Reflexivity and dialogue: Addressing methodological and socio-ethical dilemmas in research with HIV-affected children in East Africa
Skovdal, Morten; Abebe, Tatek

Published in:
Ethics, Policy & Environment

Publication date:
2012

Document Version
Publisher's PDF, also known as Version of record

Citation for published version (APA):
Ethics, Policy & Environment

Reflexivity and Dialogue: Methodological and Socio-Ethical Dilemmas in Research with HIV-Affected Children in East Africa

Morten Skovdal & Tatek Abebe

a Department of Health Promotion and Development, University of Bergen, Bergen, Norway

b Norwegian Centre for Child Research, Norwegian University of Science and Technology, Trondheim, Norway

Available online: 26 Mar 2012

To cite this article: Morten Skovdal & Tatek Abebe (2012): Reflexivity and Dialogue: Methodological and Socio-Ethical Dilemmas in Research with HIV-Affected Children in East Africa, Ethics, Policy & Environment, 15:1, 77-96

To link to this article: http://dx.doi.org/10.1080/21550085.2012.672691

PLEASE SCROLL DOWN FOR ARTICLE

Full terms and conditions of use: http://www.tandfonline.com/page/terms-and-conditions

This article may be used for research, teaching, and private study purposes. Any substantial or systematic reproduction, redistribution, reselling, loan, sub-licensing, systematic supply, or distribution in any form to anyone is expressly forbidden.

The publisher does not give any warranty express or implied or make any representation that the contents will be complete or accurate or up to date. The accuracy of any instructions, formulae, and drug doses should be independently verified with primary sources. The publisher shall not be liable for any loss, actions, claims, proceedings, demand, or costs or damages whatsoever or howsoever caused arising directly or indirectly in connection with or arising out of the use of this material.
Reflexivity and Dialogue: Methodological and Socio-Ethical Dilemmas in Research with HIV-Affected Children in East Africa

MORTEN SKOVDAL1,* & TATEK ABEBE2
1Department of Health Promotion and Development, University of Bergen, Bergen, Norway
2Norwegian Centre for Child Research, Norwegian University of Science and Technology, Trondheim, Norway

ABSTRACT This paper presents an integrated discussion of methods and ethics by drawing on participatory research with children in Ethiopia and Kenya. It examines the complex social, ethical, practical and methodological dilemmas of research with HIV-affected children, and explores how we confronted some of these dilemmas before, during and after fieldwork. The paper interrogates the role and limitations of ‘global’ ethical standards in childhood research, and the ways in which the researchers’ gender, ethnicity/race, material power, knowledge and insider-outsider position all intersect to affect: (a) the level of children’s involvement in the research process; (b) the generation of knowledge about the field; and (c) the negotiation of ethics in collaborative ways. We argue that doing ethical research with HIV-affected children should not be based solely on dominant and de-contextualised understandings of ethics, knowledge and social relations, but should be negotiated reflexively and through dialogue with participants, including the children, their guardians and ‘local’ community members—all with the aim of doing good and avoiding harm in the research process.

Introduction

Although there is a growing body of literature on the socio-ethical dilemmas of doing research with vulnerable children, most of this is situated in western contexts (see Farrell, 2007a; Thomas & O’Kane, 1998; Valentine, 1999). Only few studies have explored the ways in which ethics are ‘played out’ at different stages of the research process with children in marginalised communities in Africa (Abebe, 2009; Ansell and van Blerk, 2005; Beazley, Bessell, Ennew, & Waterson, 2009). In recent decades, the HIV epidemic in Africa has left millions of children vulnerable to poverty and distress, among other things subjecting them to scrutiny by researchers from around the world. Although children’s lives have traditionally been reported through the experiences of adults (Alderson, 2008), recent years have witnessed the recognition that they are both social actors and knowledgeable subjects capable of participating in detailed research process (Christensen & James, 2000; Hutchby & Moran-Ellis, 1998; Prout & James, 1997). However, this positive development has given rise to
new socio-ethical dilemmas (Farrell, 2007b), some of which we seek to address in this paper. In using the term ‘socio-ethical’ we hope to highlight how fieldwork with vulnerable children is situated in social relationships that go beyond mere data collection, and how researcher-related interactions are and need to be seen as a site for continuous negotiation and dialogue—taking into account local ethos in appropriating global and de-contextualised understandings of ethical standards.

Our point of departure for writing on ethics is the recognition that ethical research pertains to doing good and avoiding harm to those participating in the research (Orb, Eisenhauer, & Wynaden, 2000; Young & Barrett, 2001). As Young and Barrett (2001) point out, ethical research is predicated on the principle that participants will suffer no harm as a result of the research process or its outcome. At best, it is hoped that the findings will give something back to the participants that will help them in their situations (Young & Barrett, 2001). In so doing, ethics serves the agenda of emancipatory research by empowering those participating in research projects. However, for most researchers, ethical research involves negotiations over institutional and procedural ethics requirements (Guillemin & Gillam, 2004). As this can be very complex and multifaceted, recent years have seen a plethora of research in childhood studies, exploring the ways in which such negotiations may be achieved (Ansell & van Blerk, 2005; Cree, Kay, & Tisdall, 2002). Yet very little has been written to fully explore the underlying processes by which successful ethical research is conducted, particularly in the context of children affected by the multiple impacts of poverty, HIV and AIDS.

