

The Records of Medical Anthropology

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There is yet another note from the department administrator on my desk. What are we to do with the four tall filing cabinets filled with data from our now finished, seven-year study of persons with severe, persistent mental illness? The files stand mute but menacing in their bulk and weight in a space that now belongs to someone else. Space is perhaps the most precious commodity at a university — sought after, hoarded, and distributed for and by power the way all scarcities are spread. Virtually every phase of the investigation was carefully planned for and reviewed by the granting agency — except storing the records after the project. Neither we nor the institution made provisions for the time after the funding ended but before we were finished with the files, much less the period after our ongoing analysis was over. In graduate school, I learned how to gather and work with filed data, but there was virtually no discussion of what to do with it once gathered and used.

The records of this study are individual files, identified with numbers only, names blacked out for protection from unauthorized scrutiny. The files are full of intensely personal information and are kept locked except when in use. Only project staff and research assistants have access, and each of them has made a signed declaration of confidentiality. The declaration states that under no circumstances will information from the records be revealed to anyone (other than the informant or authorized project staff) or for purposes other than research and publication. Our data consist of transcripts of extensive interviews that cover intimate, often painful subjects like psychiatric diagnosis and symptoms, childhood trauma and abuse, and stays in psychiatric hospitals. There is information derived from medical records about civil commitment petitions, previous violence toward others, and a lifetime of psychiatric illness and treatment. There are symptom scales scored and analyzed, drawings, scribbled notes — anything we heard from or about that individual for nearly three years. There are computer files of most of the quantitative information, and the transcripts are also stored on floppy and hard disks. Yet the paper records are the bedrock information that we turn to for clarification, for exploring yet another idea for analysis. In short, we need to get to them readily and we need to protect them. What is to be done?

The Institutional Review Board (IRB) tells me that our funding source, the National Institutes of Health (NIH), requires the preservation of all records of our research for three years after the project ends. Yet the university and my departments lack the space and resources needed to

accomplish this. Microfilming is too expensive, and the library is caught up in unresolved negotiations with the university lawyers about archiving research data. Even more pressing questions about who would have access to the files and how this will be monitored are yet to be answered. Failed in our attempts to find an appropriate place for the records, our only recourse is a pick-up truck and the spare room in my home.

As this all-too-common case makes clear, logistics, and ethical implications of preserving data during — not to mention after — one's career are subjects neglected at our peril. Like the living wills or advance directives about which I instruct medical students, plans for archiving the record of a life's work are, for many of the same reasons, easily put off, disquieting and inconvenient to consider. In this paper, I discuss some special concerns of medical anthropologists with regard to preserving the records of our work. Many of the quandaries, like space, ownership, and access, are not unique to medical anthropologists, but the contexts and subjects of our research perhaps exaggerate the questions that arise for most anthropologists.

Medical anthropologists may face special challenges in archiving the record of our research for many reasons. The most prominent are: (1) the biomedical context of our work, particularly the dominance of biomedical research ethics and medical records practices and traditions; (2) the subjects and subject matter, including the force of self-advocacy and patients' rights movements; and (3) the various roles we take and our subsequent obligations to informants, collaborating colleagues, and funding sources.

Underlying all these topics are interrelated concerns about informed consent, access to data, and ownership of information that face anyone who engages in research with human subjects. Several anthropologists, invited by the editor of the *Anthropology Newsletter* to reflect on ethical issues in the discipline, one after another confessed publicly to deep and unresolved dilemmas about how to practice anthropological inquiry and scholarship in a fashion consistent with our own values and the codes of conduct of the discipline. It was gratifying to learn how many of us want to do the right thing, but also distressing to acknowledge how little guidance is available and how little agreement there is among us about practice — that is, applying basic principles easy enough to endorse in the abstract. We are at present very much in the thick of a debate about how to practice anthropology in the post-modern era. This paper contributes to that conversation from a particular corner of the field.¹

Biomedical Contexts

It would be difficult to overstate the influence of the combined forces of biomedical research ethics and medical records protocols and practices on considerations for preservation of the work of medical anthropologists. The biomedical culture that pervades the settings of our work, and often the expectations of our informants, funders, collaborators, and audience, mean working within the ever-expanding reach and gaze of biomedical research ethics. If the biomedical ethics

paradigm is colonizing the conduct of research in social science and humanities (Fox 1990; Fluehr-Lobban 1994; Cassell 1982; MacIntyre 1982), it does so from a firm (and probably needed) tyranny in its homeworld. From the ordered world of medical records we confront issues of access, ownership, and the legal status of the documents we both draw from and create. From bioethics we inherit concerns primarily about informed consent, shaped in large part by views of individual autonomy, privacy, rights, and beneficence that are central to applied biomedical ethics (Wax 1980; Beauchamp 1982).

Biomedical Research Ethics: Obligations to Protect Whom and What?

Consent is arguably the most important consideration for the medical anthropologist who intends to archive records. A persuasive argument could be made that the intention to archive, and the conditions under which access will be granted to scholars other than the original researchers, should be included in the consent process. As Warwick (1982:81) suggests:

Another issue that needs to be considered is whether respondents' consent is required to the new use of the data they originally supplied. Assuming they did not know that their data would be used in subsequent studies, their capacity to protect their interests was clearly impaired when they originally consented to providing the information. The question is whether their tacit consent to the subsequent analyses can be taken for granted.... Investigators working with data collected by others do not have a direct relationship with the respondents, but in accepting their data they incur an obligation to honor the original contract. Failure to do so deprives the respondents of the respect to which they are entitled.

