The utility and challenges of using ICD codes in child maltreatment research:
A review of existing literature

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WORD COUNT (Abstract): 263
NUMBER OF TABLES: 4
LIST OF ABBREVIATIONS
AHT – acquired head trauma
ALTEs - apparent life threatening events
CRC - Convention on the Rights of the Child
CT – Computerised Tomography
DOA – dead on arrival
ED - emergency department
E-Code - external cause of injury codes
GCS - Glasgow Coma Score
ICD - International Classification of Diseases and Related Health Problems
ICISS - ICD Injury Severity Score
ICU – Intensive Care Unit
LOS – length of stay
MVC – motor vehicle crash
NAHI - non-accidental head injury
SBS – shaken baby syndrome
SDH - subdural haemorrhage
SIDS – Sudden Infant Death Syndrome
TBI- traumatic brain injury
TC – triage category
Abstract

Objective: The objectives of this article are to explore the extent to which the International Statistical Classification of Diseases and Related Health Problems (ICD) has been used in child abuse research, to describe how the ICD system has been applied and to assess factors affecting the reliability of ICD coded data in child abuse research.

Methods: PubMed, CINAHL, PsychInfo and Google Scholar were searched for peer reviewed articles written since 1989 that used ICD as the classification system to identify cases and research child abuse using health databases. Snowballing strategies were also employed by searching the bibliographies of retrieved references to identify relevant associated articles. The papers identified through the search were independently screened by two authors for inclusion, resulting in 47 studies selected for the review. Due to heterogeneity of studies meta-analysis was not performed.

Results: This paper highlights both utility and limitations of ICD coded data. ICD codes have been widely used to conduct research into child maltreatment in health data systems. The codes appear to be used primarily to determine child maltreatment patterns within identified diagnoses or to identify child maltreatment cases for research.

Conclusions: A significant impediment to the use of ICD codes in child maltreatment research is the under-ascertainment of child maltreatment by using coded data alone. This is most clearly identified and, to some degree, quantified, in research where data linkage is used.

Practice Implications: The importance of improved child maltreatment identification will assist in identifying risk factors and creating programs that can prevent and treat child maltreatment and assist in meeting reporting obligations under the CRC.

Keywords: Child maltreatment, ICD, health data
**Introduction**

Intentional injury plays a significant role in childhood morbidity and mortality. The WHO estimates that 53,000 children died from intentional injury in 2002 and intentional injury is as much as twice as high in low-income (2.58/100,000) countries as it is in high income countries (1.21/100,000) (World Health Organisation, 2006). The Convention on the Rights of the Child (CRC) stresses the importance of reducing child mortality and ensuring the provision of necessary medical assistance and health care to all children with an emphasis on the development of primary health care (Article 24)(United Nations, 1990).

With the 20th anniversary and therefore renewed interest in the CRC (20th anniversary) it is most important that all professionals dealing with child health and development acknowledge the principles of this landmark document. Of relevance to the issues addressed in this paper is in particular Article 19, which highlights the importance of protecting children from maltreatment. The importance of applied research and surveillance in providing data to monitor and evaluate progress in diminishing child maltreatment related mortality and morbidity cannot be understated.

National statistics on the incidence and prevalence of child maltreatment rely on various disparate data sources, including child protection databases, morbidity and mortality data. Not all maltreatment is reported to children’s services, and so will not be represented in jurisdictional protection data. Identification of inflicted injury in children in a clinical setting can be complex and confronting for medical and nursing staff. Some cases of child maltreatment are not identified and/or documented adequately and therefore may not be represented in morbidity or mortality statistics. Without standardised definitions of maltreatment and methods of capturing maltreatment in datasets it is difficult to gain a reliable estimate of the true magnitude of child
abuse in the community. Definitions of what constitutes child abuse vary across organisations, jurisdictions, and cultures.

The International Statistical Classification of Diseases and Related Health Problems (ICD) is the standard system used to classify health conditions in health datasets. Morbidity and mortality data are coded using this classification and it is the standard diagnostic classification system for epidemiological research and health management purposes (World Health Organisation, 2005). Trained clinical coders translate the written medical record into the alphanumeric codes from the ICD. Using this system, conditions can be coded according to the clinical diagnosis and external cause of injury (environmental events and circumstances that caused the injury). The diagnosis code provides information on the clinical findings or chief reason/s for hospital admission. The basic ICD injury codes consist of three characters or digits, with additional digits added to the three character codes at fourth and sometimes fifth character level for added specificity. The injury diagnosis code ‘T74 Maltreatment syndromes’ from ICD-10 can be assigned to indicate a clinical finding of abuse, with the fourth digits used to indicate different types of abuse (e.g. neglect, physical abuse, sexual abuse, psychological abuse, other and unspecified maltreatment) The external cause codes (E- Code) can be assigned in conjunction with injury diagnoses to describe what happened to cause the injury, the role of human intent in the injury, the activity of the person when they were injured and where the person was when they were injured. The use of the ICD to identify abuse in health datasets may assist in providing standardised estimates of the magnitude of child abuse.

Coding of any health condition or diagnosis relies on the clinical documentation. Documentation for morbidity data is generally collected from medical records and coded by clinical coders when the patient is discharged from hospital. Mortality data codes are assigned based on the cause of death documented when the death certificate is completed. If the
information in the source documentation is complete and accurate, this enables the code assignment to be complete and accurate. A competent and well trained clinical coder will be aware of and comply with the rules and conventions designed to ensure standardised application of codes. Identification of diagnoses of fractures, SDH or illness relies on diagnostic criteria whereby clinicians can support and explain their diagnosis because they are familiar with the criteria for each condition. These codes are likely to be reliable and provide an accurate picture of the incidence and patterns of these diagnoses. Diagnostic criteria for child maltreatment are more ambiguous. Clinicians report they are inadequately trained to make that decision. Consequently the documentation of child abuse in hospital records is often incomplete (Benger & Pearce, 2002; Limbos & Berkowitz, 1998) and clinical coders may not have adequate information to assign codes for abuse from hospital records. The determination that a child death resulted from child maltreatment is a coronial issue in many jurisdictions and therefore, may or may not appear on a death certificate as the cause of death before the case has been fully investigated. If a determination of child maltreatment/assault has not been made when the statistics are compiled, and the death was a result of the injuries sustained, coders should assign the default code of accidental death, in accordance with the coding requirements of the ICD. These factors may result in an under-representation of child maltreatment in both morbidity and mortality data. Equally the coding process may lead to under enumeration of child abuse deaths or hospitalisations if external causes are not coded or if coding is limited to one diagnosis because of a lack of resources or perceived need to code more extensively. Thus, statistics or studies that rely exclusively on abuse codes may misrepresent populations at risk when only health data is used (P. G. Schnitzer, Covington, Wirtz, Verhoeck-Oftedahl, & Palusci, 2008).