This paper discusses some of our difficulties and considerations in implementing certain formal protocols (e.g. American Public Health Association [APHA], 2002; British Psychological Society [BPS], 2004)—developed to guide researchers across disciplines and contexts—in doing research with vulnerable children in East Africa (Ethiopia and Kenya). It examines how we adapted these protocols to local contexts of fieldwork and in so doing went beyond the expectations of prescriptive ethical guidelines. The paper argues that socio-ethical research is best achieved through reflexivity and continuous dialogue between all the participants in the research, including children. The ability of researchers to ‘reflect on the interrelationship between theory and praxis, seeking always to internally critique one’s approach’ (Bartley, 2005, p. 237), not only shapes the choice of research tools and the ways in which ethics, research participants and the field itself is understood, it also locates ‘the situatedness of one’s knowledge production’ (Bartley, 2005, p. 237, emphasis in the original). In arguing this, we are seeking to highlight not only the difficulties we encountered in adhering to the normative ethical principles of the Global North, but also the ways in which we negotiated these principles in the social, spatial, cultural, epidemiological, material and political contexts in which our fieldwork was carried out. The paper also discusses how designs for participatory action research projects have helped us to overcome certain socio-ethical dilemmas, including participants’ expectations that they will benefit from the research process and the obtaining of consent.

**Institutional and Procedural Ethics Protocols**

To facilitate good ethical research, researchers are increasingly being subjected to a number of codes of ethical conduct, which involves seeking approval from relevant
research ethics committees. As Guillemin and Gillam (2004, p. 263) point out, we have become used to the questions and requirements of ethics committees and to mechanically completing ethics application forms using ‘ethics-committee speak’. The Nuremberg Code, drafted by a tribunal after harmful research experiments during the Second World War, altered the ways in which research was being conducted in many places. With the Code, the research community saw the rise of ethical principles and protocols that had to be adhered to for the protection of research participants (Haggerty, 2004). The Code has given rise to many normative principles in research, including informed and voluntary consent, properly formulated scientific experimentation, and the research being of benefit to participants in it (US National Institutes of Health, 2008). Whilst ethical research regulations and protocols have targeted the medical sciences for many years, the last decade has seen social sciences being increasingly governed by these principles, institutional review boards and protocols (Haggerty, 2004). It continues to be particularly difficult for social research mentioning HIV or AIDS to escape stringent medical ethical guidelines.

The obeying and applying of universal ethical protocols within the social sciences has implications for how childhood research is being conducted. Ann Farrell (2007b) looks at the implications of moral judgments and argues that ethical protocols and guidelines play an important role in the phenomenon of risk management, acting as a tool of surveillance and protecting children from perceived harm and danger. She believes, however, that rigid ethical measures can act to inhibit the participation of children in research, in stark contrast to the growing literature in favour of collaborative research with them (Christensen & James, 2000; Farrell, 2007a). For example, although ethical research involves anonymity and confidentiality, some children may want to be represented by their actual names and express an interest in their pictures being incorporated in a report. This may infringe their privacy, but refusing to do so also contradicts taking children’s views and opinions seriously. Such debates reflect a concern as to the extent to which children’s rights and ethics can be meaningfully ensured by absolute models derived (uncritically) from Global North conceptions of individuality and autonomy, and the extent to which these models can be meaningfully applied, irrespective of the diversity in socioeconomic and cultural ethos that characterises communities across the world (Molyneux, Wassenaar, Peshu, & Marsh, 2005; Tangwa, 1996, 2003). This suggests there is tension between protocols established in the Global North and their transference to the Global South.

In this paper, we do not seek to side with either ethical universalism (global ethics) or ethical relativity (geographical or cultural ethics). While we are apprehensive about the fact that universal moral precepts for ethical research are often taken from the more or less unmodified quasi-medical contexts of the Global North, we fully believe that they are necessary and helpful guiding principles. However, as Tangwa (2003, p. 63) suggests, ethical protocols must be applied and appropriated within the constraints of the particular context under study. This is because, if their dynamic and dialectical relationship with concrete particulars is not properly appreciated, they may appear rather empty (Tangwa, 2003). It is for this reason that we seek to share our experiences of doing research with HIV-affected children in East Africa.
Ethics as a Process of Reflexivity and Dialogue

While we fully support some regulation and institutionalisation of ethical research and adherence to ethical guidelines, we believe that applying such guidelines must be complemented with a reflexive appreciation of the social structure in which the research is being conducted. In line with Bakhtin and Holquist’s (1981) conceptualisation of the ethical nature of dialogue, we believe that research processes and potential socio-ethical implications should be discussed and explored in a dialogue between the researcher and the researched. Dialogue has the potential to create a space for cultural exchange that draws on language and social representations. Reflecting upon Jovchelovitch’s (2007) criteria for an idealised public sphere, participants and researchers should meet as equals, with arguments being accepted for their intrinsic relevance and power rather than according to which speaker wields the most power. Dialogue can therefore become a tool to assist socio-ethical research and to support a move towards the goal of emancipatory scholarship and understanding. Not only does this create a potential space in which to discuss and explore how the research can be conducted ethically, it can also create a space in which socio-ethical issues could be renegotiated during the research process. However, the space for such dialogue cannot be created without an awareness of and reflection on the tensions (for example, power inequalities) that are likely to emanate between oneself (as a researcher) and the other (the researched) in the research process. These tensions are likely to be significantly affected by the socio-cultural context of the research.

