Protecting children in research

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Protecting children in research: Safer ways to research with children who may be experiencing violence or abuse.

Journal: Journal of Child Health Care

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Manuscript Type: Original Article

Keyword: Child Abuse, Ethics, Child Protection, Safeguarding Children, Research Implementation

Abstract: Our aim was to compare and contrast research practices reported in the literature related to protecting children and to recommend safer ways to conduct research. The simultaneous increase in research with children, along with an increased willingness to listen to child victims of abuse, means that researchers must consider safeguarding children in the research setting. Twenty three papers were identified in a literature review. These studies reported a wide variation of methods, methodology and came from different disciplines. Methodological and ethical considerations were identified. which have implications for rigour and validity. From the 23 papers two overarching themes were identified, social justice and research, and safer research. We concluded that safer ways to research with both adults and children are identified in the literature. Research teams should consider training, safety protocols and support for child protection, which includes support to report safeguarding concerns to social care. There should also be formal supervision which supports researchers to deal with child protection and safeguarding issues. Further work is required to ensure that training, protocols and support are effective in facilitating researchers to identify and make appropriate child abuse referrals. Ethics practices in abuse research also need further debate.
Protecting children in research: Safer ways to research with children who may be experiencing violence or abuse.

Abstract
Our aim was to compare and contrast research practices reported in the literature related to protecting children and to recommend safer ways to conduct research. The simultaneous increase in research with children, along with an increased willingness to listen to child victims of abuse, means that researchers must consider safeguarding children in the research setting. Twenty three papers were identified in a literature review. These studies reported a wide variation of methods, methodology and came from different disciplines. Methodological and ethical considerations were identified, which have implications for rigour and validity. From the 23 papers two overarching themes were identified, social justice and research, and safer research. We concluded that safer ways to research with both adults and children are identified in the literature. Research teams should consider training, safety protocols and support for child protection, which includes support to report safeguarding concerns to social care. There should also be formal supervision which supports researchers to deal with child protection and safeguarding issues. Further work is required to ensure that training,
protocols and support are effective in facilitating researchers to identify and make
appropriate child abuse referrals. Ethical Ethics practices in abuse research also need
further debate.

Keywords; Child abuse, Ethics, Research, Safeguarding, Child protection

Introduction

Whilst definitive figures for the prevalence of abuse and neglect are unknown, we do
know that child protection is a major public health issue across the world (WHO 2002,
Radford et al 2011). It would be naïve to assume that children participating in research
studies are exempt from abuse and neglect. Moreover, children with disabilities, who
are often a particular focus of clinical research, are 3-4 three to four times more likely
to be maltreated than other children (Jones et al 2012).

In the past decade there has been a move towards more participatory research with
children (Christensen and Prout 2002). It has been argued that these methods allow
for a shift in power relationships between children and researchers (Randall 2012),
which may facilitate disclosure of abuse. In addition the increased interest in many
aspects of children’s lives and the increasing use of routinely collected and stored
datasets allows more opportunities to discover relationships between factors which
may be indicative of abuse (Reijneveld et al 2012). These increased opportunities to identify abuse whilst undertaking research activities have occurred alongside a burgeoning awareness of abuse affecting children and possibly an increased willingness to listen to children as victims of abuse (Her Majesty’s Inspectorate of Constabularies 2013). Thus at a time when researchers have been developing ways to listen to children and to investigate children’s lives, there has also been a social shift to take more seriously abuse of children and victims’ accounts.

**Literature review**

To determine what might be safer ways to conduct research with children we undertook a literature review, where the research question we sought to answer was:

“What can contemporary research literature tell us about how child protection is enacted in research contexts?”