This study aimed to systematically review the use of ICD in child abuse research.
**Methodology**

**Study Question**

How is the ICD used in child abuse research in health databases, how has the ICD system been applied and what factors have been identified that affect the reliability of ICD coded data in child abuse research?

**Search Strategy**

The electronic databases PubMed, Google Scholar, PsychInfo and CINAHL were searched for peer reviewed papers using the following search phrase: ("child maltreatment" or "child abuse") and (ICD* or classification or coding) and (hospital or emergency department or ED or outpatient or inpatient)) AND injury. Google Scholar was searched without inclusion of the term “ICD” because it did not recognise the term.

This identified 512 papers to be screened for inclusion/exclusion. The abstracts of all papers were reviewed by 1 author (DS) and 380 were excluded leaving 132 papers for final consideration. Two authors (DS and KM) reviewed the 132 papers and determined 38 papers met all inclusion and exclusion criteria. Snowballing was used to identify 11 further papers (not identified from the original search) from bibliographies of relevant papers.

**Inclusion/exclusion criteria**

Papers were included if they met the following inclusion criteria:

- Specifically mentioned the use of ICD in methodology
• Demonstrated the use ICD to locate and report on injury-child maltreatment (not domestic violence unless directed to specific child maltreatment) in routinely collected health data sources such as, ED, inpatient, outpatient, hospital or mortality databases

• Published in a peer reviewed journal, not conference proceedings

• Published in the last 20 years (since 1989)

• Original paper – not comments

• English language

• The paper focussed on child abuse and not mental health issues that mentioned child maltreatment as a risk factor

• The research was not directed at research of child maltreatment perpetrators (we included cases only)

Papers that discussed identifying children or injury types from databases or health data but did not mention that ICD was the method used to identify the cases were excluded from the review as it could not be assumed that all of these studies relied on ICD to do so.

_Synthesis of Study Results_

Papers were reviewed and summarized in tabular and text form. Heterogeneity of studies precluded meta-analysis.
Results

The literature contains a number of papers where ICD codes in health databases have been used to research child maltreatment. Based on the aims of the papers, these clustered into four broad categories as follows:

1. Estimates the incidence of child abuse
2. Describes patterns and characteristics of child abuse estimating risk of death or injury from documentation
3. Evaluates concordance between databases and/or evaluates the use of child abuse codes
4. Estimates the costs of child abuse

These categories were not seen as exclusive and some papers are included in more than one category.

Articles estimating the incidence of child abuse

Table 1 identifies 9 papers where the focus of the study was on estimating the incidence of child abuse in the community (Barlow, Milne, Aitken, & Minns, 1998; Ellingson, Leventhal, & Weiss, 2008; Ewigman, Kivlahan, & Land, 1993; Herman-Giddens et al., 1999; Jayawant et al., 1998; Kelly & Farrant, 2008; John M. Leventhal, Martin, & Asnes, 2008; P. G. Schnitzer et al., 2008; Sills, Libby, & Orton, 2005). In all studies, the ICD codes were used to identify children to include in the study. Three types of child abuse related injury were identified: fatalities, fractures and head/brain injury. Most articles found that the use of the ICD codes alone resulted in under-identification of child abuse victims. Herman-Giddens found that cause of death coding under ascertained abuse homicides by nearly 62% (Herman-Giddens, 1991) and Schnitzer et al found that child welfare agencies and death certificate data underestimate abuse related
deaths by 55-75% and 80-90% respectively. In their study on SDH, Jayawant et al. noted that 18.2% of children admitted for SDH had previously presented with a diagnosis of general malaise and drowsiness (Jayawant et al., 1998).
<table>
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<tr>
<th>Author, Year</th>
<th>Study aim</th>
<th>Data source</th>
<th>Use of ICD</th>
<th>ICD codes used</th>
<th>Results/Conclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Barlow, Milne et al. 1998</td>
<td>Examine incidence and characteristics of inflicted head injury in Scotland</td>
<td>Administrative Health Database</td>
<td>ICD-9 codes for child battering or other maltreatment accompanied by diagnosis of intracranial injury in children younger than 15 years of age</td>
<td>E9670, E9679 and E9671 together with a diagnosis of intracranial injury (852, 8520, 8521, 853, 8530, 8531, 854, 8540, 8541)</td>
<td>Believe system of child maltreatment and NAHI to be inaccurate and in some instances the diagnosis may not become apparent until after discharge when social work investigation has been completed. There is a strong argument for NAHI to be given a unique ICD code.</td>
</tr>
<tr>
<td>Ellingson, Leventhal et al. 2008</td>
<td>Estimate the national incidence of hospitalisations due to inflicted TBI in infants &lt;1 year in the USA</td>
<td>Inpatient database</td>
<td>ICD-9 was used to identify TBI and abuse in children younger than 1 year</td>
<td>800.1-800.4, 800.6-800.9, 801.1-801.4, 801.6-801.9, 803.1-803.4, 803.6-803.9, 804.1-804.4, 804.6-804.9, 850.0-850.9, 851.0-851.9,852.0-852.5, 853.0-853.1, 854.0-854.1,995.5, E960-E9666, E967, E968, E969</td>
<td>TBI incidence rates of: 27, 27.5 and 32.2 cases per 100,000 for the years 1997, 2000 and 2003. During that time the number of cases of Medicaid insured children increased</td>
</tr>
<tr>
<td>Ewigman, Kivlahan et al. 1993</td>
<td>Investigate suspicion that maltreatment fatalities in Missouri were underreported</td>
<td>Data linkage</td>
<td>Used ICD-9 on death certificates to identify injury fatalities.</td>
<td>800-999 on death certificates</td>
<td>Serious under-reporting of maltreatment fatalities due to inadequate investigation of child fatalities, failure of agencies</td>
</tr>
</tbody>
</table>
Herman-Giddens, Brown et al. 1999

Describe the true incidence of fatal child abuse, to determine the proportion of child abuse deaths missed by vital records system and provide estimates of extent of abuse homicide in young US children and their under ascertainment in US vital records.