Reflexivity refers to the ways in which researchers reflect upon their research practices (Gaskell & Bauer, 2000). While reflexivity in research often refers to researchers reflecting critically on their role in constructing and producing social knowledge, Guillemin and Gillam (2004) usefully argue that reflexivity should be a part of the process of doing socio-ethical research. To this end, McGraw, Zvonkovi and Walker (2000; cited in Guillemin and Gillam, 2004, p. 276) argue that reflexivity is ‘a process whereby researchers place themselves and their practices under scrutiny, acknowledging the ethical dilemmas that permeate the research process and impinge on the creation of knowledge.’ While universal ethics protocols do encourage some level of reflection on the ethical implications of doing research in particular contexts, Haggerty (2004) argues that such protocols and regulatory systems can actively discourage reflexivity by reducing ethics to the mere ticking of boxes.

In order to move beyond the ‘ticking of boxes’, through reflexivity and dialogue, universal ethics protocols should be adapted to the specific context in which the study is being conducted (Edwards & Alldred, 1999). To facilitate this, accounts of research experiences and thoughtful considerations within specific contexts serve as promising guidelines for good moral behaviour. Numerous helpful guidelines, reflecting on the experiences of researchers working with children in particular contexts, have already been written to navigate through ethical dilemmas (cf. Ansell & van Blerk, 2005; Matthews, Limb, & Taylor, 1998; Morrow & Richards, 1996; Nyambedha, 2008; Robson, 2001; Valentine, 1999; Young & Barrett, 2001). What these studies share is a commitment to give children a chance to participate in research and to minimise their risks in doing so. However, although the importance of ethics in the context of HIV and AIDS research in Africa is well established (Ahn,
only a few studies have addressed the socio-ethical dimensions of doing participatory research with children affected by HIV and AIDS (cf. Ansell and van Blerk, 2005; Nyambedha, 2008; Robson, 2001). This article aims to provide new perspectives to this limited but growing body of literature through our experiences of working with HIV-affected children in Ethiopia and Kenya.

**Deciding on a Project**

The issue of reflexivity and ethics starts in the conceptualisation of a research project. When doing research with children, the way in which childhood is perceived and understood by the adult researchers will inevitably frame the focus of the research. If researchers narrowly view children as passive, vulnerable victims in need of protection, this might contribute to the biased emphasis of research reports on: (i) the needs and problems faced by children, rather than (ii) on how the children themselves face these problems (Abebe & Skovdal, 2010; Ansell & van Blerk, 2005; Skovdal, 2010; Skovdal, Ogutu, Aoro, & Campbell, 2009). Alderson (2007) and Morrow (2007) argue that research drawing on de-contextualised understandings of childhood and child well-being has the potential to represent children negatively, which can increase stigma and prejudice against children in difficult circumstances. On the other hand, by seeing children as social actors and learning from their life worlds and coping strategies, we will be able to develop an understanding of the pathways through which local contexts can facilitate their resilience and well-being—an understanding that is needed to develop meaningful support (Skovdal & Campbell, 2010). In light of this, both the studies upon which this paper draw view children as subjects and agents in their own right, who, despite their difficulties, manage to make sense of their social and material worlds and, through a negotiation with those around them, play an active role in coping with their circumstances.

**Project 1: The Working Lives of Orphaned and Vulnerable Children in Ethiopia**

This research explores the daily, working and spatial lives of orphaned children and working children in the two contrasting fieldwork contexts of rural (Gedeo- and Oromo-speaking) and urban (Amharic-speaking) communities in Ethiopia. It examines an often overlooked interface between orphanhood and child labour, and shows how, in the context of poverty and AIDS, children contribute to the livelihoods of extended family households and the ways in which this is valued by and enters into the equation of childcare by the latter. Eight months of fieldwork were carried out with 24 girls and 36 boys (aged 9–17 years) and their families over a period of three years (2005–2008), in which Abebe used a wide range of participatory methods to explore children’s perspectives of orphanhood, care, education, livelihoods and work.

A key aspect of this research was to document what children do in terms of work, where they do it and with whom, as well as what they think about these activities. While realising children’s vulnerability and exploitation, the research also sought to explore why and how they make important decisions that affect their life chances. The research tools used were carefully selected in order to map out children’s
spatial and temporal lives. These included observation, informal dialogues, multiple interviews, indepth- and focus-group discussions, field notes, story-writing, photo-essays (children took pictures and glued them onto flip charts which they discussed and wrote essays about), surveys and household visits. The research commenced following the approval by Ethics Committee of the HIV/AIDS Prevention and Control Office of the City Government of Addis Ababa, and the process of data collection was facilitated with the help of local assistants, who had indepth knowledge of the study areas. Although initial sampling of the research participants was made through schools and non-governmental organisations (NGOs), as we shall explore later, such affiliations proved to be problematic.

Project 2: Caregiving Children in Kenya

This second research project we report from was carried out by Skovdal. The aim of this project was to explore the needs and circumstances of caregiving children in rural Kenya and to set out the psychosocial strategies that children develop to cope with difficult circumstances. The project also explored the routes that led the children to become caregivers, whom they cared for and the type of duties (and how often) they performed them. These observations were supplemented with an exploration of local representations of childhood and young caregivers, values and customs and the ways in which these social understandings help the children endow their circumstances with meaning and construct identities. To do this, the project involved 48 children between the ages of 12–17 years from two rural communities using Photovoice (cf. Skovdal 2011), draw-and-write exercises, daily diagrams, historical profiles, community maps, and individual and group conversations. This multi-method approach was adopted to recognise and support the different ways in which the children felt most able to share their experiences and perceptions of caregiving (O’Kane, 2008). Individual interviews with 10 adults from the communities were also conducted. Data were collected between 2006–2008, and the findings highlighted children’s active participation and competence in navigating and negotiating local resources to assist them in coping (Skovdal et al., 2009). The project was approved by the research ethics committee of the London School of Economics, and permission to conduct the study was granted by the Ministry of Gender, Children and Social Development in Kenya.

