Ethical dilemmas of social science research on AIDS and orphanhood in Western Kenya

Erick Otieno Nyambedha*

Maseno University, Sociology and Anthropology, Kisumu-Busia Road, Kisumu, Nyanza, Kenya

Available online 9 April 2008

Abstract

This paper is based on the experiences drawn from a long-term social science research programme on the impact of the AIDS pandemic on orphanhood in western Kenya. It discusses the ethical dilemma of maintaining a delicate balance between research ethics, the expectations of the study population and negotiating the community’s vested interests in a health related research project in a low-income society. I argue that informed consent and the intended benefits of the study to the participants continue to be major challenges facing the justification of social research with people affected by or living with AIDS in low-income societies. The paper underscores the importance of community feedback sessions as a way of enhancing chances of acceptability of research efforts and obtaining informed consent. It further shows how community feedback sessions contribute to local knowledge of the problem being studied, creating opportunities for advocacy. This discussion adds to the existing ethical debate on the wider contexts within which research on vulnerable people affected by AIDS is conducted by arguing that research practice is inseparable from epistemological concerns of knowledge production. I suggest that ethnographers should enhance efforts to innovatively design action research projects to serve the twin purposes of data collection and deal with ethical challenges that are experienced when doing long-term research on vulnerable groups.

© 2008 Elsevier Ltd. All rights reserved.

Keywords: Kenya; Research ethics; HIV/AIDS; Informed consent; Orphanhood; Social science research; Children; Ethnography

Introduction

The AIDS pandemic has resulted in high numbers of orphans and widows in the countries of sub-Saharan Africa that are hard hit by the pandemic (UNICEF/UNAIDS, 1999; UNICEF, 2003). Orphans are children who have lost either one or both parents due to death and are below the age of 18 years (Ntozi, 1997; Nyambedha, Wandibba, & Aagaard-Hansen, 2001). In Kenya, levels of vulnerability among people affected by or living with AIDS, such as orphans and widows, have created challenges for social science research on the impact of AIDS among the vulnerable study population (see GOK/UNDP, 1999; Kenya NASCOP, 1998; Nyambedha, 2000, 2004, 2005; Nyambedha & Aagaard-Hansen, 2003; Nyambedha et al., 2001, 2003a, 2003b). The vulnerable conditions for people affected by or living with HIV/AIDS is aggravated by the increasing levels of poverty and the inability of the extended family to support vulnerable people affected by or living in the midst of the pandemic (cf. Ankrah, 1993; Ntozi, 1997; Nyambedha, 2004; Nyambedha & Aagaard-Hansen, 2003; Nyambedha et al., 2001; Prince, 2005; Yamba, 2005). Orphans and widows, therefore, depend on assistance from external donors intervening in their...
vulnerable lives because there is no functional state support mechanism in Kenya as in other parts of sub-Saharan Africa that can help to address welfare needs of people affected by the HIV/AIDS pandemic (see, for example, Ankrah, 1993; Nyambedha et al., 2001).

Delor and Hubert (2000) point out that although vulnerability is becoming far more marked, certain difficulties arise when it comes to applying the concept in understanding actual life situations. This is because we lack the language or the conceptual tools for analysing it. They further argue that the concept runs the risk of losing practical relevance through its increasingly frequent but ambiguous use. Vulnerability is frequently associated with concepts such as dependency, fragility, victimization, insecurity and risk (Delor & Hubert, 2000). However, in examining these associated concepts, one realizes that the concept of vulnerability itself is complex and diversified. This is because the associated concepts I have listed above are themselves difficult to define and change meaning depending on the particular social context. A good understanding of vulnerability, therefore, needs to focus on identifying and describing the social situations in which it emerges and develops. In social science research on AIDS and its effects, we need to create ways of analysing how vulnerability is explicit in the daily lives of people who are affected. This is important if we are to locate social science research ethics on concrete practices of interaction by the people affected by the pandemic, paying attention to relational and contextual process that raise ethical concerns.