Medical Examiner information system

ICD-9 codes for child abuse as underlying cause of death in children younger than 11 years of age.

ICD-9 codes E960-E969 as underlying cause of death

to share information, characteristics of reporting systems that fail to capture contribution of maltreatment to death.

ICD-9 cause of death coding under ascertained abuse homicides by nearly 62%. 84.9% of homicide was due to abuse with rate of 2.8/100,000 in 1994. Black children and males most at risk, most likely perpetrators were parents.

Jayawant, Rawlinson et al. 1998

Identify the incidence and outcome of SDH and to determine how many cases were due to child abuse, what investigations were conducted and what factors were associated in children <2 in Wales.

Hospital admission data

Identify diagnosis of SDH in children under 2 years of age (ICD-9)

432.1, 851.0, 852.0, 852.1, 767.0, 336.1

33 children identified (69.7% males), incidence of 12.8/100,000. 27.3% died, 45.5% had profound disability. Clinical presentation varied from general malaise to DOA (12.2%) 18.2% had previous admissions for drowsiness and lethargy. 78.8% had a CT, 81.8% had skeletal survey only 66.7% had full series of basic
<table>
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<tr>
<th>Authors</th>
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<th>Database/Approach</th>
<th>ICD-9 Diagnoses</th>
<th>Note</th>
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<tbody>
<tr>
<td>Kelly and Farrant</td>
<td>Describe the New Zealand incidence of infantile SDH, medical investigations,</td>
<td>Surveillance and Administrative Health Databases</td>
<td>P100, P528, I620, S065</td>
<td>14 cases gave clear history of shaking but not as first story</td>
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<tr>
<td>2008</td>
<td>diagnoses, short-term neurological outcome and demographic characteristics,</td>
<td>in order to guide further local research in prevention, diagnosis and treatment</td>
<td></td>
<td>126 cases were identified and 92 were deemed to be non-birth related</td>
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<tr>
<td></td>
<td>, in order to guide further local research in prevention, diagnosis and</td>
<td></td>
<td></td>
<td>trauma. Intent was undetermined in 16 cases, 48 were inflicted injuries</td>
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<tr>
<td></td>
<td>treatment</td>
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<td>and 28 were non-inflicted injury. Incidence rates were considered to</td>
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<td>be likely to be underestimates at 14.7/100000. Maori population</td>
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<tr>
<td>Leventhal, Martin et al.</td>
<td>Estimate the incidence and most common location of abuse related fractures and to describe the characteristics of children with abuse related fractures, compare observed incidence with population based study of abusive fractures in the USA.</td>
<td>Hospital discharge data. All children &lt;36 months with discharge diagnosis of fracture. Used E-codes to determine cause and child abuse was identified using assault code or maltreatment code.</td>
<td>800-829, 995.5, assault codes E960-E969 and E codes to categorise the cause of fractures (falls, motor vehicle accidents, other accidents, undetermined intent, bone abnormalities, metabolic abnormalities, birth trauma or no injury E-code.</td>
<td>Hospitalised fractures are abuse related 25% of the time (36.1/100,000) in children &lt;36 months of age. Administrative health data useful for monitoring serious injuries over time and place.</td>
</tr>
<tr>
<td>Schnitzer, Covingto n et al.</td>
<td>Describe approaches to surveillance of</td>
<td>Data linkage. Child abuse deaths were identified in ICD-10 codes, Y06, Y07 and T74</td>
<td></td>
<td>Found 258 (California) 192 (Michigan) and 60</td>
</tr>
</tbody>
</table>
2008 fatal child maltreatment and to identify options for improving ascertainment

various sources of data reviewed by Child Death Review Teams in California and Michigan and ICD-9 codes E960 – E969 and ICD-10 codes X85-Y09 in Rhode Island (Rhode Island) deaths. Maltreatment fatality rates ranged from 2.5/100,000 in Michigan to 8.8/100,000 in Rhode Island. Child Welfare agencies and death certificate data underestimate deaths by 55%-76% and 80%-90% respectively. Combining more than 2 data sources was likely to improve ascertainment to 90%

Sills, Libby et al. 2005 To describe the incidence and case-fatality rates of TBI in young children in Colorado, to compare these injuries based on intentionality and outcome

Survey surveillance data TBI was identified using ICD 9 and ICD 10 codes ICD-9 – 995.5x, E967x, E968x, E810-E829, E880-E888 ICD-10 – T74.8, Y07

340/1333 had ITBI. Incidence 16.1/100,000, ITB had higher case-fatality, in hospital death rate and severity. ITBI deaths twice as likely to occur in hospital. Effect of intentionality increased with increasing age and was significantly associated with mortality
To improve data capture, data linkage has been used with one study suggesting the combination of more than two data sources could improve ascertainment by up to 90% (P. G. Schnitzer et al., 2008). Barlow et al, suggested that in some instances the diagnosis may not become apparent until after discharge when social work investigation has been completed, and they also recommended that NAHI should be given a unique ICD code (Barlow et al., 1998).