Both research projects were fully in line with the Dakar Declaration (1995) of the African Network on Ethics, Law and HIV, which affirms that: a) ‘the interest of the research subjects or communities should be paramount, b) that research should be based on free and informed consent, c) non-intrusive, d) the results should be made available to the community for timely and appropriate action’. However, as the proceeding discussions will amply demonstrate, putting these valuable ethical principles into practice required developing flexible research techniques.

Informed Consent through Participation

Informed consent implies that research participants are given the necessary information to weigh up the risks and benefits involved in their participation (Williamson, Kent, & Ashcroft, 2005) and that they can make an informed decision on their participation. This means that participants have consented to take part in
research after being informed of and understanding the aims, methods and processes, and topics of the research and what the data will be used for, as well as making clear that they can withdraw from the research at any time (Ennew et al., 2009). This raises an important question of not only how much freedom children feel they have in choosing whether or not to participate in a study, but also their capacity to withdraw from the study (Ennew et al., 2009). This is particularly relevant with HIV-affected children, as the hegemonic adult-centredness of society is often duplicated in research involving children, with little real consideration of their disenfranchised position (Kirk, 2007; Morrow & Richards, 1996; Punch, 2002). As Christensen (2004) points out, researchers must question how different degrees of power can affect so-called voluntary participation and, in turn, how this might affect the knowledge derived from the research.

Although written consent was obtained at the outset of the study from both the children and their guardians in Kenya, securing written consent in Ethiopia proved difficult, not only because people were not literate, but also because they were reluctant to sign documents (Abebe, 2009). As one woman asked, “Why would I ‘enter into a law’ [i.e. sign a legal document that is binding] when you can simply interview the child?” During the research process, we continually confirmed the children’s willingness to participate by asking them at different stages, and for each of the different research methods, whether they still wanted to participate. We made every effort to ensure that consent was not perceived as a once-and-for-all event, but something which we continually negotiated with the children and their guardians. Our participant retention was low, with 20 out of 48 children in Kenya and 18 out of 53 children in Ethiopia having withdrawn by our second year. While this is partly explained by children migrating elsewhere in order to seek alternative livelihoods or to provide or receive support from extended family households that themselves are geographically dispersed, our continued negotiation also ensured that the children could securely drop out should they wish. While the ability of research participants to ‘opt out’ is standard in any ethics protocol (e.g. APHA, 2002; BPS, 2004), we agree with Thomas and O’Kane (1998) that children’s active agreement to continue to participate in longitudinal research must be negotiated throughout the research process and not only at the beginning. To this end, we sought to ensure their ability to ‘opt in’ by encouraging them to take part willingly in any aspects of the research activities they chose. This increased their say, choice and involvement in the type of method they could take part in. For example, many children preferred to be involved in photo-essays, story-writing and draw-and-tell techniques instead of semi-structured interviews and focus group discussions, reflecting how their relative control over the research process affected their level of participation. Through our longitudinal and multi-method study, we sought to give the children the space they needed to securely ‘opt out of’ and ‘opt in to’ the research process. The children could therefore temporarily withdraw from the research and join back in again when research methods they would feel more comfortable with were available to them.

The Use of Informed Consent in Photovoice

In our Photovoice exercises in Kenya and Ethiopia, much time was spent with the children in explaining and discussing the ethical dilemmas of Photovoice and taking
pictures. The public nature of photography infringes on privacy and confidentiality (Gold, 1989). Wang and Redwood-Jones (2001) have therefore proposed a minimum set of ethical practices when using Photovoice, which include an ‘acknowledgement and release’ consent form for those who are photographed and appear on the photos. In seeking to implement their advice, we discussed with the children some of the potential dangers of taking photos of people without their consent and agreed with them that they should carry a small notepad when taking pictures and ask those photographed to sign in the notepad consenting to the use of their photograph after the exercise and the potential use of the photos had been explained to them. We also told the children to think about and avoid taking photos of people in situations that they believed could be potentially embarrassing for the person photographed (such as a bedridden parent).

Although the children told us that they understood and would feel comfortable implementing these measures, we soon learnt that they were not always asking for the consent of those they were photographing. The reason for this could be explained by a combination of a more general fear of signing and giving consent (cf. Molyneux et al., 2005) and children’s social status, which made it difficult for them to explain the purpose of the exercise to adults and subsequently to ask for their signatures. As we went into dialogue with community members, we learned that it would be inappropriate for children in our contexts to ask adults for signatures. We were also told that that the consent of those who had been photographed was not necessary, as long as the photos did not depict people in embarrassing situations. The children were informed of this and asked to select six of their favourite photos depicting: (i) how they get by, (ii) things they lack, and (iii) something or someone that is important to them (Skovdal, 2011). If the children wanted to share a story they were unable to capture or share photographically for ethical reasons, it was collectively agreed that they could draw the situation instead. This experience highlights how ethical guidelines that have been developed in one socio-cultural context may be inappropriate in another. Through careful negotiation and dialogue with the community, we were able to come to a compromise which was more closely aligned with local expectations of ethics.