The three stage approach to literature review was undertaken as recommended by the Joanna Briggs Institute (2014). A mixed search strategy was used, including keyword (subject heading) and title word, in electronically searching of three databases (Ovid MEDLINE(R) 1996 to week 4 2014, PsycINFO 1987 to July week 1 2014, ASSIA 2000 to 30th July 2014 ) and snow balling of references. The following search terms were used with Boolean operators:
• Key words – child abuse OR child welfare OR safeguarding AND ethics AND research
• Title words - child AND abuse OR welfare OR safeguarding OR protection AND research ethics OR research OR research protocols OR research practice

NB in the ASSIA database the search terms were altered slightly to retrieve more relevant papers.

Studies were included if they were conducted between 2000 and 2014. The Victoria Climbie case in 2000 and subsequent the Laming inquiry (Lord Laming 2009) following the death at the hands of her carers provide a watershed moment in that, the case and report changed the child protection landscape in the UK and influenced other states’ approaches to child maltreatment. Also included were papers which reported on research practices which related to the safeguarding of children. This included research into adult health and social care where a link is made to the care of children.

The focus of these studies was adult partner abuse or domestic violence, substance misuse and parental mental ill health, where a connection is made between these issues for adults and their care of dependent children. In some combination these three potent risk factors are present within families of over a third of children who are killed due to maltreatment (Brandon et al 2009). Papers were excluded if child protection issues were limited to practice rather than pertaining to research. Papers were also excluded if they related to historical child abuse, or used hypothetical abuse
scenarios, where there was no opportunity for researchers to report safeguarding issues about individuals. Unpublished or grey literature and policy documents were excluded as we wanted to focus on researchers’ reports of research practice.

[Insert: Figure 1: PRISMA Chart]

**Search outcome: Quality appraisal and data abstraction**

To review the quality of the papers selected we used the scoring system developed by Pluye *et al* 2009, which allow research from different methodological traditions to be rated by factors for that tradition and gives a scoring out of 100 expressed as a percentage. We did not exclude studies based on quality, rather we provide the quality review for information only (Supplementary file 1: Table 1 Quality appraisal). Data were abstracted by the first author and checked by all authors. Twenty-three papers met the inclusion criteria and were not excluded (Supplementary file 2: Table 2 Data abstraction). The first author conducted a thematic analysis of the selected papers which was considered by all authors and agreed.

**RESULTS**

**Summary of papers reviewed and quality assessment**

The papers selected in the review reflected a wide variety of methodologies and methods. Not all the papers were concerned directly with children, some reported on
adult populations who care for children (Gondolf 2000), or had been convicted of offenses against children (Durham 2002, Cowburn 2005). We included Durham (2002) and Cowburn (2005) because we felt that in these studies there remained a possibility of uncovering continuing abuse and because along with the fact that they discussed recovery. The majority of papers reported projects which involved asking children directly about their experiences. Ries et al 2010 and Angell et al 2010 reported the perspectives of researchers and ethics committees. The mean quality of qualitative papers was 56.9% while for quantitative observational studies it was 66.62%.

Thematic analysis

Two broad themes emerged from the papers each with six sub themes:

- Social Justice and Research
- Safer Research.

Each of these had six sub themes. These are summarised in Figure 2. While we have indicated from the data abstraction (Supplementary file 2: Table 2) the references to how often themes were found (Figure 2), these are intended only to indicate the strength of themes, not to quantify qualitative data (Sandelowski et al 2009).

[Insert: Figure 2: Themes and sub themes]
Theme One: Social Justice and Research

This theme was concerned with issues of ethics, transparency and rigour in dealing with child protection concerns within research.

Transparency

Many of the papers (19/23) discussed how research teams informed participants about how they would deal with any emerging child protection issues, should they arise. There was also a focus on how participants were told about the limitations of confidentiality in cases where child abuse was suspected. The way in which transparency was established in studies obviously also relates to suggestions by researchers in the literature as to safer ways to conduct research, with transparency being seen as protective (the second main theme).