*Papers describing patterns and characteristics of child abuse*

Table 2 includes 34 studies which described patterns and characteristics of child maltreatment. These are presented as studies that used ICD codes to identify:

1. an injury diagnosis and then described characteristics related to abuse within those injury types
2. instances where abuse and injury diagnosis were identified in the data
3. abuse through the codes
4. diagnoses other than injury and then described maltreatment within those diagnosis codes.
Table 2: Papers describing patterns and characteristics of child maltreatment

<table>
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<tr>
<th>Author, Year</th>
<th>Study aim</th>
<th>Data source</th>
<th>Use of ICD</th>
<th>ICD Codes used</th>
<th>Results/Conclusions</th>
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<tbody>
<tr>
<td>Agran, Anderson et al. 2003</td>
<td>Analyse injury in children &lt;4 years to determine links between specific cause of injury and age in California</td>
<td>Hospital discharge data and death certificates</td>
<td>Children &lt;4 years old and had principal E-code of E800-E869, E880-E929 or E950-E999 were included. E-codes were grouped into major categories that would be particularly relevant for developmentally related risks of injury specific to young children.</td>
<td>ICD-9 E800-E869, E880-E929 E950-E999</td>
<td>Children aged 15-17 months had highest rates of injury. High rate of battering injury among infants 0-5 months, suggesting the need to address potential child maltreatment in the perinatal period. Injury from battering may be underreported because of insufficient or incomplete information at hospital discharge regarding intention. Unrecognised or undocumented cases of abuse may inflate other causes, such as falls.</td>
</tr>
<tr>
<td>Arbogast, Margulies et al. 2005</td>
<td>Study presenting characteristics of deaths through intentional and unintentional neurologic injury in infants and toddlers in Pennsylvania</td>
<td>Trauma Outcome Study</td>
<td>All children &lt;48 month of age with fatal head injuries with E-codes (ICD-9-CM) for inflicted injury, falls, MVCs were selected from database.</td>
<td>E967,E880-E888, E810-E819</td>
<td>Status at presentation is dependent on age and mechanism of injury. Children &lt;24 months with inflicted injury were more likely to present with moderate GCS than those from car crash and &lt;2 also more likely to present with GCS score of &gt;12</td>
</tr>
<tr>
<td>Barr, Trent et al. 2006</td>
<td>Use age specific incidence of hospitalised cases of SBS to determine if there is a link between the ‘normal crying curve’ and crying as a stimulus for SBS</td>
<td>California discharge data</td>
<td>Identified cases of SBS using ICD-9-CM</td>
<td>995.55</td>
<td>There are similarities between the normal crying curve and incidence of hospitalised SBS, with the peak occurring 4-6 weeks later in the SBS sample. This may be due to the possibility of repeat shakings prior to hospitalisation. The importance of crying as a stimulus</td>
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<tr>
<td>Study</td>
<td>Research Question</td>
<td>Data Sources</td>
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<tr>
<td>Brown and Fisher 2004</td>
<td>Describe femur fractures from national database</td>
<td>US hospital discharge data</td>
<td>Used ICD-9-CM codes for fracture of the femur to identify children &lt;6 years</td>
<td>ICD-9-CM 820-821.39 Data suggest that an infant has as great a chance of sustaining a fractured femur from abuse as an older child does from all causes. Efforts to prevent femur fractures in children should focus on preventing physical abuse in infants and accidental injury in the 2-3 year old child</td>
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<tr>
<td>Chadwick, Bertocci et al. 2008</td>
<td>Develop an estimate of the risk of death resulting from short falls in children under 5 in USA</td>
<td>Literature and Injury surveillance data</td>
<td>Identified cases using ICD</td>
<td>Morbidity – E-codes from ICD-9-CM. Mortality – W-codes from ICD-10 967.0-967.9 Best current estimate of the mortality rate is &lt;0.48 deaths per 1 million children per year. More research is needed</td>
<td></td>
</tr>
<tr>
<td>Chang, Knight et al. 2004</td>
<td>Define the characteristics of a group of abused children presenting to a paediatric trauma service in the USA</td>
<td>Trauma Registry data</td>
<td>Cases and their perpetrators were identified using ICD codes</td>
<td>E-codes from ICD-9-CM. Mortality – W-codes from ICD-10 967.0-967.9 Abused children higher injury severity score, had longer LOS, higher risk of death</td>
<td></td>
</tr>
<tr>
<td>Chang, Knight et al. 2005</td>
<td>Validate the Screening Index for Physical Child Abuse (SIPCA)</td>
<td>Hospital discharge data</td>
<td>ICD-9-CM</td>
<td>800-959 Child abuse cases were successfully identified by E codes and certain ICD-9-CM codes in the 995.5x range</td>
<td></td>
</tr>
<tr>
<td>Guenther, Knight et al. 2009</td>
<td>Examine whether there are specific patterns of ED use unique to children later found by child protective services to be maltreated compare with the general ED population</td>
<td>Utah child protection data, birth certificate, death certificate, data</td>
<td>ICD was used to describe patterns of ED use and to compare patterns between abused and non-abused groups</td>
<td>Top 6 ICD-9 diagnosis codes from discharge data grouped into broad categories for analysis Most abused children are not seen in ED prior to abuse diagnosis. Most visits occur 1 month or more prior to abuse diagnosis and the diagnostic codes don't differ between abused and non-abused groups. No flags to allow early identification of children at risk of abuse in EDs were identified</td>
<td></td>
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<tr>
<td>Jaudes and Mackey-</td>
<td>Examine whether chronic health conditions place</td>
<td>Illinois Medicaid and child</td>
<td>Used ICD-9-CM to identify children with Asthma – 49390, 49300</td>
<td>Young, low-income children receiving public health insurance</td>
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</table>
Bilaver 2008  young children at risk of abuse, and to what extent this occurs protection data (probabilistic data linkage) chronic conditions. Developmental delay or mental retardation 3153.9, 3158, 3155, ADHD, emotional disturbances, conduct disturbances 3140.1 3138, 3129 with an identified behavioural/mental health issue are at an increased risk of maltreatment. Future research should examine causal pathways between these factors. This research points to the need for child protection agencies to identify behavioural/mental health conditions as a risk factor for maltreatment. In 1997 only 7 states listed disability in their records.