**Disclosure of Sensitive Information**

Since the two studies we refer to in this paper were both framed within the context of the HIV epidemic, it was important for us to know that the participating children were affected by HIV. However, as a result of the stigma associated with HIV and AIDS (Deacon, Stepney, & Prosalendis, 2005; Rankin, Brennan, Schell, Laviwa, & Rankin, 2005), it was imperative to be very careful in how we approached and sampled the children. One of the dangers of doing research with children in the context of HIV is that their participation in a known ‘AIDS study’ will identify them publicly as the children of parents with AIDS, which they might prefer keep secret. This might lead to an involuntary disclosure of parental HIV or AIDS status, which not only adds a burden to the sick parent (Campbell, Nair, Mainmane, & Nicholson, 2007; Reis et al., 2005; Turan, Miller, Bukusi, Sande, & Cohen, 2008), but might also increase the vulnerability of the children themselves to stigma and discrimination (Murphy, Roberts, & Hoffman, 2002; Murphy, Steers, & Dello Stritto, 2001).
The aim of good research interviewing is to build trust and rapport with the informants so that they feel confident in sharing things they would otherwise not have told anyone. Building a safe research context allows children to talk openly about sensitive issues in their lives—issues they have not previously discussed or had any intention of sharing. Whilst this can be very beneficial for them, on some occasions it may lead children to disclose their family members’ HIV status without being properly prepared to do so. In a number of cases, boys and girls reported information about their private lives which they may not have wished to talk about had it not been for the nature of the interviews and the mutual trust that was established during the research process. While we treasure the many benefits of such trusting and open research contexts, we found ourselves questioning whether the children were disclosing something they may not have intended, or were not emotionally prepared to (cf. Cree et al., 2002).

Many of the children in our study were sampled through local community organisations that provide home-based care for people living with HIV and AIDS, as well as providing support for children affected by HIV. We told the ‘professional gatekeepers’ in these organisations to help us identify children living with adults who were ill and often bedridden. Once the children became involved in the project and shared details of their circumstances with us, it became clear that their sick guardians were in fact suffering from AIDS. While the HIV status of their parents was never explicitly mentioned, the children’s descriptions of their guardians constituted a verbal diagnosis of their parents. Twelve year-old Philip (pseudonym) from Kenya, for example, in describing his caring for his father, highlighted some of the classic symptoms of people living with AIDS: ‘I was always the one caring for him. I washed his feet, his swollen joints, giving him drugs and by then my mother also got sick. His hands were all swollen and I put Vaseline on the legs. I prepared his food and spoon-fed him. He also had sores all over the body’.

Although the children most probably knew that their parents were HIV-positive, many children consciously decided not to speak of AIDS explicitly, but chose to use a more implicit, coded language, such as using metaphors or simply explaining the symptoms (Wood & Lamberth, 2008). We felt it was important to respect the children’s decision not to reveal explicitly their parent’s HIV status, or to facilitate stigma involuntarily. Therefore, we did not use ‘AIDS talk’ when working with the communities. However, our decision not to identify our two studies as specifically AIDS-focused meant that we were breaching certain ethical codes, namely those that highlight the need to explain all aspects of the research when seeking consent. We failed to explain fully what our studies were about. This particular ethical dilemma has been discussed in detail by Ansell and van Blerk (2005), who found it inappropriate to declare the HIV and AIDS focus of their study while conducting research with young AIDS migrants in Lesotho and Malawi. Reflecting on the implications of their decision, they explain that their passivity in confronting stigma and not encouraging an open dialogue stemmed from the pressure an AIDS focus can place on individuals who might be at risk of heightened stigmatization through their participation in an HIV and AIDS research project (Ansell & van Blerk, 2005). Our experiences resonate with those of Ansell and van Berk (2005), who highlight the need for researchers to be critical and reflective about how they go about
explaining their study to research informants and projecting themselves to the wider community. 

One of our research tools that facilitated the possibility of exploring sensitive issues was story-writing, a method that utilises young people’s particular talents (colouring, drawing, writing, creative thinking), thus affording them greater control over the process by being open and non-prescriptive (Ansell, 2001). Story-writing proved successful in exploring the children’s views on rather difficult issues such as their experiences of exploitation and their emotional reactions to parental death due to AIDS. These issues were evidently difficult to gain insights into by using, for example, face-to-face interviews. Story-writing became useful in overcoming the power hierarchies not only between the researchers and the researched, but also among the research participants themselves, a problem commonly encountered in group interviews and focus group discussions involving mixed sex and age groups. It has been established that interviews and focus group discussions can be more confrontational and may not ensure the privacy of individual participants (Robson & Ansell, 2000). Many children in our research found such methods more restrictive and, as a result, they were inhibited in articulating their views more fully compared to the use of story-writing or essay composition. Research with children is commonly characterised by power differentials reflected in everyday life between adults/children and socioeconomic differences which, in their turn, leave many children in a rather inferior position in relation to the wider society (as well as in relation to [male] researchers). 