Transparency in these studies is also linked in the next sub theme of participant rights vs public health/safety, in that researchers attempted to make clear the limitations of participants’ rights to confidentiality which when a researcher may have to break in order to report abuse of children. This debate was influenced by the legislation of the states in which the research was undertaken. For some researchers, for example in North America, there is a statutory requirement to report abuse, while for others the responsibility of researcher to report abuse is less clear (e.g. in England and Wales where there is currently no mandatory reporting system).
Participant rights vs public health/safety

The legal context of the research also influenced this theme, in which researchers debated the rights of participants in the research process: for example, the right to informed consent, right to withdraw, and confidentiality, and the responsibility of researchers to fulfil a public duty to safeguard children. This included debates on the duty to safeguard other vulnerable people such as victims of partner abuse or other forms of violence (Gondolf 2000, Totten 2001). An interesting aspect raised is that of other family members, who are not research participants, but about whom the participant may disclose information. Such individuals who are not covered by any ethical protocols, because they are not deemed to be research participants, but they may become the subject of researchers’ reports to social care about child protection. In addition, Totten (2001) suggests that confronting perpetrators of abuse may sidestep this assumption of the perpetrator assuming tacit approval for their action, although such challenge is difficult and potentially dangerous work for the researcher. Kennan et al (2012) raise more complex public health issues in their study of young people, who provide care to adult family members.

Research methods, practices and abuse
In five papers (Johnson 2000, Gondolf 2000, James et al 2010, Ybarra et al 2009, Knight et al 2000) it was recognised that research methods could be misinterpreted by participants as feeling like further abusive behaviour, despite researchers’ intentions. Perhaps the most obvious example, given, was asking questions which the participant might feel were oppressive. However, even the practice of following up with participants who have forgotten an appointment with a researcher, could feel to a participant like grooming or stalking behaviour (Johnson 2000).

Practitioner vs researcher

Four papers (Totten 2001, Durham 2002, Ensign 2003, Garland et al 2008) identified difficulties for practitioners in the blurring of their roles as health and social care practitioners and their roles as researchers. This included, but was not limited to, the potential for child protection issues to conflict with data collection.

Avoidance

A concerning feature of some In some studies was the deliberate attempts were made by researchers to avoid detecting or reporting abuse (Cowburn 2005, James et al 2010, Kotch 2000). This was either a feature of the research design or took the form of encouraging participants to withhold vital information. This included obscuring the nature of the offense, the identity of the victim and or the perpetrator, or the time and
place where abuse occurred. Researchers attempted to justify such avoidance by pointing out that perpetrators of abuse are unlikely to participate if the information they give could be used to convict them of crimes. Certificates of confidentiality were used in American studies, however it was not always clear if participants were informed that researchers were exempt from reporting concerns and in some studies, although a certificate was in place, researchers also informed participants that concerns about child protection would be reported to other health and social care agencies (Langhinrichsen-Rohling et al 2006, Stiffman et al 2005, Kotch 2000, Knight et al 2000).

**Ethical concerns for the “vulnerable child”**

One paper (Angell et al 2010) reported on adult gatekeeper behaviour which seeks to protect children from any potential risk of being involved in research. Although 90% of the 80 letters from ethics review bodies gave a favourable opinion (allowing the research to progress), 59 raised ethical issues of which 48 (81%) were concerned with the vulnerability of children. However, only seven made explicit reference to child protection, of which four suggested excluding children from the study and three required adults to be present when the child participated in the research (Angell et al 2010).
Theme Two: Safer Research

This theme concerned issues of making research practices safer for children and also for dealing with the emotional labour of this work by the researchers.

Training needs of researchers

In 14 papers the need for specific training on child protection issues was recognised. In some several papers the need for training was acknowledged, while others gave more details of programmes provided. In some various papers the previous experience of practitioners was valued as an asset to the research team and for some, experience of child protection work was a requirement of researchers.