Keenan, Marshall et al. 2004 Determine if TBI in children increases during a disaster in North Carolina Medical records Children <2years who were admitted to ICU or died from TBI (via medical records using ICD-9 codes for TBI retrospectively, and through the office of the medical examiner for deaths 800.0-800.4, 800.6-800.9, 801.1-801.9, 803.1-803.4, 803.6-803.9, 804.1-804.9, 850.0-850.9, 851.0-851.9, 852.0-852.5, 853.0-853.1, 854.0-854.9, 959.8-959.9 Study shows that following a natural disaster there is an increase in both inflicted TBI and non-inflicted TBI in children under 2 years of age

Kelly and Farrant 2008 Describe the incidence, characteristics, diagnoses, investigations, outcomes and demographics of infantile SDH in New Zealand to inform further study, treatment and policy Surveillance data and Hospital discharge data Search for codes related to SDH P100, P528, I620, S065 New Zealand SDH in infants is similar to other countries

King, MacKay et al. 2003 Describe clinical characteristics and outcome of children admitted to hospital with SBS Hospital discharge data Records were reviewed for ICD-9 codes relative to SBS to ensure case ascertainment. 1988 to March 1996 - 995.5, E967.0, E967.1, E967.9 April 1996-1998 – 995.55, 995.54, E967.0, E967.9 SBS typically has a non-specific presentation and is a serious condition for children. More research to establish true incidence of SBS, identify vulnerable children, develop and evaluate prevention strategies

Lane, Rubin Determine if reporting and Hospital Used ICD to identify Fractures of Suggests there is a difference in
<table>
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<th>Data Source</th>
<th>Main Findings</th>
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<tr>
<td>et al. 2002</td>
<td>Evaluation of abuse in children with fractures varies by race in the USA</td>
<td>Discharge data</td>
<td>Cases of fractures of long bones or skull; humerus, radius, ulna, femur, tibia or fibula (actual codes not specified) reporting based on race, particularly in toddlers</td>
</tr>
<tr>
<td>Leslie, Landsverk et al. 2000</td>
<td>Determine influences for children in foster care for outpatient mental health service use in the USA</td>
<td>Medicaid Claims data</td>
<td>Identification of ICD-9 mental health diagnoses during the 18 months post placement in care</td>
</tr>
<tr>
<td>Leventhal, Martin et al. 2008</td>
<td>Estimate the incidence and most common location of abuse related fractures and to describe the characteristics of children with abuse related fractures, compare observed incidence with population based study of abusive fractures in the USA</td>
<td>Hospital discharge data</td>
<td>Identification of ICD-9 mental health diagnoses during the 18 months post placement in care. All children &lt;36 months with discharge diagnosis of fracture. Used E-codes to determine cause and child abuse was identified using assault code or maltreatment code.</td>
</tr>
<tr>
<td>Loder and Feinberg 2007</td>
<td>Describe characteristics and demographics of abuse related hospitalisations in the USA</td>
<td>Hospital discharge data</td>
<td>Identified children &lt;21 with ICD codes for musculoskeletal and related injury and supplemental codes for identification of the perpetrator of abuse (E967)</td>
</tr>
<tr>
<td>McPhilips, Gallaher et al. 2001</td>
<td>Determine if infants hospitalised in first 3 months of life are at increased risk for serious injury in childhood</td>
<td>Discharge data and death certificate data</td>
<td>Discharge diagnosis, ICD-9-CM N codes and ICD9-CM E codes (specific codes not specified). Fractures of skull, femur, ribs, sternum, humerus; children under age of 2, particularly if associated with Medicaid are all associated with increased likelihood of abuse. 17% of abused children also had psych related conditions. A child hospitalised in first 90 days of life has 50% increased risk of serious injury in remainder of childhood. They are also 3 times more likely to be</td>
</tr>
<tr>
<td>Source</td>
<td>Title</td>
<td>Description</td>
<td>Methodology</td>
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<tr>
<td>Myhre, Grønhaug et al. 2007</td>
<td>Describe the presenting characteristics, type of injury and hospital course in young children with TBI in Norway</td>
<td>Hospital discharge and Trauma Registry data</td>
<td>Children with head injury were identified using ICD codes provided</td>
</tr>
<tr>
<td>Overpeck, Brenner et al. 1998</td>
<td>Assess the timing of deaths and risk factors for child homicide</td>
<td>Linked birth and death certificates</td>
<td>Homicides were identified using ICD Ecodes</td>
</tr>
<tr>
<td>Peclet et al, 1990</td>
<td>Describe patterns of injury among children admitted to an urban paediatric trauma centre</td>
<td>Registry data</td>
<td>Identified children &lt;15 admitted between 1985-1988 with ICD-9-CM codes for injury</td>
</tr>
<tr>
<td>Petridou, Moustaki et al. 2001</td>
<td>Describe the epidemiological patterns risk factors of hospital-treated intentional</td>
<td>ED data</td>
<td>Prospective collection of children &lt;15 presenting for treatment of an injury</td>
</tr>
</tbody>
</table>
childhood injuries in Greece. between September 1985 and June 1988 Intentional injury was classified ICD-9-CM prolonged hospital stay), increase with age, are more common in migrant children, among boys, on the weekend, later at night or early morning hours.
ICD codes are frequently used to identify a specific injury type or group for further analysis. Agran et al, Peclet et al, Saluja, Siegel et al and Smith and Adler used the broad categories of external cause codes or injury diagnoses to provide more detailed information on those injuries related to abuse (Agran et al., 2003; Peclet et al., 1990; Saluja, Marquez, Cheng, Trumble, & Brenner, 2007; Siegel et al., 1996; Smith & Adler, 1991). Smith and Adler and Peclet researched children under the age of 15 and found that abuse was only coded in 1% of injury cases (Smith & Adler, 1991) and Peclet et al found that victims of child maltreatment related injury, when compared to other injury mechanisms, were younger, had most severe injury, stayed longest in hospital, had higher associated costs of care, and the highest mortality rate (Peclet et al., 1990). Saluja et al used ICD codes from injury surveillance data to identify adolescents who had been maltreated and found females were more prevalent than males and that the most common type of injuries were contusions and the most common to the head and neck and contusions (Saluja et al., 2007). Agran et al investigated injury in children under 4 years of age with an ICD code for injury and found that those between the ages of 15 and 17 months had the highest rates of abuse (Agran et al., 2003). Siegel et al investigated infant injury deaths with injury as a primary or secondary cause of death and found that young maternal age, marital status and black race were significant risk factors for abuse related deaths (Siegel et al., 1996).