Story-writing helped us to overcome this barrier and improved the degree of children’s participation in the research. However, in spite of these advantages, the method leaves little scope for co-creating ‘oppositional knowledge’, that is, knowledge constructed by the researcher and the research participants through dialogue (oral exchange) for consumption by the researcher (data collector) in the immediate fieldwork context (Ansell, 2001, p. 112). Moreover, the researcher and the researched may not contest ideas from stories composed by the latter through, for example, a focus group discussion (or interview), especially if the stories are interpreted after the fieldwork is completed and when the researcher has already left the field. This may lead to the reproduction, in any given research, of only the dominant discourses in society (in stories, children may not only reproduce discourses upheld by the mainstream society, but may also compose what they generally think are ‘good’ and ‘appropriate’ stories by adult researchers, with clear implications for the nature of the empirical material one obtains). We partly overcame this challenge and addressed the importance of questioning dominant discourses by using a draw-and-tell approach and photovoice, in which we explored children’s perspectives by asking them, for example, why they took particular pictures and drew specific drawings, and asking them what they actually meant to them.

Class, Ethnicity and Knowledge in Fieldwork

In this section, we consider the ways in which our status as educated and privileged researchers (both men) shaped our research and, most importantly, the different ways in which ethnicity was experienced. We also reflect on the debates and
implications of the insider and outsider status of researchers for the nature of the knowledge acquired from the field. Representations of the knowledge of self and other (for example, researcher and informants) play a critical role in shaping the nature of knowledge encounters in a research setting (Jovchelovitch, 2007). Furthermore, doing international research can be problematic and requires an awareness of colonial histories, the development industry and local realities (Sultana, 2007). As a Caucasian, born, raised and educated in the Global North, Skovdal had to enter the field in Kenya with an awareness of his position as ‘other’ and an outsider. As an outsider he constantly had to negotiate the politics of representation, which called for reflexivity and a constant awareness of his positioning amongst the children, their guardians and the community as a whole.

Whilst Skovdal interacted with the children participating in his study through, for example, sports activities, his inability to speak the local Dhluo language and commit more than eight months in the field meant that all the data collection workshops were facilitated by two local youths. These two youths were trained by Skovdal and were around to support and talk to the participating children from the start of the programme in 2006. This long-term and local arrangement meant that the children were able to build rapport and trust with the research team. It was important for us not to do ‘parachute research’, with members of the Global North entering a community only to ‘extract’ data. We wanted to ensure local involvement, long-term commitment and rapport, and the availability of practical outcomes as a result of the children’s participation. While the lack of experience of our young and local researchers in conducting academic research may be seen as a methodological limitation, their understanding of the local context served both to ensure acceptance by local communities—as gate-openers—and as means of conducting socio-ethical research. The local researchers actively challenged and modified some of the more Eurocentric procedural ethics protocols that Skovdal had envisaged, sparking a dialogue on how the study could proceed ethically.

Nevertheless, despite these measures, the imagined presence of Skovdal among the children during the entire research process undoubtedly had an impact on how the latter responded and interacted with the local research team. Who and what did Skovdal represent to the children? What did they perceive Skovdal’s expectations to be? How did they understand their participation in the research process? What did the children expect and anticipate from participating in the study? Most researchers, including ourselves, do not have the answers to these questions, yet the latter not only shape the empirical material we collect, but also influence the applicability of more procedural ethics protocols and the space in which ethics are negotiated. Our multi-method approach highlighted a number of tensions and inconsistencies, which suggests that the children approached the phenomena under study from different angles (Gaskell & Bauer, 2000), possibly influenced by their shifting understandings of the above questions over time and context.

Although Abebe is an Ethiopian himself, his insider position did not give him unproblematic entry into the field. Amharic, the lingua-franca of Ethiopia and the medium of fieldwork, was used during interviews, photo-essays, story-writing and focus-group discussions involving both children and adults. However, nearly all the participants of the research in southern Ethiopia also spoke local languages (Oromo and Gedeoffa), which presented both opportunities and challenges during
fieldwork. Learning to speak the local language has been recognised as a central aspect of fieldwork in cross-cultural research (Watson, 2004). It is believed to facilitate easy entry into the social worlds of participants and, in most cases, creates a turning point in researchers’ acceptance by local communities. Moreover, learning a language may be a step towards shifting the balance of power from the researcher towards the researched, and may help generate insights that could otherwise be ignored (Watson, 2004, p. 59). Although this reality was experienced by Abebe’s commitment to communicate with the children in the local Oromo language, of which he has a fair command, the fact that the former were multilingual rather than bilingual (as the researcher is with respect to Ethiopian languages) revealed the complexity of such communication. In these contexts, language can be a barrier or a factor even for a native researcher. While being an ‘outsider-insider’ enabled him to understand the nuances of the cultural and social environments within which children’s actions, behaviours and realities have to be contextualised, this is not always a straightforward matter when working in and with multi-lingual and multi-ethnic communities. For instance, research participants used Abebe’s limited language competence of Gedeoffa as way of exclusion during fieldwork, especially in circumstances when they wanted to discuss matters which they believed to be private and confidential. Furthermore, some respondents may have been more fearful of the possible consequences of disclosing sensitive information during interviews to a local researcher than to a foreigner, thus highlighting how his local social status and background at times work at cross-purposes with his shared national identification. Being an insider researcher therefore presents a different set of dilemmas in terms of winning the trust and confidence of research subjects. An outsider-insider status may both facilitate the research process and close off opportunities for more detailed knowledge in interesting and contradictory manners.