The ethnographic work and ethical dilemmas that I shall address in this paper are primarily related to an extended research programme conducted on the livelihoods of orphans and widows in western Kenya. Orphans and other vulnerable children in the community were provided assistance through indigenous kinship-based institutions such as duol (Nyambedha, 2000). The term duol is used in this paper to refer to the indigenous institution of Luo collectivity for feeding orphans and vulnerable children in the extended family. Churches have transformed this indigenous institution in the post-colonial period to reach their congregations and with the advent of HIV/AIDS pandemic, are using duol to provide assistance to orphans and widows (see Nyambedha & Aagaard-Hansen, 2007). This assistance has been scaled-up by the missionaries who help to educate, clothe and provide food rations to orphan households. They also help to construct houses for widows before the emergence of AIDS (Nyambedha & Aagaard-Hansen, 2003). Such assistance has continued during this time when the prevalence of orphans has rapidly increased due to the AIDS pandemic. However, the available resources for orphan support have not been sufficient for the high number of orphans, leading to high levels of desperation. Such a historical past, in which assistance was provided to the orphans and widows initially through kinship systems and later through the church, has complicated the field contexts in which current research on AIDS and orphanhood takes place (Robbins, 2003).

There are challenges that coincide with doing ethnography in these contemporary settings where AIDS, poverty, and high number of orphans and ailing widows has created ever-shifting tensions between anthropological research, ethics and politics of intervention. This scenario calls for a careful reconsideration of ethical issues in this setting (see Schoepf, 2001). I will describe the experiences and ethical challenges of balancing responsibilities to the research participants and host community on the one hand, as well as the ethnographic interests and responsibility to the academic community as an anthropologist. My point is that there is a need for anthropologists doing extended research among groups such as those affected by AIDS to combine the scientific and moral aspects of the knowledge production process. Moral aspects of knowledge production include recognizing the individual sense of agency of the study population while at the same time respecting the responsibilities of doing research in such contexts to avoid harm and exploitation of the research participants (Hoeyer, 2005). Such an approach can enable anthropologists to be more accountable to the people studied by moving from personal commitment as individual anthropologists to an engagement with the wider context where the research is practised (Harper & Jimenez, 2005; Hastrup & Elsass, 1990; Herzfeld, 2002).

Thus, I raise a debate on moral issues and the challenges of researching the effects of AIDS and orphanhood by applying the principle of informed consent in resource limited settings (see American Anthropological Association, 1998; CIOMS, 2002; Nuffield Council on Bioethics, 2004). The discussion, therefore, contributes to an on-going debate on social science research ethics in general (e.g., Herzfeld, 2002; Meskell & Pels, 2005; Schoepf, 1991) and specifically, the ethics of doing anthropological research on the effects of AIDS in sub-Saharan Africa, where it is argued that research practice is inseparable from theory, methodology and the political economy of the context within which it is conducted. Robbins (2003) explains that anthropology should strive to generate scientific understanding that is not tarnished by the social situations of the ethnographers and should not simply be a reflection of the differential power relations between ethnographers and the study population. I argue that in the case of social science research on the
effects of AIDS, such a scientific understanding should be derived from the knowledge of pre-existing intervention efforts as an essential prerequisite for moral action by anthropologists who translate pure research into action research (e.g., Schoepf, 1991).

Study setting

I have lived and conducted anthropological research on AIDS and orphanhood in Obalo division in western Kenya since 1998. Most of my research activities have been concentrated within one village where I interact on a daily basis with my informants. There are many fish landing beaches on the islands of Lake Victoria, which surround Obalo division. However, the inhabitants are mainly subsistence farmers. There is a Catholic mission in the area and an orphanage. Both the Catholic mission and the government operate schools within the division. There are two medical facilities in the division. One is a government dispensary, which is relatively cheaper, while the other is owned by the Catholic mission. A survey carried out in late 1999 showed that a third of children (33.6% of the 724 sample size) in the area are orphaned. About half (49.2%) of these had lost their biological fathers, maternal orphans comprised 19.6%, while double orphans were 31.2% of the total number of orphans studied in the survey (Nyambetha et al., 2003a, 2003b). Most of them had lost their parents due to AIDS pandemic. They live either with their widowed mothers or grandparents.