Barr et al and King et al investigated SBS in children (Barr, Trent, & Cross, 2006; King, MacKay, & Sirnick, 2003) and noted that SBS typically had a non-specific presentation, ranging from decreased levels of consciousness, seizures and decreased levels of consciousness, and they indicated that measuring the true incidence of SBS was a challenge given the secrecy of the
injury circumstances and the range of presenting characteristics and risk factors. (King et al., 2003).

Keenan et al, Kelly and Farrant, Myhre et al, Sanders et al and Sills et al investigated TBI, subdural haemorrhage and head injury in children using ICD-9 diagnostic codes (H. T. Keenan et al., 2003; Kelly & Farrant, 2008; Myhre, Grogaard, Dyb, Sandvik, & Nordhov, 2007; Sanders, Cobley, Coles, & Kemp, 2003; Sills et al., 2005). Kelly and Farrant noted that data collection on NAHI was spread across health, child protection and law enforcement agencies, making identification of all cases difficult (Kelly & Farrant, 2008). Keenan found there was an increase in inflicted and non-inflicted TBI in children under 2 years of age following a natural disaster (Heather T. Keenan, Marshall, Nocera, & Runyan, 2004). Sills et al used ICD codes to categorise intentionality and to calculate the injury severity using the ICISS and found the injury mechanism to be documented in 96% of cases and of those with an intentional injury, 93% had data related to the perpetrator (from the 4th digit of E-code 967). They commented that because intentionality is not well documented in ICD-9 codes, the intentional injury may have been underestimated, weakening the effect of intentionality (Sills et al., 2005). Trokel and Lane included fractures of the long bones and skull or femur fractures and TBI in their research (Lane, Rubin, Monteith, & Christian, 2002; Trokel, Waddimba, Griffith, & Sege, 2006). Trokel investigated the role that hospital type played in the diagnosis of abuse finding that younger, more severely injured, privately insured and those admitted to a children’s hospital were twice as likely to be diagnosed as abused as those admitted to general hospitals (Trokel et al., 2006). Lane et al found that there is a difference in reporting and evaluation of abuse in children with fractures based on race, particularly in toddlers (Lane et al., 2002).

Brown and Fisher, and Strait et al examined fractures of the femur and humerus respectively by using ICD codes to identify specific fractures (Brown & Fisher, 2004; Strait, Siegel, &
Shapiro, 1995) and found that an infant has as great a chance of sustaining a fractured femur from abuse as an older child does from all causes (Brown & Fisher, 2004) and suggested that any child less than 15 months of age presenting with a supracondylar fracture of the humerus must have a diagnosis of maltreatment considered (Strait et al., 1995). Trokel et al made similar recommendations stating that if an abdominal injury is not associated with a motor vehicle crash, child maltreatment should be considered (Trokel, DiScala, Terrin, & Sege, 2004).

Researchers have also used combinations of injury diagnoses, external cause codes, and specific codes for abuse to identify cases for inclusion (Arbogast, Margulies, & Christian, 2005; J. M. Leventhal et al., 2007; Loder & Feinberg, 2007; Ricci, Giantris, Merriam, Hodge, & Doyle, 2003). Leventhal et al identified fractures using ICD-9-CM codes and abuse by the presence of an E-code for assault or the ICD-9-CM code for maltreatment and concluded that fractures requiring hospitalisation in children under 36 months were abuse related 25% of the time (J. M. Leventhal et al., 2007). Loder et al identified an association for children under the age of 2 years between fractures of the skull, femur, ribs, sternum and humerus and child abuse (Loder & Feinberg, 2007).

Arbogast compared presenting characteristics of deaths through intentional and unintentional neurological injury in infants and toddlers and found that children younger than 24 months with inflicted injury were more likely to present with moderate GCS than those from a car crash (Arbogast et al., 2005). Ricci et al used linked data to describe the clinical characteristics of a sample of children, by using ICD-9 codes for intra-cranial trauma to identify the children, perform medical record reviews and then to compare results between medical, child protective and law enforcement agencies. In many circumstances, children with AHT are seen by medical providers but not identified as having been abused. In contrast, all cases of abuse were identified for children from two tertiary teaching hospitals (Ricci et al., 2003).
Chang et al. and Petridou studied children who were identified as having presented to hospital for an injury, through inclusion in a trauma registry database or via an electronic patient register and ICD codes were used to identify abuse cases and perpetrators (D. C. Chang et al., 2004) and to further classify intentional injury details gained from survey data (Petridou, Moustaki, Gemanaki, Djeddah, & Trichopoulos, 2001). Overpeck used data linkage of birth and death certificates and identified homicides using ICD codes and found that infanticide was more common in children where mothers had numerous children when very young (Overpeck, Brenner, Trumble, Trifiletti, & Berendes, 1998).

Links between mental health conditions or other chronic diseases and child abuse were the focus of a number of other studies with two studies investigating links between child abuse and chronic illness and finding chronic health conditions, mental health or behavioural conditions placed children at increased risk of child abuse, particularly in low income families (Jaudes & Mackey-Bilaver, 2008; Spencer et al., 2005). Leslie et al reviewed a group of children who had been placed in foster care and found that nearly half required at least one outpatient mental health visit and the number of visits increased with the age of the child (Leslie et al., 2000). Truman and Ayoub used ICD codes to identify ATLEs, SIDS or unexplained deaths in children under four and recommended that risk factors for abuse should include; presence of blood in the mouth or nose, bruising that was inconsistent with resuscitation efforts, and siblings with apnoea, ALTEs or SIDS (Truman & Ayoub, 2002).