Although class and ethnicity both play an important role in the process of data collection, as Mayall (1994) argues, the real power differentials between the adult researcher and the children lies at the level of data analysis and interpretation, when the researcher has actually left the field and where often specialised theoretical knowledge is required. The power to interpret the empirical material and represent children’s lives in abstract terms is something which is generally unavailable to them, indicating how knowledge becomes a source of inequality, difference and power. Although it is argued that the hegemonic adult-centredness of society and the inferior position of children reproduces researcher–researched power differentials (Kirk, 2007; Morrow & Richards, 1996; Punch, 2002), this discussion must be extended beyond the actual fieldwork experience. Researchers are powerful in the representation of research subjects, the production and dissemination of information, and the ways in which research impacts on policy. Ignoring the involvement of research participants in this crucial stage could be disempowering for them in fundamental ways.

An important approach we employed during fieldwork was to use what James et al. (1998, cited in Ansell, 2001) call the ‘adult child model’, that is, treating the children as mature and knowledgeable persons. By considering children as participants in the research—as opposed to ‘informants’ and ‘respondents’—we encouraged them to enter into a dialogue and reciprocal relations with us, which in its turn enabled them to become active in the research process. One important
approach we pursued was to employ diverse research methods that the children are comfortable with and have a good command of, like photography, story-writing and the draw-and-tell method. In addition, whereas both our studies interpreted the empirical material within a set of theoretical frameworks, our use of participatory research approaches allowed us to work within the themes that emerged from the children’s participation in the research process. The analysis of data also involved someone from the community to check for inter-code reliability. While the transcription of the material from the field was accomplished verbatim by native speakers of the local languages, we also discussed some of our findings with research participants in order not to miss important inputs and facilitate a better representation of their life worlds.

**Incentives and Reciprocity**

Reflecting on a decade of research experience with community members in western Kenya, Nyambedha (2008) points out the dilemma of research participants having higher expectations of benefiting from their participation in the study than most researchers can live up to. Although Nyambedha is a Kenyan, people in his study area could not believe that someone working closely with a European organisation could come all this way to speak with orphaned children and their caregivers without providing assistance. As a result of his research experiences with marginalised communities, Nyambedha (2008) calls for an increased commitment of researchers by design research protocols (for example, action research projects) that reflect the socioeconomic context and address the expectations of the study population. While there is some debate over whether research participants should be paid or given incentives for their participation, this debate has been restricted to Western research settings (Borzekowski, Rickert, Ipp, & Fortenberry, 2003; Fry et al., 2005). Codes of conduct and practice manuals for social researchers (Ennew & Plateau, 2004; Mikkelsen, 1995) recommend not giving any money to research participants. They are also ambivalent about paying children, arguing that it creates divisions and perpetuates power differentials. Similarly, researchers based in the Global North who come to sub-Saharan Africa and provide their research participants with financial or material incentives, can provide problems for local researchers who do not have the funds to pay participants and can raise expectations. Another potential danger of paying research participants and, in our case, bringing them development assistance is the dilemma that a person giving their consent to participate in research might have difficulties in assessing the risks and benefits of their involvement if they are enticed by payment or any other kind of assistance (Fry et al., 2005).

Despite these assertions, both our studies provided incentives to our participants to acknowledge their contribution, effort and time. As Grenier explains:

> [R]esearch is a two-way street. The researcher can’t really expect to go into local communities and just take. If a person is going to do research, something has to be given back. The community has to gain from the research process. Why would someone want to waste their time because local people’s time is valuable. Moreover, before people give their knowledge you usually have to build some friendship. And until that friendship or relationship is built, people
may not give you correct knowledge, or accurate knowledge or the real piece of information that is critical to your understanding. (Grenier, cited in Lan & Jones, 2005, p. 5)

This quote captures our own position and field experiences. Since research does not take place in a vacuum, and since time is a valuable resource for children, we believed that they should be compensated. As most of our participants were from low-income groups, and many of the children were juggling their responsibilities in different places in order to earn their daily income, like Langevang (cited in Abebe, 2009), we felt that giving them a certain sum was an adequate reward for them to give up their business time and labour and hopefully a way of sustaining their participation. In Ethiopia this involved multiple approaches. In schools where Abebe taught social studies classes as a volunteer; he gave or paid for children’s football shoes (as they themselves requested) and stationary materials (books, pens and exercise books). However, since the children in the study also included those who were not attending school, he gave money to them and paid for the meals he frequently shared in shai bets or local cafes. In Kenya, Skovdal provided research participants with lunch and bars of soap as incentives to bring the children together for our workshops. However, our relationships with many of the children were deep and mutual. We not only provided them with incentives, but also gave them the tools and resources for social change. While the lunch and soap incentives were explicit, we decided not to inform the children participating in the Kenyan study of the community initiative funds (equivalent to €50 per child) available to them at a later stage of the project. Once the children had developed an action plan as a result of their reflections using photovoice, we released the resources to make their plans actionable. This commitment to provide groups of children with a community initiative fund reflects the dilemma outlined by Nyambedha (2008), as well as our immersed understanding of the social representations that characterise outsiders in this context, gained through dialogue with local community members. Although we were careful at the beginning of the research project not to suggest that financial support would be made available at a later stage, we also knew that the children at one level hoped for support from us by virtue of our affiliation to an NGO (WVP Kenya). While the children’s perceptions and hopes for support might have influenced their consenting to participate, we felt, reflecting Nyambedha’s (2008) observations, that they would still have had expectations and hopes for support, regardless of our affiliation to an NGO.

