

Searching for a lost cow

Ethical dilemmas of doing medical anthropological research in Bangladesh

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In this paper we present our dilemmas regarding ethical issues in doing medical anthropological research in Bangladesh. Our previous works include hospital ethnography, life histories of childless women, sexual and reproductive health issues, and community health interventions. We argue that following the Euro-American framework for research with human subjects may be completely out of place in a context where respondents are extremely poor and have no institutional education, and where relationships between people are generally very hierarchical. We found it difficult to make the villagers understand what 'research' is, as there is no equivalent term for it in rural Bangladesh. The formal Bengali word derived from the Sanskrit language has a meaning connected with 'finding a lost cow'. By presenting several scenarios from our research experience we show how the Euro-American ethical codes for informed consent, confidentiality, respondent protection, deception and compensation may appear absurd in Bangladeshi villages. With this paper we would like to contribute to the debate on the universality of research ethics. We argue that acting ethically while responding culturally is a complex job. It is time that we think of indigenising bioethics.

[ethics, research, medical anthropology, informed consent, confidentiality, Bangladesh]

This paper is based on our personal experiences of doing anthropological research in Bangladesh for more than a decade. Both of us are Bangladeshi and medical anthropologists. Our researches are primarily of qualitative in nature. The first author (Zaman) is a physician by training and the second author (Nahar) has a background in the social sciences. Our previous work includes a hospital ethnography (Zaman 2005), life histories of childless women (Nahar 2007), sexual and reproductive health issues, community health interventions. In this paper we like to present our dilemmas concerning various ethical aspects of doing ethnographic research in communities where respondents are extremely poor and have no institutional education, and where relationships between people are generally very hierarchical. We would like to contribute to the debate on the universality of research ethics.

What does it mean to do ‘research’?

“To the people we study we owe disclosure of our research goals, methods and sponsorship.” This is the first clause of the *Statement on Professional and Ethical Responsibilities*, drawn up by the Society for Applied Anthropology (Van Willigen 2002: 59). However, both of us always found it difficult to explain our research activity to Bangladeshi villagers. The villagers have never heard of an activity called ‘research’ and there is not even any word available in the Bangladeshi villages for this activity. The Bengali word for research, *gobeshona*, is known only to the educated middle class. During our fieldwork whenever we told the villagers that, “We have come to the village to conduct research *gobeshona*,” they looked at us with blank faces and were confused. All our efforts to disclose the research goals, methods and sponsorship of our research meant nothing to them. Alternatively, sometimes we tried to say that we were planning to write a book and for that we needed to talk with them. This approach was not very helpful either as the respondents had never read a book, had no idea how a book would be written, and wondered why an educated person needed to talk to an unlettered person in order to write a book.

One day an elderly person in the village told Zaman, “Yes *gobeshona* is something that the earlier generation used to do when they lost their cows.” Later we found out by consulting a linguist that the Bengali word ‘*gobeshona*’ is actually derived from *Sanskrit* and has its roots in the ancient rural life of Bengal. The first part of the word *gobeshona*, ‘*go*’, means ‘cow’, while the second part, *eshona*, means ‘searching’. The literal meaning of *gobeshona* therefore is actually ‘searching for a lost cow’. We are sure that the villagers indeed needed to do some research when they lost their cows. We wish we knew their methodologies. However, it was difficult for us to make the villagers understand that we were doing something that had nothing to do with cows.

Most of the time the villagers considered us to be development workers. There are several Non Government Organisations (NGOs) in Bangladesh that work in the villages, parallel with the government, in the areas of health, education and micro credit. It is through these NGOs that the villagers see many educated men and women working in their environment. The villagers therefore thought we were doing something related to the activities of the NGOs. We carried out most of our fieldwork with this altered identity of being development workers rather than researchers.

How ‘informed’ is consent?

According to the American Anthropological Association Statement on Ethnography and Institutional Review Board (2004), informed consent includes three key components: the communication of information, the comprehension of information, and voluntary participation. As we have just mentioned, because research is an unknown term in the rural settings, even when we had communicated the information regarding research, we were never sure about the comprehension of information by the respon-

dents. When Nahar told her respondents that she was talking to them in order to obtain a Ph.D. degree, this was beyond their comprehension.