My study on the effects of AIDS on orphanhood in this division began when I was a postgraduate student at the University of Nairobi and was linked to a foreign collaborating institution in one of Kenya’s bilateral donor countries in Europe. The collaborators from Europe frequently visited the project site and interacted with the people in the study area together with myself. Many non-governmental organisations (NGOs) have initiated intervention activities to support the orphans and widows who are affected by AIDS. Many of these activities are concentrated in the neighbouring localities of my research area. Apart from these, there are other research projects in the neighbouring localities that do research in public health problems in the division. In some cases, many of the activities of the NGOs operating in Obalo division provide assistance to orphans in their programmes.

Many people see children in these programmes as being lucky because they have been sponsored by the NGOs. Thus, people in the area do not differentiate between the activities of these NGOs, other researches in the neighbouring localities and my study on the impact of AIDS on orphans and widows. Ethical issues of seeking informed consent in these field contexts are, therefore, entangled in complex circumstances where interventions in the situation of orphans and their widowed mothers raise expectations that are perceived to go beyond the usual relationships in ethnographic contexts.

Results

Informed consent and raised expectations

For a study on the orphans, members of the community most often asked ‘What are you going to do to the orphans after you have studied them?’. For example, many wanted to know whether my proposed research would ‘take’ the orphans. ‘Taking’ the orphans (kawo nyithind kiye) is a phrase used to refer to the activities of many NGOs in the neighbouring communities, involving sponsoring orphans to attend school by paying school fees and buying school uniforms. It refers to a long-term commitment that an NGO or a financially capable member of an extended family undertakes to shape the entire childhood of an orphaned child — mostly by educating the orphan and not just helping irregularly with immediate material assistance. These expectations, requests and the living conditions faced by orphans and widows affected by or living with AIDS in a poverty stricken community forms the wider context with which I had to engage as an ethnographer.

According to the American Anthropological Association (AAA, 1998) guidelines, researchers are expected to explain to the research participants the purpose of the research. This is done in order to inform and protect the participants who are expected to understand the reasons for the research and the consequences of taking part in it. It is felt that genuine consent can only be obtained after the purpose of research has been carefully explained to prospective participants (see also CIOMS, 2002; Nuffield Council on Bioethics, 2004). This process of obtaining informed consent should be a continuous exercise that enables research participants to understand the aims and consequences of participating in the research. However, because of the living conditions of people affected by AIDS, many people in the study area did not believe that somebody working closely with a European organisation from the West could just come all the way from Nairobi to ask the orphans and their widowed

---

1 My stay in the field was funded by the DBL-Institute for Health Research and Development between 1998 and 2003 and a Ph.D. grant by the Danish Council for Development Research (RUF) through DBL-Institute for Health Research and Development, Denmark, and the Institute of African Studies, University of Nairobi, Kenya.
mothers, questions regarding their lives without providing assistance. Many people believed that my intention in the long run was to ‘take’ the orphans. There were rumours in the village that the researchers in the area had been given a lot of money to help the orphans and widows and all they did was ‘eat all that money’ themselves. They frequently asked the field assistants why we were not doing the same as other donor-funded organisations in the neighbouring localities that were ‘taking’ orphans. The concerns by the study population affected by AIDS in this community can be illustrated by the case I present below:

