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Informed consent among analog people in a digital world ☆

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ABSTRACT

This paper addresses the concept of informed consent when working with remote, non-literate groups. By examining both the legal and moral obligations of informed consent, it will be argued that "erring on the side of caution", for instance by not publishing on the Internet because the consultants/community do not have exposure to such things, is just as paternalistic as assuming that they would consent if they understood. It is further argued that the researcher has an obligation to explain the research to the consultants/community as fully as possible and to engage in an ongoing negotiation of consent, but that the researcher must respect the autonomy of the consultant/community decision, even if the consent was not fully "informed".

1. Introduction

Often, when fieldworkers think of the phrase "informed consent", it is with irritation. The phrase calls to mind the ethics review processes of the Institutional Review Board (IRB) that many linguists and anthropologists dread. They lament that the IRB (or similar ethics review board for researchers based outside the US) does not understand social science research, let alone the realities of fieldwork in remote areas, where obtaining consent in writing may be counterproductive or even impossible. This paper will address some of the thornier issues involved in obtaining informed consent, focusing especially on the perspective of field linguists working with remote non-literate populations in the third world.

Ensuring that consultants and collaborators understand our research is not always straight-forward. As academics, we often have a hard time making ourselves understood to lay people in our own communities (*What is it that linguists do anyway*?), and this problem is augmented by the difficulties of cross-cultural communication and language barriers, especially when dealing with a non-literate, remote community. Can a consultant or collaborator give informed consent to a language documentation program involving audio and video recording, archiving and dissemination on the web when they have never even seen a computer? According to the definitions of "informed consent" that most IRBs adhere to, the answer is no. People cannot consent to something they do not understand. Does this mean that we should not do research with such isolated ethnolinguistic groups? Is it paternalistic to say that such individuals, who are of sound mind and legal age, cannot give their consent to language documentation projects? Is it more paternalistic to say that we believe that they would consent if they understood?

These questions will be explored in this paper, which will make reference to the author's fieldwork among a hunter-gatherer group in the Philippines. Unlike many American Indian and Australian groups, the Dupaningan Agta ethnolinguistic group does not see their language as sacred and has no qualms with making information about their language public. They enjoy being photographed and video recorded and are excited about the prospect of making such materials public. Can I take that as consent, even though I was never able to adequately explain that the materials would be available through an archive?

☆ The title of this paper was somewhat troubling, as it seemed patronizing to call a people "analog", but, in keeping with the conclusions of the paper, I decided that being true to the situation is more important than an arbitrary aversion to paternalism.

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In the following sections of this paper, I will address both the legal and moral obligations of informed consent, including the legal obligation to obtain consent in writing, how to obtain oral consent, the problems raised by sacred or secret linguistic materials, obtaining informed consent for open-ended research, obtaining informed consent for that which the consultants/community have no experience (such as the Internet), paternalism, vulnerable classes, and autonomy. It will be argued that "erring on the side of caution", for instance by not publishing on the Internet because the consultants/community do not have exposure to such things (and thus could not possibly consent to them), is just as paternalistic assuming they would consent if they understood. It will be further argued that the researcher has an obligation to explain the research to the consultants/community as fully as possible and to engage in an ongoing negotiation of consent, but that the researcher must respect the autonomy of the consultant/community decision, even if the consent was not fully "informed".

2. The research background

The ethical dilemmas described here are informed by the author's field experiences in the northern Philippines, living with a group of semi-nomadic foragers for a year while writing a descriptive grammar of their language (Robinson, 2008). Dupaningan Agta is a threatened language; while there are some children who no longer command the language, most children do. On the other hand, borrowing and code-switching are rampant, and many children who are capable of speaking Dupaningan Agta nevertheless do not respond to their parents in the language, preferring instead the trade language, Ilokano. All of these are signs which suggest that language shift could be imminent. There are about 1400 speakers of the language in some 35 communities scattered across approximately 3000 square miles along the northeastern coast of Luzon Island, Philippines. The Dupaningan Agta are members of the Negrito ethnic and racial minority, which consists of some 33,000 people throughout the Philippines (Headland, 2003) as compared to a total population of approximately 90 million in the country. Negritos, including the Dupaningan Agta, are often discriminated against in terms of health care, jobs, land titles, and other basic human rights. The Dupaningan have a subsistence economy based on fishing, gathering, horticulture, and hunting, and they often move camps for reasons of both subsistence and interpersonal relations. The camps where the Dupaningan Agta live lack basic infrastructure, such as roads, electricity, and running water. Very few Dupaningan Agta go to school, and the majority is illiterate.

Crucially for the question here, the Dupaningan Agta and other Negrito groups have been very friendly and receptive to outsider-researchers. They welcomed me into their community and were disappointed when I left. They consented to the research and to being recorded, although I believe many never fully understood my research and most were not interested in the research, per se. They did not realize that their language was endangered (I was only able to convince one person of the seriousness of the situation), and language issues, in general, were of low priority, especially as questions of land and of subsistence were quite pressing. The community as a whole, though, was quite interested in my presence, as I brought both prestige and wealth.

Due to barriers of language and background, I generally gave quite simple descriptions of my research. I said that I was interested in their language, and that I was going to write a dictionary. My actual research was a grammar, dictionary, and texts, but most Dupaningan people would not have had familiarity with the concept of a descriptive grammar, so I chose to frame the project as a dictionary, since this was a concept that most individuals would have been familiar with. After explaining the project in those simple terms, I explained my present purpose to that individual (e.g., I would like to have you translate some words so I can see how your vocabulary is different from Dupaningan speakers in other areas, or I would like you to tell a story, etc.). Next, I would explain that I was recording them (luckily, a concept familiar to most Dupaningan Agta), and finally, I would ask if it was all right to "share the recording with my companions". They always consented to this, and were generally uninterested in the consent process.

I did not go into specifics about how the data would be disseminated (e.g., on the Internet) or stored (in an archive), although, in retrospect, I probably should have. I wish I had been more explicit about dissemination, asking, for example,

Who would be allowed to see this material?:

- nobody
- only you
- only a subset of the community
- only the community; only the community, the researcher, and the researcher's colleagues
- everyone

I also did not use written consent forms, and I did not read aloud the consent form approved by the IRB at my institution, as I believe this would have been a hindrance to true understanding and thus would have violated the spirit of the consent process.

With long-term consultants, I also explained that they would be paid, and I discussed with them what the longer-term commitment entailed. I then negotiated with such individuals about how the research would be scheduled and allowed them to negotiate for additional payment schemes. My primary consultant and I agreed, for example, that I was also responsible for ensuring that his family would not go hungry and that I would buy a water buffalo upon leaving the community (both obligations which I lived up to).

I never encountered any taboos on any part of the language, and I was never told that anything should remain secret or restricted. In contrast, the Dupaningan Agta were generally excited to be photographed, and video and audio-recorded. The adult