Safety protocols

Four studies (Gondolf 2000, Stiffman et al 2005, Carroll-Lind et al 2006, Hutchfield and Coren 2011) provided helpful-useful suggestions for safety protocols which may help participants to feel safe and which could prevent further maltreatment. Strategies included post research debriefing, allowing participants to process distressing issues which may have surfaced for them during the research and constructing questionnaires and interview schedules so in a way that meant participants could avoid upsetting questions of an upsetting nature. Included in this theme were safety protocols which attend to the researchers’ safety (Sikweyiya and Jewkes 2011).
**Ethic of care and supervision**

Although the need for ethical frameworks and protocols was recognised in the papers, so was the complexity of child protection work. Some writers suggested that ethical frameworks and protocols alone are not sufficient and that researchers in this field should have expert supervision from senior colleagues to facilitate their reflexivity (Gorin et al 2008). Such supervision may assist researchers to make appropriate referrals to children’s social services.

**Collaboration**

Researchers reported working collaboratively with both participants (Carroll-Lind et al 2006, Knight et al 2006) and with health and social care services and other professionals to safeguard children during the research process. This included agreed safety protocols (Gondolf 2000, Carroll-Lind et al 2006) which allow children and adults who are victims of abuse to agree ways in which researchers could ask them about abuse and to allow participants to give researcher permission to contact other agencies. It also included working with existing child protection services.
Cultural safety

Although it is widely accepted that child abuse is socially constructed and culturally and historically bound (Taylor et al 2000), only three papers reported on cultural aspects (Veena and Chandra 2007, Vreeman et al 2012, Stiffman et al 2005).

Discussion

Much has been written about child protection issues and about research with children. It appears however, that these issues are rarely considered in conjunction. Whilst research ethics committees are rigorous in safeguarding participants, they appear to have variable focus on child maltreatment issues (Angell et al 2010). Specific training requirements on child protection were recognised. Although only three studies mention cultural aspects despite the large literature on cultural safety and particular concerns about cultural practices in child protection practices (Taylor et al 2000). Some research teams accessed safeguarding training, but many more did not and may not have had access to adequate preparation for researchers prior to data collection. The Royal Colleges in the UK (RCPCH, 2010) have delineated the minimum requirements for training for all health service staff except physicians. So whilst some clinical staff should comply with this guidance (and it is only guidance), it is unclear to what extent this is felt to apply to clinical researchers who may, or may not have a health professional registration.
Existing ethics approval procedures appear to be insufficient to address the concerns of researchers, nor are they an adequate response to the complexities of researching with children who may be experiencing violence and abuse. Rather, as identified by a number of studies, an “ethic of care” is required in which experienced child protection practitioners can advise researchers as to appropriate ways of dealing with situations as they occur. While some studies obviously had such supervision collaborations in place, these are far from standard.

In light of recent revelations about historic child abuse (Her Majesty’s Inspectorate of Constabularies 2013), it was of real concern that some researchers made conscious efforts to avoid detecting or reporting maltreatment. Justification of these attempts was methodologically weak and morally despicable. None of the papers considered the methodological challenges of guaranteed anonymity for perpetrators, which would allow “fantasists” to indulge their sexual delusions free from the fear of discovery.

Thus the claims by researchers that avoiding detecting and reporting abuse is justified because it reveals more valid statistics on incidence of abuse is undermined, as there is no way of verifying that what the perpetrator reports is fact, fiction or sexual fantasy (Cowburn 2005). Equally there is conflicting evidence as to whether disclosure in research is affected by reporting abuse (Langhinrichsen-Rohling et al 2006, Stiffman et al 2005). Kotch 2000 argues that research confidentiality should be held as more
important than reporting abuse, as the outcomes for children of social intervention is far from certain. However Stiffman et al 2005 found that abuse issues reported in research were often historical or already being addressed. They also showed that transparency about reporting, and working with community leaders, can result in rates of self-reported disclosures of abuse close to abuse rates found in other studies. There is then, little evidence that avoiding responsibility to report concerns is the only way to obtain rich, reliable and valid data.

We know that paedophiles very often will seek qualifications and roles that allow them to work closely with children and young people and this may apply to research (Craven et al 2006). None of the papers considered this as a potential risk to children or reported any screening for working with children, despite this being a legal requirement in some states.