Beatrice’s family
I met Beatrice, a widow in her forties, in November 1998. Her husband had died the previous year in 1997 and her elder co-wife had died in October, a month before I met her. Beatrice was ailing and could not engage in any subsistence activities. She lived alone in the home of her late husband. She had one son who was still attending the local primary school. Four orphaned children of her dead co-wife also stayed with her. Most of the time, the orphaned children did subsistence farming. When I introduced my study to Beatrice, the first question she asked was whether I was also ‘taking’ orphans. I explained that I was not really ‘taking’ orphans but when there was a serious problem that could result in the children being sent away from school, then she could tell me as a person who visited her family regularly. I could explore a possibility of providing assistance, without making promises of ‘taking’ her orphaned children. Such a response coming from me as a researcher could have raised her expectations. However, given the circumstances, I considered this to be the most reasonable way of responding to polite requests of ‘taking’ the orphans from a widow I was going to interact with for a long time. After our conversation, Beatrice accepted that I could talk to her and also the orphans who were living with her. From this time, I became a friend of Beatrice’s family and regularly visited them, sharing with them discussions about events in the village and her struggles in life. She explained that she was not able to produce enough food to feed herself and the orphans because of her sickness. During my numerous visits, I related closely to the orphans living in Beatrice’s household and allowed them to tell me if they lacked things in school. One day, Beatrice informed me about one of her late co-wife’s daughters who could not raise Kshs. 350 (about USD 5) to register for the Kenya Certificate of Primary Examination (KCPE). Without this, the orphaned child would not have any document to show that she had ever been to a school in Kenya. I paid for her examination but informed Beatrice that it would not be possible for me to provide support in secondary school if she qualified, because I did not have enough money.

Beatrice used to make sisal ropes to sell as a way of generating income. The orphans staying with her would prepare the sisal and then Beatrice made the ropes for children to sell in the local markets and village. I became a frequent customer for Beatrice’s ropes. I could buy many ropes and sometimes gave her money in advance to make ropes, which I would pick up whenever I went to visit her. When Beatrice’s sickness became severe in mid-2002, she came to me and asked for assistance to receive medication in Mombasa. Her brother lived in Mombasa and they wanted to try treatment in Mombasa. She explained that the members of her local church group (duol) (see Nyambedha, 2004) had agreed to pay part of the money to send her to Mombasa for treatment. When she died, two months later after coming back from Mombasa, I went to the funeral and the village headman, who knew that I was a regular visitor of Beatrice, asked me to say a word before she was lowered into her grave. Giving eulogies are important Luo funeral customs. I suspected that the people in the village expected me to say something about my research, my association with Beatrice and whether my research project would ‘take’ the orphans since the only caretaker was dead. Although I avoided this topic and failed to address the expectations of the villagers who gathered to bury Beatrice, it was morally difficult for me as an ethnographer to see how ineffective my research project was in addressing the massive needs of orphans I had known for years.

Another case, which is related to the one I have narrated about Beatrice, occurred in one of my field encounters in 2004. I was doing a study on movements by children affected by AIDS and went to trace the movements of a young 15-year-old boy, a double orphan who had dropped out of school. The orphaned boy had been previously fostered by a maternal uncle. He later went to stay with a brother at a fish landing beach settlement on the shores of Lake Victoria. When I arrived at the beach settlement, I first reported to the beach leader who upon hearing that I was making inquiries about an orphaned child, immediately pleaded with me to ‘take’ the orphaned boy and sponsor him in school. The beach leader, who knew that the orphaned boy’s paternal uncle would be jealous of my visit to the boy due to expectations of possible material assistance, cautioned me against being misled by the orphaned boy’s paternal uncle. True to the fears of the beach leader, the paternal uncle to the orphaned boy rushed to caution me against “taking” the boy. He told me this immediately upon my asking him to allow me to see the boy and before I
had explained to him why I was looking for the boy. “He is a spoilt child and cannot go to school”, the paternal uncle in his seventies explained. He expected that people who ask for orphaned children have money to sponsor them in school. However, I explained to them [the paternal uncle and the beach leader] the nature of my visit and that I did not work for NGOs that help addressed the problems of orphanhood in the era of AIDS.