We are also not sure whether we can call the participation of the respondents in our research 'voluntary' in the strict sense of the term., Messer (2004) points out that a person acts voluntarily to the extent that he or she initiates the action without being under the control of another's influence. We tried to ensure that the respondents did not feel any sort of coercion or manipulation concerning their participation in the research, but in a society which is robustly hierarchical and divided into class based on economy and education, a tacit pressure is inbuilt in any encounter between people from two different classes. Nahar who is trained in feminist research, tried to maintain equality with the spirit of 'sisterhood' in her relationship with her female respondents. But she found it extremely difficult to practise a non-hierarchical approach while conducting the research, particularly with rural illiterate women. As much as she tried to dress neutrally and talk in a respectful manner, it was impossible to delete the class barriers in the encounter. The moment she took out a pen and notebook from her bag simply to take notes on the interview, a hierarchy was established, something which is inevitable when the researcher is holding a pen and the other person is not and never has.

Having failed to make our explanation about research understandable to the people, we used to ask them whether they would agree to the discussion of certain issues with us. In the hierarchical context of society in Bangladesh, it is usually culturally unacceptable for a person in the lower strata to refuse a request from someone who is in a higher position. Thus agreed, but we are not sure whether we can qualify this as voluntary participation. During our fieldwork in the villages the household members always offered the only chair in the house for us to sit on, and they sat on the ground. We refused the chair and sat on the ground with the others to establish equality. But an air of discomfort always remained in the encounter. As Farmer (1999: 6) writes,

The tragedy, of course, is that this equality, however comforting to the anthropologist, is entirely illusory. Anthropologist and informant are not separate and equal; both are caught up in a global web of unequal relations.

Zaman, who had previously carried out ethnography in a public hospital, found the issue of informed consent problematic from another angle. In order to conduct research he had to hang around in the ward and talked with patients, many who had come from a poor socioeconomic background. The patients initially considered him to be a doctor or a journalist. After several days of spending time in the ward and chatting with patients, he managed to gain their trust. Most of the data for the ethnography came from informal chatting, and the patients openly shared their worries, frustrations and concerns with him. However, at one stage when he asked patients whether he could quote them in his book, the entire spontaneity of the discussion disappeared. They worried that their complaints about the hospital could harm their treatment, even though the researcher reassured them that the comments would be anonymous. He also emphasized that it would take at least another year to publish the book, and by that time the patients would definitely have been discharged, it was still not possible

to regain the previous warmth of the earlier discussions. The same reaction came from the doctors, who considered the researcher to be part of their team and shared various opinions and information with him. When he asked whether it would be okay to use their views in the book, suspicions grew which greatly hampered the discussion. The method of gather data from friendly discussion became converted into a hostile situation. Thus, the issue of continuing consent during the ethnographic research became a dilemma not expected at the onstart.

Gaining written consent was out of the question, as none of our respondents was literate. Acquiring fingerprint signatures was also highly problematic, as fingerprints have huge historical negative connotations in Bangladesh; for example, in history feudal lords exploited illiterate farmers by seizing their land and taking their fingerprint signatures as proof of their 'cooperation'. Presently, ethics committees request verbal consent, but this is also problematic, because, as mentioned earlier, although the respondents give consent they have no idea what the research entails and what its implications are. We also found that in many cases individual consent was not possible, particularly when the research involved women respondents. For example, Nahar studied the life experience of childless women in Bangladesh and had to gain separate consent from the husband as well as the mother-in-law of the childless rural women in order to talk to them.

Could this research have been done without deception?

