



ETHICAL RESEARCH INVOLVING CHILDREN

Centre for Children
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NEW ZEALAND

HARMS AND BENEFITS

Dilemmas of dealing with distress during interviews with children

Background context:

We conducted research projects involving interviews with young caregivers in the context of the HIV epidemic in Zimbabwe, Tanzania and the UK. The children had recent or current caregiving responsibilities looking after a chronically sick family member (often a parent with AIDS). Some children had recently been orphaned following a period of being a carer.

The ethical challenge:

Interview questions about children's caring responsibilities, and parental illness and/or death sometimes led to tears and emotional upset of the young carer. At times the young people became distressed during interviews when describing the emotional and physical demands of caregiving or recalling the loss of their loved ones. Some young people broke down crying.

In response to their emotional distress we had to decide whether to continue, pause or cease the interview with the young person. We also had to consider whether to continue to investigate the child's experiences of caring by continuing the interview at another time, using a different research method or to discontinue research with particular individuals altogether. We had to reflect on our role as researchers regarding whether the distress we caused was ethically justifiable – were the interviews worth the tears?

Choices made:

Some interviews where young carers broke down in tears and were too upset to continue were rapidly brought to a close. This resulted from situations when the young person no longer responded to questioning (i.e. withdrawing their active participation), confirmed that they did not want to continue when asked by the interviewer, when another person present (e.g. guardian, parent or older sibling) requested an end to the interview, or when the interviewer judged it inappropriate to continue. We tried to be sensitive to signs of distress and offered opportunities for breaks, to continue the interview at another time, or to end the interview. In the Tanzania and UK research, the use of participatory methods, such as talking about photographs children had taken, drawings or a life story book they had completed, sometimes provided a helpful means to divert attention from emotionally distressing topics.

Reflexive questions/considerations:

Responding as professionals and fellow human beings to the distress experienced by the young carers interviewed led us to reflect on the ethical appropriateness of our research approach and its method. Our intention was to listen directly to children as experts on their own lives - to make children's voices heard, not to access their experiences

indirectly through adults. However, when recounting their caring lives was traumatic, embarrassing, uncomfortable and stressful for the young interviewees, in the Zimbabwe research, our approach was described as “unfair”, “uncalled for”, even “cruel” by the social worker employed to conduct the interviews in local languages (Shona and Ndebele). In the research in Tanzania and the UK, however, young people who shed tears during the interview wanted to continue and appeared to value the opportunity to talk about their experiences, with one young woman saying afterwards that no one had ever asked her about her caring responsibilities before. This raises a number of questions:

- How can researchers balance the potential (short-term?) harm, such as emotional distress and tearfulness, that may be caused by interviews against the potential long-term benefits of the research process for children, both individually and collectively? Potential benefits include the opportunity for an individual young person to share their feelings and voice hidden experiences which may lead to a sense of empowerment and collective identification with other children in similar circumstances by contributing to research which may improve the situation of other young carers in the future.
- How can researchers best listen to children and be sensitive to signs of distress? What skills and preparation are needed for interviewers and interpreters?
- How can the privacy of interview settings be ensured so that children feel comfortable to express their emotions? This may be particularly challenging when conducting interviews in people’s homes where there may be little space to talk to children away from hearing of other household members or neighbours.
- How can researchers best evaluate whether and when interviews should be continued or terminated if children being questioned are emotionally distressed?
- What steps can be taken to consider how children’s access to emotional support (e.g., counselling) from project workers and others may be facilitated when appropriate?
- What alternatives can be used instead of interviews? Providing children with other methods of engagement and a range of ways to express their feelings and experiences (such as drawing, photography, story boards, body- maps, and diaries) may be less distressing.

References

Evans, R., & Becker, S. (2009). *Children Caring for Parents with HIV and AIDS: Global Issues and Policy Responses*. The Policy Press: Bristol.

Robson, E. (2001). ‘Interviews Worth the Tears?: Exploring Dilemmas in Research with Young Carers in Zimbabwe’ *Ethics, Place & Environment*, 4, (2) 135-142. DOI: 10.1080/13668790125512

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