Such expectations of providing support to orphans by people who make inquiries about orphans were not only limited to the adult caretakers of orphaned children. Orphans too had expectations that a visitor making inquiries about their life after the death of their parents would provide assistance. It was not easy to determine whether orphans accepted to participate in my study because they gave true informed consent or whether their acceptance was due to the influence of and their respect for adult authority, generated by the their socialisation. In most cases, children would agree to participate in research because their parents or adult caretakers had agreed that a researcher should talk to them. However, as researchers, we are obliged to study children as their own agents and thus fully explain to them what the research is all about, the consequences of participating, and deal with the issue of expectations of any benefits in an honest way. Some orphans and their caretakers would accept to participate in the research because they did not want to miss chance of being ‘taken’ in future because they were not studied. In one field encounter in 2004, I had just completed an in-depth interview with a 14-year-old female orphaned child and gave her a chance to ask me questions regarding some of the issues we had just discussed. She asked:

- Do you people [meaning myself and the organisation I work for] also provide assistance (kony) to orphans? I have heard that researchers in Agondo (a neighbouring locality) pay school fees and give clothes to orphans?

I argue that ethnographic work in such settings needs to re-examine the concept of informed consent in studies on people who are vulnerable, such as those affected by or living with AIDS and those in crisis due to civil strife or war situations. For example, we need to reflect on how we achieve informed consent both at the community and individual level in the context of broader moral issues that our ethnographic work is likely to create (see, for example, Harper & Jimenez, 2005). It is a challenge for researchers who possess knowledge about informed consent to argue that the communication we receive from study participants whose lives are affected by the AIDS pandemic is informed consent. This is primarily because of the expectations that many visits to such family members raise. The impossibility of determining informed consent is further complicated by the presence of many NGOs that intervene in the living conditions of people affected by AIDS.

These NGOs operating in neighbouring locations, coupled with the history of early missionaries, who began to provide assistance to orphans and widows before the effects of AIDS were felt, raise the expectations of orphans being ‘taken’ by anybody making inquiries about their lives. This challenge is greater when seeking informed consent among orphans themselves. Orphans may accept to participate in the research because they want to show respect to the adult caretakers who have allowed you to talk to them; or, they may accept because they associate the research exercise with an intervention to assist orphans directly (i.e., themselves). In most cases, it is not easy to ascertain whether the orphans accept to participate in the research because they have been fully informed and fully understand the consequences of being part of the research. I suggest that informed consent for ethnographers doing research for longer periods can be achieved by continuously sensitizing the host community and research participants on the importance of research. It is also important to explain the relationship between research and interventions in the lives of vulnerable people such as the orphans and widows affected by AIDS so that the study participants may make informed decisions regarding their participation in a research project.

**Negotiating vested interests and paying back to the community**

The American Anthropological Association (AAA, 1998) ethical guidelines, in my view, do not adequately provide guidelines on how to ethically handle field contexts in which expectations for assistance to vulnerable populations such as those affected by or living with the AIDS pandemic influence their willingness to participate in a study. Furthermore, the available literature on harm and how to avoid harm as an ethical obligation for researchers is dominated by procedures for doing biomedical research involving clinical trials (CIOMS, 2002; Nuffield Council on Bioethics, 2004). We need to broaden the definition of harm to exhaustively address ethical challenges of doing social science research on vulnerable populations. In doing extended research on AIDS and orphanhood, researchers can cause harm if no action is taken to address the high expectations raised in the study population through their visits and questions asked to informants. Thus, it is appropriate that our study designs incorporate the need to address both the
long-term and short-term consequences of researching vulnerable populations by exploring possibilities of interventions during and after the study period and a budgetary provision of acute needs of the informants during the lifespan of a research project. Designing action research or interventions can help prevent the researched community from feeling that they are being exploited by researchers (see, for example, Akeroyd, 1984).

This reality presents an ethical challenge to ethnographers who are expected to find better practical solutions to the problems of the vulnerable people they study. Additionally, ethnographers can benefit in terms of their careers from individuals who agree to participate in studies and whose life experiences are used to produce academic publications and theses that are often, in turn, referred to in global policy documents. Many people in the study community know that students obtain higher academic degrees in Universities after writing theses from the information they gather from the study population. This understanding of academic research was well-articulated in a community feedback session when a local leader asked what our research project would do to the study population, as they had seen many students coming to do research and later earning higher degrees. The main argument by the study population is that these degrees translate into good employment opportunities and better income for students and researchers while the life circumstances of the study population remains the same (see also Geissler, 2005).

