



ETHICAL RESEARCH INVOLVING CHILDREN

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INFORMED CONSENT

Responding to real world ethical challenges when conducting research with young children in Tanzania

Background context:

This case study describes the ethical dilemmas faced in the conduct of a recent study that sought to answer the question “How do young Tanzanian children experience care?” The study explored the heterogeneous practices that are used by families to care for their children across diverse tribal, lifestyle and geographical groupings. This study was commissioned by an international NGO. An experienced researcher assisted with the design of the study, data analysis and writing the report. People who lived in the communities where the research was conducted collected the data. Technical support and field leads were undertaken by child rights practitioners and a play therapist who had limited qualitative research experience, but significant contextual knowledge of child development and the issues facing children in Tanzania. All parties were challenged to set aside what they deduced about the situation of children from their practical work in the field and to remain truly open to what they may induce from the data and stories of children. All carried prior assumptions about what young children were capable of knowing.

The ethical challenge:

The ethical challenge lay in ensuring that the mechanism to support the data collectors and technical leads to conduct ethical research were actually used in the field. I explore this challenge by examining the choices that were made in negotiating access, aligning expectations, allaying the fears of care-givers and obtaining informed consent from the children and their care-givers. During the design of this research study considerable attention was paid to thinking through the ethical ramifications of conducting research with young children. However, the standards that were set in the design of the study were not always applied during the fieldwork. Why was there this gap between intention and practice?

Choices made:

- Was a formal commitment to child protection made?

The data collectors signed no formal commitment to child protection, even though that was part of the original study design. Rather, child protection was discussed informally during the training of the data collectors and during an initial meeting with the children's caregivers. In practice, many researchers and study participants do not see the value of making formal statements of commitment; because there is no real liability that accrues to researchers, nor any form of redress for participants should poor ethical behaviour occur in the research process.

- Negotiating access and aligning expectations

Researchers who come into poor communities can often be objects of speculation, be perceived as agents of the government, or as the bringer of services and interventions (Ebrahim, 2010; Morrow, 2009). Thus it is critical to spend time explaining the purpose of the research and the limits of its scope so that the communities' expectations are not unjustifiably raised. The issue of power dynamics pervades research with disadvantaged communities and children. The ethical symmetry (Christensen & Prout, 2002), where professionals and outsiders who have both social and economic power, interact with poor research participants is deepened when children are the research subjects and the power differentials of age are considered.

All adult participants wanted to see benefits to children as an outcome of the study. Given that the outcomes of this study are so intangible; namely that it will inform the advocacy initiatives of the commissioning organization, there was no easy response to these adult expectations, and to this day the issue feels unresolved.

The research design took into account the social and cultural positioning of children and strove to find ways to lower the power imbalances (Bergstrom, Jonsson & Shanahan, 2010). They did this by using community insiders who voluntarily run early childhood services for children as the primary data collectors. They sought access to children and parents within the communities via political and traditional leadership and through their contacts with parents and community groups in the area (Ebrahim, 2010). The feeling of the programme officers was that there was more co-operation than challenges in the recruitment of participants and that the main challenge was not accessing participants per se, but the time involved to do so because of the need to use community leaders to mobilize participants.

- Obtaining consent

There is a distinction between the provisional consent that adults and children may give at the outset and the ongoing consent that is then negotiated on a minute-by-minute basis as the research unfolds (Simons & Usher, 2000). This places responsibility on the data collectors to nurture relationships with the research subjects, to be sensitive to the impact of the research on them and to create a non-judgmental space for them to withdraw from the study or not to participate in specific study activities. The data collectors provided the care-givers with clear and precise information about the research in the initial group meeting where they described the study, but this was the only time where adults were able to ask questions. They did not leave additional time in the interviews for the participants to reflect on the experience, even though this had been part of the initial design.

Reflexive questions/considerations:

- Technical leads and data collectors did not get sufficient opportunity to internalize the seriousness of ethical dilemmas nor to practice reflexivity. There was a gap between what was planned in the research design and its implementation. Data collectors did not use the protocol that had been designed to support daily reflection on the ethical dilemmas that they faced. They only met to consider practical matters of logistics and so forth, but not to engage in conversations that were reflexive in nature. They did not reflect deeply on their posture, on the non-verbal signals that they were getting from the participants; on potential sources of

unexpressed resistance amongst the participants; nor on how they managed the power dynamic between themselves and the participants.

- The challenge in building a reflexive practice partly lay in the structural design of the study; which involved multiple parties, each of whom brought different expectations, skill sets and capacities. At the apex was the commissioning organization, which was more concerned with the ultimate research product and the design of data collection tools over the ethical processes that were used to engage with research participants. There is a real tension when doing ethically led research with the need to go slow, listen and think deeply and to continually ask questions about one's own posture as a researcher. Because the NGO and its staff espouse a set of claimed values about putting children's best interests to the fore, practitioners within these agencies often tend to assume that they know what is best when it comes to engaging with children. There is some resistance towards deeply scrutinizing their own posture when they interact with a child. They struggled to jettison the hat that they wore as advocates and carers for children and to adopt a new hat that would require them to undertake a disciplined qualitative research practice. This involves setting aside preconceptions, listening deeply, creating space for the child to narrate their stories, and not prematurely and partially interpreting the children's stories, namely the essence of a reflexive practice.
- In conclusion, the challenges that an ethical researcher faces start from the moment of contracting with the commissioning organization and the cultivation of shared expectations that good research is ethical research. From the outset everyone has to understand that it takes time to design an ethical study, and that building the mindsets and skills of all parties to engage in reflexive and ethical research is as critical to the success of the study - and to its eventual legitimacy - as conducting fieldwork, analyzing data or writing the research report. The greater the number and the more diverse the people involved, the greater the amount of time and attention that needs to be paid to building a shared understanding, commitment and practice to reflexive ethical research.

References

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