**Discussion**

To explore some of the processes by which ethical research can be conducted with children affected by HIV in an African context, we have described and reflected upon our experiences of our research in Ethiopia and Kenya. We have presented some of our encounters and the ways in which we dealt with socio-ethical and methodological dilemmas. More specifically, we have discussed how privacy, confidentiality, power differentials, reciprocity and issues of insider and outsider statuses are translated into practice when conducting research with children in the context of HIV and AIDS. We also discussed how ethical considerations like informed consent and voluntary
participation are not something that researchers simply get from the researched; instead, it is something they should seek to obtain through trust and honest discussions about the research project. Informed consent should therefore not be seen as a one-off event done at the outset of the project to satisfy ethics review boards, but something that is continually negotiated through honest discussions about the research project and its objectives. A comprehensive ethical strategy (including methods of seeking informed consent) needs to be devised in order to create spaces where it is possible for children to be able to opt out, or say ‘No!’ if they wish to.

We suggest that the designs of our participatory action research projects have helped to overcome certain socio-ethical dilemmas, including local expectations that participants will benefit from the research process. This involved building a rapport and developing friendships based on reciprocity and shared identities with respect to empathising with the children’s situations, and trying to understand their lives from the points of view of the children involved. While we believe that in cases such as our participatory action research and the involvement of NGOs through a prolonged period can be advantageous, we also acknowledge that this can result in a new set of socio-ethical dilemmas. For example, participants can fabricate stories in the hope that this may give them access to the resources of NGOs and their staff.

Based on our experiences of working with children affected by HIV and AIDS, we believe that socio-ethical research is best achieved if researchers strive to be reflexive about the research process (by acknowledging power and cultural differentials between researcher and researched, adults and children), as well as creating spaces for dialogue in which socio-ethical and methodological issues can be discussed and negotiated contextually. To illustrate this argument, we propose a model that depicts a multi-dimensional continuum of socio-ethical research designed to encourage researchers to strive for reflexivity, dialogue and children’s participation in research (see Figure 1).

![Figure 1. Multi-dimensional continuum of socio-ethical research.](image-url)
The aim of this model is to situate the methodological and socio-ethical dilemmas discussed in this paper within a wider debate on how we can best seek to do socio-ethical research. Most researchers will be able to place themselves and their studies within one of these four quadrants. Starting from below, quadrant IV represents those researchers who conduct research on children and perhaps consult adults to gain an insight into the lives of children. In this process, the researcher enters into a dialogue with local stakeholders (albeit adults) to negotiate ethics and local expectations. They try to learn about children, but not from them concerning their own lives. In quadrant III the researcher also investigates the lives and circumstances of children without consulting them and in the process ignores local expectations and understandings of ethics. A researcher in this quadrant ticks the boxes of global ethical standards and may reflect little about how these ethical standards are understood in the context in which the study is located. Researchers in quadrant II are committed to research with children as opposed to on children and encourage children’s participation. However, such researchers follow global ethical standards and have little interest, or time, to consult local representations and understandings of ethics. Researchers in quadrant I are probably closest to those doing socio-ethical research. They strive to follow global ethical standards, but also involve children in the research process and enter into a dialogue with locals and the research participants in an effort to communicate, understand and negotiate ethics, all with the aim of seeking to do real good and avoid real harm. That said, the local ethos is not inherently any more ethical than global ethics. Local contexts might be ethically fraught with unequal power relations, and it is the responsibility of the researcher to find the right balance in applying global ethical standards in a meaningful and ethical manner. We also acknowledge that a ‘real dialogue’ may not be possible and that this may just be another opportunity for researchers to convince the researched that they should participate, rather than a real opportunity for the researched to raise objections and take ownership of the process.

In suggesting this model, we are by no means seeking to box ourselves or other researchers into one of these quadrants. We appreciate that there are different levels of participation, dialogue and use of global ethical standards, and that researchers are constantly moving between these different levels. We are also aware of the limitations of justifying research that occasionally has to ignore global ethical standards, as this can potentially leave disempowered populations subject to abuse and exploitation in the name of empowerment. However, we hope that this model of ‘reflexive dialogue’ will open up space for a debate on socio-ethical research that furthers our understanding of how we achieve socio-ethical research by considering the intersection of local ethos, reflexivity, participation and dialogue. In doing so, we argue that ‘global’ ethics standards need to be reworked by taking into account the local ethos, and by fostering children’s participation in the research process. More specifically, institutions, including Internal Review Boards and National Ethics Committees need to acknowledge that societies around the world have their own understanding of how to ‘do good’ and ‘avoid harm’—understanding these world views are central to undertaking socio-ethical research with children and achieving what Ennew et al. (2009) call the “right to be properly researched”.

This model, as well as the methodological and socio-ethical dilemmas that we have highlighted in this paper, contributes to the emerging body of literature which
discusses the ethical considerations of researchers who conduct research with children in difficult circumstances. As childhood experiences differ, presenting researchers with unexpected moral and ethical dilemmas (Young and Barrett, 2001), documenting and sharing such experiences will contribute significantly to this all-important reflexive process of doing socio-ethical research. We have made a case for community participation and the creation of spaces for dialogue, thus agreeing with Molyneux et al. (2005), who argue that ethics should be negotiated with community members and be informed by local issues and practices.

**Acknowledgements**

We would like to thank Professor Catherine Campbell and the anonymous reviewers for their helpful comments on earlier versions of this paper.

**References**


Molyneux, C. S., Wassenaar, D. R., Peshu, N. & Marsh, K. (2005) ‘Even if they ask you to stand by a tree all day, you will have to do it (laughter)…!’: Community voices on the notion and practice of informed consent for biomedical research in developing countries, Social Science and Medicine, 61, pp. 443–454.