Thyen et al identified that physician reports of child abuse and neglect varied according to other conditions seen in children, with poisoning more likely to be associated with concerns about neglect than abuse and more likely to be reported to child protection authorities than other conditions, and head trauma associated with concerns of maltreatment (Thyen, Leventhal, Yazdgerdi, & Perrin, 1997).
Two studies used ICD codes to describe patterns of hospital use and found that children hospitalised in the first 90 days of life were also three times more likely to be hospitalised with an abuse related injury before 24 months of age (McPhilips, Gallaher, & Koepsell, 2001) children with more than one injury presentation were more likely to have been maltreated and children with public insurance and African-American heritage were most likely to have a maltreatment report and substantiated maltreatment (Spivey, Schnitzer, Kruse, Slusher, & Jaffe, 2008).

Guenther et al examined whether there were specific patterns of ED use unique to children later identified as having been maltreated and showed that most abused children are not seen in ED prior to a maltreatment diagnosis and that the diagnostic codes for other conditions do not differ between abused and non-abused groups, with no flags to allow early identification of children at risk of abuse identified in EDs (Guenther, Knight, Olson, Dean, & Keenan, 2009).

The final paper included in the review used ICD codes for abuse to validate a screening tool developed by the authors by identifying maltreatment cases by E codes and certain ICD-9-CM codes in the 995.5x range. It was found that an application of the instrument could assist clinicians in detecting physical child abuse cases among paediatric trauma patients (David C. Chang, Knight, Ziegfeld, Haider, & Paidas, 2005).

**Papers Comparing Findings in Databases or Validating Coding**

Table 3 shows five papers that aimed to compare results across different databases or to validate coding in existing databases. These papers fell into two broad categories; those that used linked data to compare child abuse information in separate databases (Olsen & Durkin, 1996; Patricia G. Schnitzer, Slusher, & Van Tuinen, 2004) and those that attempted to validate codes for abuse related hospital admission or presentation (S. Rovi & Johnson, 1999; Sue Rovi & Johnson, 2003; Winn, Agran, & Anderson, 1995).
<table>
<thead>
<tr>
<th>Author, Year</th>
<th>Study aim</th>
<th>Data source</th>
<th>Use of ICD</th>
<th>ICD codes used</th>
<th>Results/Conclusions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Olsen and Durkin 1996</td>
<td>Describe concordance between health data and death certificate data in relation to fatal paediatric injury intent</td>
<td>Hospital discharge and death certificate data</td>
<td>Used ICD to select fatal injuries from discharge data for comparison with death certificate data</td>
<td>E929.0-E929.9, E870.0-E879.9</td>
<td>Hospital data underestimate intentional fatal injuries in children, particularly in very young or white children</td>
</tr>
<tr>
<td>Schnitzer, Slusher et al. 2004</td>
<td>Use linked health and child protection data to describe the epidemiology of nonfatal child abuse in Missouri</td>
<td>Discharge data and child safety data</td>
<td>ICD codes for maltreatment in discharge data were used to identify children for inclusion</td>
<td>995.0-995.59, 994.2-994.3, E967.0-E967.9, E968.4, E904.0-E904.2, V15.41, V15.42, V15.49, V61.21</td>
<td>Medical data was more likely to identify female, African American infants, physical abuse or children seen at urban hospitals. Neglect not well identified in PAS data. 12% more cases were identified using data linkage than using only child protection</td>
</tr>
<tr>
<td>Rovi and Johnson 1999</td>
<td>Determine whether or not physicians code child or adult abuse.</td>
<td>National Ambulatory Medical Care Survey (NAMCS) and the National Hospital Ambulatory Medical Care Survey (NHAMCS)</td>
<td>Frequency counts of ICD codes for abuse were conducted</td>
<td>To 1997-995.5, 995.81 From 1997-995.50, 995.51, 995.52, 995.53, 995.54, 995.55, 995.59, 995.80, 995.81, 995.82, 995.83, 995.84, 995.85</td>
<td>93 cases of adult or child maltreatment between 1993 and 1996 in 351, 359 patient visits. There were more abuse diagnoses by ED physicians than other physicians. Child abuse was more likely to be coded than adult abuse. The numbers identified using either the maltreatment codes or the E-codes for assault resulted in an underestimation of abuse. Most 'experts' are reluctant to assign codes for abuse because of potential problems with insurance, lack of resources to deal with the problem once coded to abuse and not something else and the fear that it will do more harm than good More education on the use of codes and more resources to address the underlying issues of violence</td>
</tr>
<tr>
<td>Rovi and Johnson 2003</td>
<td>Gain an understanding on reasons why ICD diagnostic codes for maltreatment (adult and child) are underutilised</td>
<td>Qualitative study</td>
<td>Focus groups were conducted to ask experts questions on coding of issues related to abuse.</td>
<td>NIL</td>
<td></td>
</tr>
</tbody>
</table>
Winn, Agran et al. 1995  | Determine how well violence related injury in children is identified by E-coded hospital data  | Injury surveillance data  | Injury related hospital admissions or deaths were identified using ICD E codes  | E950- E969, E980  |

are needed. 25% of violence related injury was not identified by E-code Using violence related E-codes is likely to underestimate ascertainment of violence related injury
Olsen et al linked hospital discharge data and death certificate data to describe the concordance between health data and death certificate data in relation to fatal paediatric injury intent. Their results found that hospital data underestimated intentional fatal injuries in children, particularly in very young or white children compared to death certificate data and suspect that this may be partly explained by health professionals choosing to deny or ignore evidence of child abuse (Olsen & Durkin, 1996).

Schnitzer et al linked hospital discharge data to child protection data and found that medical data was more likely to identify female, African American infants, those with physical abuse or children seen at urban hospitals. They also found that neglect was not well identified in discharge data as ICD codes are not a sensitive indicator of child neglect. The authors suggested that by accessing the patient record, they may have been better able to assess the magnitude of this underestimation. However, even with the under-estimation the authors found that approximately 12% more cases were identified using data linkage with hospital morbidity data than using only child protection data (Patricia G. Schnitzer et al., 2004).