Before beginning his hospital ethnography Zaman approached the hospital director and asked for permission to conduct the study in the hospital. The director said that he should formally write to the Ministry of Health, Government of Bangladesh. As a native of Bangladeshi culture, and from experience of doing research in a government setting, he knew that – given the extreme bureaucratic systems in the government – this process might take several months or even a year. At the end of this time, he might still be denied permission to conduct the research by doctors who have been widely reported to be hostile to social science research in medical settings (Mathews 1987; Van der Geest 1989). He therefore decided to take an informal route by using a hospital contact, he arranged to meet the professor of the orthopaedic department, who he knew to be open minded about social science research. He gave the professor a carefully organized overview of the research and highlighted that the research was mainly to explore the patients' experience. The professor, who knew that Zaman was also a physician, said:

You are one of us. You are welcome to do your research here. The journalists regularly write stupid things about hospitals; they know nothing about the medical world. I hope you will not just write how bad we are.

The professor also assured him that he would not have to bother about gaining any formal permission. He would introduce him to the staff in the ward and then he could

feel free to carry out his research. Zaman was relieved to hear this positive response; however, he knew the professor's belief that the researcher was 'one of them' was not quite true, since he had by now become an anthropologist and had left clinical medical practice. Moreover, the professor was probably unaware that he and his colleagues would also be observed during the research.

Zaman's role in the ward was also ambiguous. The patients sometimes considered him to be a doctor, sometimes a journalist, and sometimes a visitor. The hospital staff thought that he was doing research concerning medical issues, so they would bring all the crucial medical cases in the ward to his attention. Some of the staff from the lower hierarchy thought that he was an evaluator from the government. Zaman never completely clarified his role in the hospital to the doctors and staff, and oscillated between different roles, 'playing' each role according to when each allowed most access to information. He took inspiration from Scheper-Hughes who had once been in the same position; she took on interchangeable identities while studying organ trafficking, and asked, "How else, except in disguise, could I learn of the hidden suffering of an invisible, silenced and institutional population?" (Scheper-Hughes 2004: 45). Similarly Anspach and Mizrach (2006) discussed how in order to navigate through the conflicting demands of the medical and ethnographic field the researchers carefully package the descriptions of their research to the gate keepers. We therefore agree with Van der Geest (2003) when he writes, "After all, are we not always playing roles and – to some extent – deceiving others about our true intentions?" Zaman has described his challenges of carrying out the field work in another paper (Zaman 2008).

Respondent or researcher protection?

The research on childless women in Bangladesh conducted by Nahar was sponsored by an Australian university. The probable risks and harms of the research were assessed by the ethics committee. In their assessment the committee noted that participation in the research might increase the anxiety and stress of the respondents, therefore they asked Nahar to provide the contact address of a counsellor to all the respondents. They mentioned that this was to ensure that if the respondents were psychologically distressed by the process of data collection, they should be able to contact a professional counsellor for help. The researcher was puzzled, as she had never heard of any available counsellors in the rural areas; indeed, they are hardly to be found even in the capital city of Dhaka. There are psychiatrists and physiotherapists in Dhaka, but counselling is not a common practice in Bangladesh. She had never been to a counsellor herself and did not know anybody who had ever been to one. She had however observed that attending counselling sessions was quite common in western countries. While she was doing her Ph.D. in Australia, many of her fellow students had regular sessions with counsellors for various personal matters, a service which was included in the students' health insurance.

She remembered vividly one incident during her stay in Australia. One day a student shot a fellow classmate in the university. The next day, she saw several tents on

the campus, with queues outside them. She found out that special counselling sessions had been organised for all the university students, to help them to deal with the shock. She was certainly shocked by the incident, but this huge arrangement of counselling sessions also took her by surprise. Her fellow students wondered why she did not show any interest in counselling. She told them that she was 'shock-proof' because shootings, killings and deaths are part of the everyday experience of a Bangladeshi.

The ethics committee of the Monash University, Australia was however insistent about providing contact details for a counsellor for the research participants. Nahar replied to the committee that as there was no such person around the area, she could provide them with the address of the psychiatrist in Dhaka, the capital city, but that it was extremely unlikely that they would ever travel to Dhaka, which is about 200 km away from the village, for such a purpose. The committee then asked her to provide at least the telephone number of the therapist in the research proposal, and to promise that she would give this information to the respondents during the data collection. The researcher did put a telephone number of a psychiatrist living in Dhaka in her research proposal to satisfy the ethical committee. However, she didn't mention to the committee that at that time there was no telephone facility in or near the village.