Perhaps the most interesting finding of this review, is the lack of literature which addresses the issues of child protection in research. While the research community may seek to improve the lives of children through their studies, little consideration appears to have been given as to how to do this safely, and without colluding with individuals and social practices that subject children to maltreatment.
Limitations

Our consideration of the literature has been undertaken by a small team with limited funding. We concentrated only on peer reviewed published literature and it may be that evidence of researchers engaging with child protection issues in research contexts exists within the grey literature. The work may also have been improved by consulting more widely with experts in the field to identify other sources, particularly by contacting researchers in social care.

Further work is required on whether researchers who access clinical healthcare training on child protection, can and do translate this education effectively to protect children in research contexts. How research protocols and practices may protect children and result in appropriate referrals, and support for researchers, along with research into the cultural aspects of child protection in the research context is needed.

A first step in ensuring safer research for children is to seek international consensus on a proposed approach which recognises the responsibilities of all researchers to conduct their work in ways which support all children to live free of the threat of violence and abuse, to support those children who have experienced maltreatment to
receive timely appropriate help, which prevents further maltreatment and aids recovery.

References


Her Majesty's Inspectorate of Constabularies (2013) “Mistakes were made” HMIC’s review into allegations and intelligence material concerning Jimmy Savile between 1964 and 2012. Available at [http://www.hmic.gov.uk/publication/mistakes-were-made/](http://www.hmic.gov.uk/publication/mistakes-were-made/)


Figure 1: PRISMA Chart

**Identification**
- Records identified through electronic database search
  - Medline(R)/PsycINFO Key word=312 title word=156
  - ASSIA subject heading=66 title word=297
- Total 831
- Additional records = (from reference lists) 4

**Screening**
- Records after duplicates removed = 809 (26 duplicates)

**Eligibility**
- Papers assessed for eligibility = 130
- Papers excluded = 107
  - Rationale:
    - Not relevant to research question
    - Adult accounts of child abuse

**Included**
- Studies included = 23

Adapted from Moher et al 2009
Table 1 Quality appraisal

<table>
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<th>Author(s)( year of publication) and study location</th>
<th>Methodology</th>
<th>Qualitative objective or question</th>
<th>Appropriate qualitative approach or design or method</th>
<th>Description of the context</th>
<th>Description of participants and justification of sampling</th>
<th>Description of qualitative data collection and analysis</th>
<th>Discussion of researchers' reflexivity</th>
<th>number of 'presence' responses divided by the number of relevant criteria X 100</th>
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Quantitative observational QUAN (Obs)

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### Table 2 Data abstraction

