Ethics in research with children

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Violence against children (VAC)

- Increasingly recognised as an important area of public health and social policy research
- Dearth of international, comparable epidemiological data on children’s experience of violence, especially in low and middle income settings where literacy levels may be low and CP systems not well developed
- Fear of causing psychological trauma or distress – few studies have found evidence of this however (DePrince and Freyd 2004)
- The United Nations Secretary-General's Study on Violence against Children specifically calls for more investigation to provide accurate and up-to-date prevalence, prevention and intervention data.
- Researchers, donors and policy makers taking an active interest
- Most researchers consider asking young people to self-report their experience of violence using tools such as the ICAST-C
- Asks about specific acts of violence
Ethical and methodological considerations when collecting data on VAC
All research involving human subjects should be conducted in accordance with 3 basic ethical principles:

1. Respect for persons including
   - Respect for autonomy
   - Protection for persons with impaired or diminished autonomy

2. Beneficence
   - Maximise benefits and minimise harm (reasonable risk in light of expected benefits, sound design, competence of investigators to conduct research and safeguard welfare of research subjects
   - Nonmaleficence (do no harm)

3. Justice
   - Treat each person in a way that is right and proper and give each person what is due to him/her
Children’s consent to participate

• Council for International Organizations of Medical Sciences (CIOMS) 2002

  – Provide guidance on ethical medical research involving human subjects
  – Scope reflects the changes, advances and controversies that have characterised biomedical research and ethics in the past
  – Particular aim is to reflect the conditions and needs of low-resource countries
  – Guideline 14: Research involving children
CIOMS guideline 14

Investigator must ensure:

• The research might not equally well be carried out with adults
• The purpose of the research is to obtain knowledge relevant to health needs of children
• A parent or legal representative of each child has given permission (consent)
• The agreement (assent) of each child has been obtain to the extent of the children’s capabilities
• A child’s refusal to participate or continue in the research will be respected
– Age of consent may vary from country to country or even between jurisdictions within the same country
– Research on cognition and capacity of young people has shown young people’s significant ability to provide informed consent/ability to make informed decisions about whether to participate in research is similar to adults’. (Society for Adolescent Medicine 2003)
– 14 year olds have been found to be as skilled as adults in understanding multiple viewpoints and in considering conflicting information (Weithorn 1983)
– Investigator must obtain the permission of a parent or guardian in accordance with local laws and established procedures
A child is a child is a child?

• Who is a child?
  – Determined by age?
  – What about 16 year old married mothers?
  – Developmental capacity of children to understand the question being asked?

• Emancipated minors
  – In some jurisdictions some individuals who are below the general age of consent are regarded as ‘emancipated’ or ‘mature’ minors and can provide consent without agreement or awareness of parent/guardian

• Topic/subject of research
  – Investigations into children/adolescents’ beliefs or behaviour regarding sensitive subjects (eg sexuality, recreational drugs, sexual abuse) may put children at risk of questioning or intimidation by parents
  – Ethical review committees may waive parental permission in these cases (subject to other consent conditions being met)
Implications

The experience and procedures in the Good Schools Study, Uganda
The Good Schools Study

Aim
- To evaluate the Good School Toolkit – whole school intervention designed by Raising Voices which seeks to reduce violence in schools and improve learning outcomes

Methodology
- Conducted in a district close to Kampala
- Baseline 2012, follow-up 2014
- RCT, qualitative evaluation, process analysis, economic costing
- 42 schools (21 intervention, 21 control)
- Interviewed students, teachers, school administration, parents/carers

Domains
- Views and experience of violence (from school staff, peers, others)
- Mental health
- Educational tests
Consent

- Permission obtained from the Ministry of Education and Sport at the national and district levels
- 3-tiered consent process
  - Consent for participation sought from head teachers for school participation and to approach parents and students – 100% agreement
  - Parents given opportunity to opt their children out of participation (in person, on the phone, in writing, information meetings)
    - Were aware that questions related to violence, that some questions might be upsetting, and obligation to report harm
    - Voluntary
      - Individual students selected to participate in the survey were approached and informed consent (assent) sought
        - Emphasied that participation was voluntary
        - Obligation for reporting
        - Availability of referral services
Interviewer recruitment & training

- Experience of previous work with children - references (CRB checks in other places)
- 3 weeks of full time training
- Violence against children and child rights
- Strategies to maintain privacy and confidentiality eg in a school setting
- Consent
- Techniques for building rapport and making children feel comfortable
- Practicing! role play sessions on interview techniques, handling disclosures of sexual violence
- Strategies and the importance of remaining non-judgmental
- Child protection protocols
- Trained an excess of interviewers and hired the best
Referring children who experienced violence

• Study employed counsellor
• Comprehensive protocol to handle disclosures of violence,
  – Developed in consultation with local child protection experts
  – Specific pathways of action depending on the severity and time frame of what the child disclosed
    • Urgent
    • Serious but less urgent
    • Serious but non-urgent
  – Decisions on disclosures that would necessitate referral and to where they would be referred were made considering the legal requirements in Uganda and the local child protection systems
• In practice
  – Baseline – high number of referalls
  – Follow up – mental health impact added
  – Support well received by students
Thank you

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