In order to be ethically 'correct', she did give some of her respondents the telephone number. However the respondents were very surprised at this, because not only did they not know where to call from, but they also wondered why they would want to talk to someone whom they had never met about such personal issues. Providing the telephone number might have not protected the respondents, but this definitely protected the researcher and the ethical committee.

Is maintaining confidentiality a must?

Anonymity and confidentiality are a major part of research ethics. On many occasions we experienced these issues in different ways; for example when Zaman carried out research on health interventions by the government and NGOs in a village, the people seriously objected when they learned that the village would remain anonymous in the research report. They said they had been deprived of health facilities for many years, and if the author had come to write about this, he should clearly mention the name of the village, so that the government and NGO would pay attention to them. On another occasion, while doing a study on the adherence to diabetic treatments, Zaman told the patients that their names would remain confidential on their in-depth interviews. They were not concerned about their anonymity, and one patient said: "Having diabetes is not a crime. Why should I hide my name?"

We have had similar experiences with asking for permission to take photographs. Most of our respondents in villages had never been photographed as they could not afford to have a camera or to go to a studio to get a photograph taken. Taking their photograph for the research was a first-time event for most of them. Whenever we asked them to be photographed they were more than willing and when we presented them with their photos they were highly pleased and thankful. We saw that some of

the respondents framed the photograph and kept it at home as a treasure. If we did not show any interest in taking their photograph, they felt deprived. Some of them spontaneously requested that we include their photographs in the book that we were going to write about them; they said they would feel very honoured if we did so. We feel that the requirements of asking for permission to take pictures were not necessary in this context. We did follow ethical guidelines by asking permission from the respondents to take their pictures, and told them that we would give them the pictures, but we do not think that it made any difference to them on ethical grounds.

Ethical rules about confidentiality have to do with the issue of privacy. We experienced that the sense of privacy varies in urban and rural areas of Bangladesh. While doing a study of the sanitation practices in a village, Zaman found that many people defecated in the open air, often together in a group. Thus, an act like defecation, which is usually regarded as very private, becomes public in some rural contexts. While trying to identify infertile women as respondents, Nahar faced some difficulty in the urban areas, as infertile women were reluctant to expose their problem with fertility, whereas in the village everyone knew who the infertile women in the village were. In her initial days of the research a little girl from the village took her to all the households where the childless women lived. The line between public and private information is indeed blurred in the villages.

However, it could be quite complicated as well; for example, when a husband of a rural childless woman approached Nahar and told her that he had something confidential to talk about. When she agreed, the man told her, "I have come to you because I heard that you are working with infertility. I have never met anyone who works on this issue. I have come for advice but you have to promise me that you will not share with anyone what I am going to tell you now." She was surprised about his direct approach but promised to keep his question confidential. The man then told her,

Many years back during a national population control campaign I have done vasectomy in exchange of money. But I have not told it to my wife. I didn't want her to know that I am the reason of our childlessness and I also feared that if it becomes known to others the community might force me to divorce my wife. I don't want to lose her. I am telling you because I heard it is possible to undo the vasectomy. I want some advice on this from you. Can I become father again?

She informed the man that she was not a medical expert but she would ask the relevant people and get back to him. She did and informed him that the vasectomy could not be reversed. However, this case posed a big ethical dilemma for her. The wife of this man was one of her respondents and she knew that this woman was following various traditional treatments in order to get pregnant, being ignorant about her husband's vasectomy. Keeping this information confidential meant that the woman would continue taking treatment despite of the fact that she did not have a problem and she would continue to be stigmatised as a childless woman. But, if she shared the secret with the wife, the information could result into a breakdown of the marriage which could also make the research field work impossible; the husband might become hostile to her for

not keeping her promise. In the end, she did not tell the wife, but she is still not sure whether this was a right decision.

We therefore argue that the issue of confidentiality is quite complex and demands reconsideration in the context of cultural variations about the sense of privacy. Van der Geest (2003) expressed a similar dilemma with confidentiality and the use of pseudonyms while doing research in a Ghanaian community.