To deal with this challenge, one would expect that anthropology through its primary method of participant observation should sustain a relationship in the long-term through practical contributions such as doing interventions. However, this might not be possible because the institutional framework by which funding is provided for ethnographic work may not permit this double role. This is a challenge that requires proper co-ordination of research activities, intervention programmes and donor activities. This can be handled effectively if those who sponsor research and those who sponsor intervention work closely in a more co-ordinated way than is now happening, leading to instances where pure academic research can be transformed into action research (e.g., Schoepf, 1991).

Individual researchers should take personal responsibility for addressing the problems of the people they study by either being part of an intervention study or designing action research to address vulnerable life conditions of their study population. In social science research on AIDS and orphanhood, I suggest that researchers should scale-up advocacy efforts by explaining to relevant NGOs the situation of the people they have studied to attract intervention. Individual researchers should sensitise local community-based organisations and help such organisations attract funds for intervention. A possible way of doing this is to assist the grassroots organisations to come up with better proposals and link them up with appropriate donor agencies. Although our research colleagues who maintain the principles of objectivity in field research might contest this suggestion, my argument is that such an approach has both ethical and epistemological advantages (see also Herzfeld, 2002; Robbins, 2003; Schoepf, 2001). In addition, the intention of the researcher to advocate for support or the intervention to address the difficulties identified should be clearly stated in the research design and not be thought of solely as an add-on at the end of the research. While the need to find better ways of negotiating vested interests and paying back to the community is an ethical challenge facing all researchers, it is more crucial for ethnographers who spend more time in the field and learn more about the people they interact with for years. In my view, the depth of the ethical responsibility is different than that of a researcher conducting a cross-sectional survey in a community and who moves out of the community after the survey. Ethnographic methods include a continuous situational analysis of the problem being investigated while the ethnographer is still in the field.

The role of community feedback sessions

Experiences from my involvement in research on AIDS and orphanhood show that continuous education through community feedback sessions can be effective. In these sessions, the host community is given the chance to listen to the results of various studies on orphans conducted in their community. They are also given the opportunity to react to the findings and express their experiences of the encounters they have had with researchers in the community. These meetings have provided me with opportunities to review my approach in studying the orphans in the community and explain to people some of the reasons why I was not able to ‘take’ the orphans. Through an understanding of the different roles of NGOs and researchers, some members of the community were able to appreciate research efforts and allowed us to interview orphaned children and their caregivers without necessarily expecting or asking for assistance. However, this is not to justify pure research at the expense of intervention, because we need to advocate for a research process that takes into consideration the needs of the study population and the production of expert knowledge. The feedback sessions can be useful in educating people on the role of researchers as opposed to the intervention work carried out by NGOs. These community feedback sessions have positively contributed to
the efforts to obtain informed consent because some people in the community have begun to appreciate the role of researchers. Providing feedback about study findings has been one way through which this research has contributed to local knowledge and action in relation to orphans affected by AIDS at the local level and increased advocacy. However, the mode of interaction in these community feedback sessions is characterised by the donor/recipient or the elite/non-elite relationship, which in some cases may negatively affect free exchange of ideas between researchers and the study population.

A positive outcome of these meetings in my study has been that the host community sometimes proposed the kind of studies they wanted to be conducted in relation to the problems of AIDS and orphanhood. For example, in one such meeting in the year 2000, the community requested for a study on prevalence rates of orphanhood and the community-based solutions to the problems of the orphans and widows in the area. Thus, what we (foreign collaborators and myself) started as the community feedback sessions ended up being referred to by members of the host community as education forums (puonjruok). During informal meetings or conversations, people asked me when we were likely to organise another session for puonjruok where the researchers would ‘educate’ the community about their problems. Members of the community who attended puonjruok were requested to spread the message to those who were not able to attend. Later encounters in the field showed that people who attended puonjruok were more receptive to the researchers visiting their homes and asking them questions than those who did not attend puonjruok. However, they still asked for the possibilities of some orphans being ‘taken’, an indication that the impact of the pandemic had led to inconceivable levels of desperation in the community.