Two studies attempted to determine how well abuse or violence was coded in health and injury surveillance data (S. Rovi & Johnson, 1999; Winn et al., 1995). Rovi and Johnson used the ICD-9 codes for abuse to identify the frequency of use of the codes. The authors expected to find abuse related codes in at least 1% of patient visits but found only 93 cases in a sample of 351,359 patient visits. The authors suggest that physicians are treating cases but not coding the abuse as a diagnosis (S. Rovi & Johnson, 1999). Similarly, Winn et al used injury surveillance data to determine how well E-coded data identifies abuse or violence related injury in children under 15 years of age. Cases were identified using E-codes and then a medical record review conducted. They found that 25% of violence related injury was not identified by E-code and that using violence related E-codes is likely to underestimate the number of violence related injuries. The
authors suggest that this under-representation may be due to a lack of training for clinicians on assigning the E-codes, the subjective aspects of the interpretation of these codes and inadequate documentation in the medical record to determine intentionality (Winn et al., 1995). Rovi and Johnson sought to gain an understanding of reasons why ICD diagnostic codes for maltreatment (adult and child) are underutilised and through qualitative survey results found that most 'experts' are reluctant to assign codes for abuse because of potential problems with insurance, lack of resources to deal with the problem once coded to maltreatment and the fear that assigning abuse codes will do more harm than good (Sue Rovi & Johnson, 2003).

**Papers using ICD to estimate health care costs of child maltreatment**

Two papers used ICD codes to estimate health-care costs associated with maltreatment related hospital admissions (Libby, Sills, Thurston, & Orton, 2003; Sue Rovi, Chen, & Johnson, 2004). Rovi et al used ICD-9-CM codes and found that, when compared to non-abuse related admissions, children admitted for abuse had twice the levels of cost ($19266 vs. $9513), were more likely to have come via ED, have longer stays, have more diagnoses, be black and to be insured by Medicaid. They comment that their study is limited because of the under-identification, under-diagnosis and under-coding of child abuse, particularly in non-teaching hospitals (Sue Rovi et al., 2004). Similarly, in their research on the costs associated with TBI, Libby et al found that children under three years who were admitted with an inflicted TBI (ICD-9 codes), had a higher percentage of Medicaid insurance, higher mortality and higher average injury severity, and inflicted TBI was significantly related to LOS and TC (52% higher LOS and 89% higher TC). The authors comment that their study is limited by the potential mis-categorisation of intent due to the reliance on coded data and the likelihood that cases of inflicted injury were missed (Libby et al., 2003).
### Table 4: Papers using ICD to estimate health care costs of child maltreatment

<table>
<thead>
<tr>
<th>Author, Year</th>
<th>Study aim</th>
<th>Data source</th>
<th>Use of ICD</th>
<th>ICD codes used</th>
<th>Results/Conclusions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Libby, Sills et al. 2003</td>
<td>To estimate the effect of early childhood abuse on medical costs of head trauma in Colorado, USA</td>
<td>Hospital discharge data</td>
<td>Identify children for inclusion</td>
<td>800.0-801.9, 803.0-804.9, 850.0-854.1</td>
<td>Those with inflicted TBI younger, male, more likely to be insured with Medicaid, more severely injured but there were no racial differences between groups</td>
</tr>
<tr>
<td>Rovi, Chen et al. 2004</td>
<td>To assess the costs for hospitalisations due to child maltreatment</td>
<td>Nationwide Inpatient Sample of Healthcare Costs and Utilisations Project</td>
<td>Identify children for inclusion</td>
<td>995.50, 995.51, 995.52, 995.53, 995.54, 995.55, 995.59</td>
<td>Children admitted for abuse higher cost ($19266 vs. $9513), were more likely to have come via ED, have longer stays, have more diagnoses, be black, be insured by Medicaid and to be identified in urban areas and in teaching hospitals</td>
</tr>
</tbody>
</table>

**Discussion**

This review of the literature highlights both the utility and challenges of ICD coded data. ICD codes have been widely used to conduct research into child abuse in health data systems. The codes appear to be used primarily to identify diagnoses and conduct further research to identify child abuse patterns within those diagnoses and/or identify instances of child abuse by using the ICD codes assigned for maltreatment or external cause of assault and conduct the research on those children identified as being abused.

A significant limitation to the use of ICD codes alone in child abuse research is that child maltreatment has been found to be underestimated. This is most clearly identified and, to some degree, quantified, in research where data linkage is used. ICD codes are predominantly assigned by trained clinical coders but the assignment of these codes is dependent on the documentation in
the medical record or on the death certificate, and where documentation does not exist to support the use of a code, the code cannot be assigned.

The inclusion of a ‘possible abuse’ ICD code to indicate that there was a suspicion or investigation of child abuse in the medical record may circumvent issues where a determination of abuse does not occur until after the child is discharged, and may flag concerns for future medical investigations. This may be a worthwhile inclusion in future iterations of ICD. In death data if a determination of child abuse/assault has not been made when the medical certificate is completed then accidental death is the default code assigned by coders. These factors may result in an under-representation of child abuse as a diagnosis in both morbidity and mortality data. A code suggesting that the case is still ‘under review’ where there remains a question over the intent would also serve to diminish some of the misclassification issues surrounding abuse.

Before researchers can reliably use morbidity and mortality data the evidence needs to be strengthened considerably from its current form. Doctors need to recognise and document abuse, clinical coders need to be diligent about coding abuse and end users of the data require a strong understanding of the limitations of coded data. This must then be accounted for in research design. Some studies in this review failed to record specific ICD codes used, making replication of studies and the interpretation of results more difficult for other researchers.

Conclusion

Article 19 of the CRC highlights the importance of protecting children from maltreatment and Article 24 stresses the significance of reducing childhood mortality. This study illustrates that quality and consistency of data underpin research initiatives, and the value of applied research and surveillance in providing data to monitor and evaluate the incidence of child abuse and the impact of interventions cannot be understated.
References