Should monetary compensation be provided for respondents' time?

In some research projects we were asked by the ethics committee to pay the respondents for their time. We had mixed experiences about this demand. Whenever we had asked villagers for time to talk to them, no one ever requested money from us. However, we did offer compensation whenever we found that our research was going to affect the daily income of a respondent. The respondents were usually happy when we offered money, but there were also occasions when they refused to accept money. One farmer, when offered money, told Zaman,

I do not go to an office like you from nine to five. I go to the field whenever I want. So you are not taking any of my work time. Please, note that we may be very poor but that does not mean that we will ask for money just for talking to people.

On another occasion one respondent told Zaman that he felt very honoured that he had decided to talk to him, because usually educated people from the city have no interest in poor villagers. He considered the interview to be a privilege and a great opportunity. In her research on 'pregnancy related food behaviour', Nahar once offered money to a poor rural pregnant woman. The woman refused the money instantly and said: "If I take money in exchange for selling my experience of pregnancy it might harm my child inside the womb."

We sometimes received false respondents when we declared that money would be provided for participating in the research. Nahar was involved in a research project on the homosexual community in Bangladesh. As this is a taboo subject in Bangladesh, it was quite difficult to get respondents. However, when it was decided that monetary compensation would be given volunteers for the research, there suddenly was a large group of willing participants, many of whom were not actually homosexuals. Clearly, meanings and effects of compensation vary between cultures.

Discussion and conclusion

In this paper we have presented the dilemmas encountered in doing anthropological research in Bangladesh according to ethical research standards developed in Europe and North America. Gold (2001) discusses the complexities of interpersonal relationships in the production of anthropological knowledge and how ethnographic research

greatly depends on mutual trust. Although the ethical codes were developed to ensure the trust between researcher and researched, in our case these codes proved to be rather counterproductive and worked against building trust. The reason seems clear: these ethical rules were formulated by scientists and ethicists who are far removed from the realities of research with people as described in this article. These situations would appear as extreme cases to them; even though, they had been part of our everyday reality as researchers for many years.

A number of scientists have already challenged the notion of universalising ethics designed for qualitative and socio-cultural research with human subjects. Ethics committees for quantitative research on humans, (clinical trials, experimental medical procedures, etc.) have an international set of rules which have been in effect for decades. Qualitative research about social phenomena has other considerations. Van der Geest (2003: 18) writes, "Anthropologists have done their utmost to combat ethnocentrism in intercultural communications, but they have been ethnocentric in applying their own ethical standards in their fieldwork." Quoting Elliot, Finkler (2008: 157) suggests that ethics cannot stand apart from the society in which they are embedded. She writes, "Generally speaking anthropologists recognize that the content of any ethical system, be it formally codified, or informally expressed in lived experience is socially constructed – emerging not just out of rationally produced doctrines but out of the lived world." Similarly Marshall (2003) while describing the problem of anthropologists in dealing with International Review Boards (IRBs) specifically highlighted how IRBs fail to recognize the "social construction of informed consent" as an act of communication and ignores the underlying assumptions embedded in the Western notion of voluntary informed consent.

We argue that because no research situation is isolated from broader social, economic and political circumstances, research ethics cannot be dealt with in isolation from these contexts. Simpson (2004), in his studies on organ transplantation and the use of reproductive technologies in Sri Lanka, demonstrated the problems of acting ethically in a Western orientated bioethical framework in a non-Western context. He showed how the alignment of body-part transactions is embedded within Buddhist tradition in Sri Lanka, and is beyond the scope of discussion in the Western model of bioethics. By redefining the concept of triage, Olweny (1994) argued that in an environment with limited resources, as in the developing world, the notion of ethics must be changed. Triage was originally a military concept which prioritised the medical care of wounded soldiers: e.g., a slightly wounded soldier, who would resume fighting after treatment, would be given priority over one with a life-threatening injury who would probably not regain combat fitness. Olweny argued that the military goals of triage are guided by a policy which conflicts with 'patient-centred ethics'. Even so, the ethical decisions must be different in a context where the resources are limited; for example, should individuals with incurable malignancies consume resources that could be applied to immunize children? The answer would be different in a developing country context than in a resource-rich one. Olweny therefore talked about "ethics of scarcity and sacrifice." In line with this argument Finkler (2008) emphasised that if we need to universalize anything in the research world it should be the principle