I have provided these examples in order to underscore the importance of community feedback sessions as a way of dealing with ethical challenges of negotiating vested interests and giving back to the community in ethnographic research. Through these feedback sessions, it is possible to broaden people’s understanding of the benefits of research to the community even if researchers are not able to carry out large-scale interventions in the situation of orphans and widows affected by AIDS. By translating our feedback sessions to puonjruok, the study population began to accept that one of the aims of research is to investigate their problems, educate them on the magnitude of such problems and how they can go about dealing with such problems. This reduced the feeling of exploitation and the demands of ‘taking’ the orphans. However, I still had to help in a few critical cases in the village when I was approached, as I have already shown above.

Apart from advocacy to the NGOs as well as government authorities and the small material assistance to the communities studied, ethnographers should be sensitive to the impacts their interview questions have on the study population. This sensitivity is a way through which we can engage in meaningful efforts to address ethical challenges of researching people affected by or living with AIDS. Yamba (2005) shows how research with people affected by AIDS commands the involvement of the researcher in such a manner that the line between research and activism becomes blurred (see also Hastrup & Elsass, 1990). Thus, negotiating for vested interests and paying back to the community can be enhanced when the gap between the researchers and the study population is bridged. Related to this argument is a suggestion by Hastrup and Elsass (1990) that we need a renewed theoretical debate on the role of the participant observer in development of the study population. Generating knowledge from the study population ought not to be divorced from the ethical responsibilities of participating in the solutions to the problems that are encountered by the study population.

**Conclusion**

The ethnographic experiences I have presented in this paper question the relevance of informed consent as described in documents about ethical regulations in contexts of suffering populations. My argument is that the current procedures of obtaining informed consent are inadequate and need to be updated to keep pace with the changing realities of research contexts. Evidence in this paper shows that it is difficult to ascertain the protective role of informed consent in situations where the research informants are eager to explain their problems to a researcher because they expect assistance in return. In some cases, the researcher understands that the expectations of support have overwhelmingly overcome the objective reason of the participants to either accept or refuse to be interviewed. This raises an ethical dilemma regarding whether to proceed or not with the interview session.

This paper has also discussed the idea of negotiating vested interests and paying back to the community. The paper shows the importance of community feedback sessions as a mechanism for addressing the issues that arise in the field due to expectations that the study population develop in the course of their interaction with ethnographers. I have argued that apart from disseminating the findings of the research to the local population, the community feedback sessions have provided a forum for the exchange of ideas between researchers and the study population. These community-based feedback sessions,
therefore, provide a framework for dealing with ethical challenges of negotiating vested interests and giving back to the community in ethnographic research.

The above ethical issues contribute to the current debate evident in the wider literature around the position of ethnographers in field contexts where the population is considered a vulnerable one. The issues contribute to the role of ethnographers in advocacy and interventions by calling upon ethnographers doing research among vulnerable groups to design more effective research protocols that are responsive to the socio-economic contexts in which their research is conducted. Such an innovative approach to research design is likely to contribute to better levels of addressing the expectations of the study population. This argument is particularly relevant when conducting research among vulnerable people affected by or infected with HIV/AIDS, such as the orphans and widows in many sub-Saharan Africa countries. This may also apply to extended ethnographic work in areas that are ravaged by war and hunger and where the people being studied expect some material benefits from those who study them.

Acknowledgements

The author is greatly indebted to the DBL-Institute for Health Research and Development and the Danish Council for Research in Developing countries (RUF) for financial support. To Dr. Paul Wenzel Geissler and Dr. Sassy Molyneux for their critical comments on the initial drafts of this paper. Special thanks to Linda Amarfio and the organisers of the conference on Ethnography of Medical Research in Kilifi Kenya and to the conference participants who provided comments to the paper. I am also indebted to Dr. Jens Aagaard-Hansen for the fruitful long-term collaboration and his constructive comments on the earlier drafts of this paper. Finally, thanks to colleagues at the Institute of Anthropology, University of Copenhagen.

References


