could be missed:** The way in which information was stored could lead to information being missed. For example, it was not inevitable that the death, or near death, of a sibling would be notified, or that previous attendances in A & E would be picked up if over two years ago or in a different area.

**Not all information is recorded:** Information can be passed on to others, noted (verbally or in note form) for future use or recorded in a file. Not all information was written down and sometimes staff would only pass information on if they thought it was relevant. This clearly opens up opportunities for information loss as staff change roles, shifts and locations. Information gathering is a shared process and no single person has responsibility for it.

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## Summary of findings from the national survey of paediatricians

■ Of the respondents, 45% felt that recording about child death was about right and 31% considered it to be inadequate. This indicates that practices vary between hospitals and information collection concerning child death is not standardised.

■ The majority of respondents considered that health professionals had a role in collecting a broad array of information, including family relationships, health history of siblings, mental/physical health of parents/carers, and quality of supervision. This applied to deaths caused by maltreatment, accident or self-harm. Only a small minority considered that it was not the task of health professionals to collect this information. The questionnaire did not probe the extent, depth or quality of information collected and it may be that these aspects are enquired into but, as the observations and interviews found, this may be limited in scope.

■ Inconsistent accounts most frequently alerted medical practitioners to suspicious deaths (80% rated this as 1st, 2nd or 3rd). This was followed by unusual bruising (62% rated this as 1st, 2nd or 3rd) and the death of another child in the same family (46%). Knowledge that the child was on the Child Protection Register and previous medical history were important for just over a third of respondents.

■ A significant majority of respondents (79%) indicated that targeted support for high-risk children and their carers was the most important intervention to prevent child death. This figure was closely followed by those who identified a need for closer monitoring of at risk children to be prioritised (75%). Better training for health professionals was identified as a priority by 61%. Information collection was considered less of a priority and there was little difference in the percentage that considered it a priority to improve information collection on all child deaths (38%) contrasted with improved information about suspicious deaths (35%).

■ 89% of paediatricians stated that social services should be the lead agency in working with high-risk families, followed by health, then education. Less than a quarter of respondents thought the police should be involved in monitoring. Many stressed the importance of the multi-disciplinary nature of monitoring, with social services taking the lead. Some new ideas for monitoring responsibility were proposed by a few respondents such as: GPs, an independent body, a trusted relative, and a dedicated police unit.

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## Recommendations

There is no collective learning about possible strategies for preventing child deaths in the future. The assumption is the statistics gathered by the ONS that we present in the introduction to the main report are sufficient for epidemiological data. Our research shows that behind each category of cause of death there is a range of life and death stories. These stories reveal that it is not enough to make assumptions about what is in any

category, for example ‘accidents’, and to work in preventative ways with it. It is not enough, for example, to accept that a certain number of children die from accidents and then to move from that figure to general accident prevention. Accident may be the ‘best fit’ category at the time, for a specific child, in specific circumstances. But that may not be because it is the most accurate category, or the most appropriate for prevention. Those involved in the categorising believe it to be so, but it cannot be known absolutely because, in the absence of a child death review process, the level of enquiry is inevitably limited. The accounts and observations in this report show that there is a lot that could be learned by enquiring more thoroughly into the deaths of each child, under any circumstances. In order to improve that enquiry process we recommend the following:

■ **Take an ecological approach to information gathering such as that recommended in the *Framework for the Assessment of Children in Need and their Families* (DoH et al., 2000).**

■ **Extend the scope of information gathering to cover the period prior to death to understand better how the child lived, either through interview or verbal autopsy through an extension of the family group conferencing model, used in child and family social work.**

■ **Improve recording of all information from admission into hospital to death or survival and transfer. Consider the possibility of using tape recorders or video to do this.**

■ **Gather better information on children who nearly die but survive.**

■ **Make interpreters more easily accessible to hospital staff and families when dealing with a life-threatening situation or death of a child.**

■ **Improve co-ordination of information to counteract fragmentation. A child death liaison role is required to work within the hospital.**

■ **Provide families with consistent follow-up, liaison with staff, open and honest information.**

■ **Implement in all hospitals a child death protocol such as the ‘green folder’ system in Hospital A.**

■ **Improve opportunities for staff to debrief and follow case outcomes, and identify staff support and training needs.**

■ **Improve liaison and integration of multi-disciplinary information between hospitals and community-based health and social services.**

■ **Extend current child death review procedures to make a more ecological approach; the US models of fatality review can be improved upon and adapted to a UK context. In particular, greater emphasis should be placed on the importance of social information, the child’s relationships and patterns of child rearing. An example of the type of information required is that given by the *Framework for the Assessment of Children in Need and their Families* (DOH et al., 2000).**

■ **A continued focus on serious case reviews only where child maltreatment has been a consideration, as proposed by the Victoria Climbié Inquiry (Laming, 2003) is likely to miss an unknown number of child maltreatment related deaths, since cases must be a priori categorised as child maltreatment and such a categorisation may not emerge unless there is further review.**

■ **Give further consideration to the extension of the role of the coroner in line with the *Review of Coroners* (Luce, 2003) and suggest that the coroner’s office is an appropriate place to situate the review process.**

- **Extend the child death review process to include a review of ‘near misses’.** This would require the development of a different protocol.
- **Responses should develop in acknowledgement of the difficulties of obtaining clear evidence and offer a more supportive approach to children and their siblings who could be identified as ‘uncertain’ cases by medical staff.**
- **Ensure there is greater support for children and their families where: a child who has come close to death for reasons which may be specified as ‘accidental’, *possible* or actual maltreatment, self-harm or where there are repeated admissions to hospital and the cause of the injury/illness is unclear, children in the same household as such children and those in a household where a child has died. Infants under 1 year may be considered vulnerable by virtue of their over-representation among children who die. Special consideration needs to be given to disabled children who may have repeated admissions that are not directly linked to their disabling condition.**
- **Increase levels of training for health and social care professionals on child death. However, training alone will not solve the difficulties of detection and needs to be accompanied by concerted action that resolves mistrust between agencies and identifies the impediments to pursuing cases as maltreatment related.**

These recommendations should be considered in light of the fact that hospital departments are routinely under-staffed and poorly resourced with little time for staff to provide follow-up on child death cases. Many of these recommendations would need more resources, although some require the development of different working practices within extant resources. In particular, more routinised systematic information collection on child deaths and near deaths could be incorporated at minimal cost with the required cooperation of staff.

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