of justice and the notion of responsibility. One approach to addressing the issues of universalistic bioethics is through a focus on justice and responsibility in anthropological research to identify 'the particular' within 'the universal' in the bioethics discourse. Castro (1999), while discussing the idea of 'Asian bioethics', highlighted that although one must be careful not to commit the mistake of universalising (among Asians) a single Asian perspective, there is some room for a kind of universalist ethics that is founded on a collage of culturally inspired perspectives, rather than on a single standard of morality.

In conclusion, acting ethically while responding culturally is a complex challenge. The discussion and debate around this topic is gaining momentum. With this paper we have participated in that debate and pleaded for a process of 'indigenising bioethics' (Simpson 2004).

Note

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References

- American Anthropological Association
2004 Statement on Ethnography and Institutional Review Board. Downloaded on 5 November 2010 from <http://www.aaanet.org/stmts/irb.htm>.
- Anspach, R.R & N. Mizrachi
2006 The field worker's fields: Ethics, ethnography and medical sociology. *Sociology of Health & Illness* 28 (6): 713-31.
- Castro, L.D.D.
1999 Is there an Asian bioethics? *Bioethics* 13 (3/4): 227-35.
- Farmer, P.
1999 *Infection and inequalities: The modern plague*. Berkeley: University of California Press.
- Finkler, K.
2008 Can bioethics be global and local, or must it be both? *Journal of Contemporary Ethnography* 37 (2): 155-79.
- Gold, A.G.
2001 Research ethics from the cultural anthropologist's point of view. <http://www.researchethics.org/uploads/pdf/anthropologist.pdf>. Downloaded on 11 January 2011.

- Marshall, P.L.
 2003 Human subject protections, institutional review boards, and cultural anthropological research. *Anthropological Quarterly* 76 (2): 269-85.
- Mathews, J.
 1987 Fieldwork in a clinical setting: Negotiating entree, the investigator's role and problems of data collection. In: H.A. Baer (ed.), *Encounters with biomedicine: Case studies in medical anthropology*. New York: Gordon & Breach, pp. 295-314.
- Messer, N.G.
 2004 Professional-patient relationship and informed consent. *Postgraduate Medical Journal* 80: 277-83.
- Nahar, P.
 2007 *Childless in Bangladesh: Suffering and resilience among rural and urban women*. Doctoral dissertation, University of Amsterdam.
- Olweny, C.
 1994 Bioethics in developing countries: Ethics of scarcity and sacrifice. *Journal of Medical Ethics* 20: 169-74.
- Scheper-Hughes, N.
 2004 Parts unknown: Undercover ethnography of the organ trafficking underworld. *Ethnography* 5: 29-73.
- Simpson, B.
 2004a Impossible gifts: Bodies, Buddhism and bioethics in contemporary Sri Lanka. *The Journal of the Royal Anthropological Institute* 10 (4): 839-59.
 2004b Acting ethically, responding culturally: Framing the New Reproductive and Genetic Technologies in Sri Lanka. *The Asia Pacific Journal of Anthropology* 5 (3): 227-43.
- Van der Geest, S.
 1989 Censorship and medical sociology in the Netherlands. *Social Science & Medicine* 28 (12): 1339-42.
 2003 Confidentiality and pseudonyms: A fieldwork dilemma from Ghana. *Anthropology Today* 19: 14-18.
- Van Willigen, J.
 2002 *Applied anthropology: An introduction*. Westport: Bergin & Garvey.
- Zaman, S.
 2005 *Broken limbs, broken lives: Ethnography of a hospital ward in Bangladesh*. Amsterdam: Het Spinhuis.
 2008 Native among the natives: Physician anthropologist doing hospital ethnography at home. *Journal of Contemporary Ethnography* 37 (2): 137-54.