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<tr>
<td>Ries NM, LeGrandeur J, Caulfield T (2010) EU and USA</td>
<td>6 self identified researchers</td>
<td>Semi structured telephone interviews</td>
<td>✓</td>
<td>✓ ✓ ✓ ✓</td>
</tr>
<tr>
<td>Knight ED, Smith JB, Dubowitz H et al. (2006) USA</td>
<td>1,354 primary caregiver-child pairs</td>
<td>Retention rates for participants referred to social care</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Gondolf EW (2000) USA</td>
<td>Researchers/experts/IRB and participants across a number of studies (4 batter programmes 840 men and partners)</td>
<td>Longitudinal Evaluation of domestic violence programmes semi structured interviews</td>
<td>✓</td>
<td>✓ ✓ ✓ ✓ ✓</td>
</tr>
<tr>
<td>Author(s)( year of publication) and study location</td>
<td>Population Characteristics</td>
<td>Data Collection method/Details of Study</td>
<td>Social Justice and research</td>
<td>Safer research</td>
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<td>--------------------------------------------------</td>
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<tr>
<td>Johnson B (2000) South Australia</td>
<td>South Australian children 5-14 intervention group n=193 control group n=121</td>
<td>Non experimental post treatment comparison of personal safety programme</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td>Angell E, Biggs H, Gahleitner F et al (2010) UK</td>
<td>80 provisional and unfavourable opinions of REC</td>
<td>Ethnographic content analysis</td>
<td>✔️</td>
<td></td>
</tr>
<tr>
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</tr>
<tr>
<td>James RV, Kimonis ER, Donoghue C (2010) USA</td>
<td>Researcher experience of conducting Internet based research</td>
<td>Personal reflection</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Garland AF, McCabe KM, Yeh M (2008) USA</td>
<td>3 case studies research projects children 3-18 n not given includes adult carers</td>
<td>Mental health research projects with children various methods</td>
<td></td>
<td></td>
</tr>
<tr>
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</tr>
<tr>
<td>Veena A, Chandra PS (2007) India</td>
<td>13 states in India 2,447 children, 2,324 young adults, and 2,449 stakeholders.</td>
<td>Interviewed in the family environment, in school, at work, on the streets, and in institutions</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Durham A (2002) UK</td>
<td>7 men 15-24</td>
<td>In depth interviews</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Ensign J (2003) USA</td>
<td>Hard to ascertain personal research experience</td>
<td>Various observation interviews</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Cowburn M (2005) UK</td>
<td>9 White men 25-61 6 of who had been convicted of sexual offences against children</td>
<td>Life history interviews</td>
<td>✓</td>
<td>✓</td>
</tr>
</tbody>
</table>

1 In Veena and Chandra’s (2007) study safety protocols are not employed the –ve sign indicates absence of this theme
<table>
<thead>
<tr>
<th>Author(s) (year of publication) and study location</th>
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<th>Data Collection method/Detailed Study</th>
<th>Social Justice and research</th>
<th>Safer research</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vreeman R, Kamaara E, Kamanda A et al (2012) Kenya</td>
<td>Two Mabaraza or community groups 108 participants including 60 caregivers</td>
<td>Group interview about research participation of orphaned and vulnerable children</td>
<td>✓ ✓</td>
<td>✓ ✓ ✓ ✓</td>
</tr>
<tr>
<td>Kennan D, Fives A and Canavan J (2012) Ireland</td>
<td>26 young carers</td>
<td>Interviews</td>
<td>✓ ✓</td>
<td>✓ ✓ ✓ ✓</td>
</tr>
<tr>
<td>Langhinrichsen-Rohling J, Arata C, O'Brien N et al (2006) USA</td>
<td>1,540 young people (783 boys and 756 girls) from four sites</td>
<td>Qualitative survey</td>
<td>✓ †</td>
<td>✓ ✓ ++ ✓ ✓</td>
</tr>
</tbody>
</table>

**Social Justice and research**
- Transparency
- Participant rights vs public health/safety
- Research methods, practices and abuse
- Clinical Practitioner vs researcher
- Ethical concerns for the “vulnerable child”
- Avoidance
- Training needs of researchers
- Safety protocols
- Ethic of care and supervision
- Collaboration participants
- Collaboration service / profession
- Cultural safety
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<th>Safer research</th>
</tr>
</thead>
<tbody>
<tr>
<td>Totten M (2001) USA</td>
<td>30 male gang members</td>
<td>Interviews</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kotch J (2000) and Knight ED et al (2000) USA</td>
<td>Both papers use methods and data from longSCAN studies 663 mothers (pooled sample 1400 children)</td>
<td>6 Interviews with mothers and children at specified child ages up to 12 yrs</td>
<td>✓</td>
<td>✓</td>
</tr>
</tbody>
</table>


†† Langhinrichsen-Rohling J. Arata C. O’Brien N et al (2006) used a federal certificate of confidentiality to prevent data being used in legal proceedings all participants made aware of this. Stiffman A. Brown E. And Striley CW et al (2005) obtained a certificate but state that confidentiality would be broken to protect children (or others) Kotch J (2000) and Knight ED et al(2000) secured a confidentiality certificate but the projects within longSCAN took different approaches including “blinding” researchers to data to avoid reporting possible abuse.