Our consent form assured the participants that the information they gave us would be used for purposes of research only — presumably for research by us. How would they feel about graduate students or other researchers they do not know or trust reading their interview transcripts — the private stories of their lives communicated to a known and trusted interviewer? We did not make explicit that others might know their secrets in raw detail, that is, other than in our publications. How many of them would have consented to be in the study if we had so informed them? Does this omission obligate us to restrict access to *these* records? Several scholars (e.g. Warwick 1982; Appelbaum et al. 1984) argue that it does; that protecting the rights of informants to weigh the risks and benefits of research participation and publication requires us to inform them of all potential uses of the information and to renew consent when an unanticipated use arises (Powers 1993).

Murray and Pagon (1984) describe the distress of the parents of a child with severe disabilities who encountered a photograph of their child in a scholarly publication about the deformities of this particular malady. When they objected, they discovered that several years before they had indeed consented to the production of educational and research materials about their child. But they had forgotten about the consent and had given it to a clinician other than the one who published the picture.

The hospital ethics committee decided that while this use of the photograph was probably covered by the initial consent, the researchers should have re-contacted the parents to get their permission for this publication.

The tentacles of consent and informants' rights arguably extend to the record. Applying this standard to field notes (or other empirical data) poses enormous problems for anthropologists who inherit or use the archived data of other scholars. When the informants may be either far away or deceased, how can consent be renewed? Medical anthropologists working under the watchful gaze of a medically oriented IRB, or with colleagues who endorse these principles, will have a difficult time justifying why they should be held to a different standard. Viewed from the biomedical ethics framework within which most medical anthropologists function, the archival nature of data does not relieve the anthropologist from obligations regarding consent and protection from the possible wrong or harm of publication based on our own records or those of others (Cassell 1982; MacIntyre 1982). Instead, once we create the record of the other, we incur ongoing obligations not only to protect their privacy (Pinkard 1982; Capron 1982), but to fulfill the promise to benefit (beneficence) as well as to avoid harming them (non-maleficence) (Beauchamp 1982).

One way to honor these obligations is the responsible archiving of data. This means anticipating future use, making careful arrangements for storage and access, and taking care that the consent of informants is ongoing and not tacit. While we cannot and should not seek to control the interpretations of others who may eventually use our data, the persons whose records are used have a right to know of and arguably to approve that use (Stoller 1988; Liebow 1993). We should try to implement these principles in current and future work, although the opportunity is scant to meet these standards for the records and informants of the past. One step to consider is the use of statements of confidentiality or of respect for the privacy and dignity of informants. Scholars who use the archived data of others can be asked to fulfill the same moral and professional contract with informants as that of the original researcher.

Fluehr-Lobban (1994) has argued that "informed consent without forms" is one solution to anthropologists' aversion to the imposition of potentially intrusive, disruptive, and sometimes culturally meaningless consent forms. This proposal would almost never persuade a medical school or hospital IRB. The carefully reviewed and often IRB-edited consent form is a taken-for-granted necessity in the world of biomedical research. Our signed forms must be available for inspection by the institution upon demand. While we may argue about the applicability of biomedical research ethics to the far reaches of our own research, most medical anthropologists do not have this luxury. This is the scholarly and professional world within which much of our work takes place, wherein we are granted access to informants, and these are the standards by which our conduct is judged by our colleagues and the audience for our findings.

Beneficence, the positive obligation to help or to enhance the well-being of others, is a value shared by anthropologists and biomedical researchers. The question at hand is the identity of the "others" — ones' colleagues and future anthropologists or the informants. A potential conflict may arise between the obligation to advance knowledge — to contribute to the information base of the discipline — and the duty to honor obligations to informants' privacy and autonomy. Again, one could argue that the planned preservation of records with appropriate safeguards is the best means to accomplish both ends. On the other hand, the destruction of records at death or when their active use ceases may appeal because this gives the anthropologist the sense that he/she has complete control over their use and is honoring the contract with informants. It is possible, however, that informants who worked with us in part *in order* to contribute to the knowledge base of the discipline, which might improve their social or material circumstances, would be wronged by destroying data.

Medical Records Practices

Within the culture and practice domains of biomedicine the *record* has a history and significance quite different from that of traditional field notes or other anthropological data. Medical records are quasi-legal documents held to be especially sacred and private. The records of medicine are protected by administrative arrangements in hospitals and clinics and managed by professional medical records librarians. The medical record may be inscribed by many, but it is intensively *about* one person. Within the health professions, access to active charts and records is loosely regulated — students, faculty, and nursing staff read and write in them at will. Outsiders face stringent requirements for access, often needing the permission of both the individual subject of the chart and the institution that generated and stores the record (Appelbaum et al. 1984; Powers 1993).

Storage space and protection of records are customarily supplied to clinician researchers by medical records departments and personnel. Once a chart becomes part of a hospital or clinic's records, access is controlled by the librarians, who in turn defer to authorized physicians and patients themselves. None of these facilities or protocols is available to medical anthropologists other than those who are also clinicians. While most of us would appreciate the space, we would no doubt object to someone else telling us when and how we could use the records we created.

Although our data differ from medical charts in important ways, there are also similarities. Each file contains personal information gathered by someone privileged with the authority of science or scholarship. Each also contains uncensored impressions of the clinician or researcher in the form of chart notes or field notes. This information is not usually made available to the subject of the record, although patients do have the legal right to read and make copies of their charts. Should we follow suit?

In part because of the records culture within which we work, in our study we have offered the participants access to their own records if they

so choose. None so far has requested access, but many want to (and do) read everything we write down during interviews and visits. What they do not see are the notes we make about the interviews, afterwards. These are more like traditional field notes, and we remain uncertain about revealing them to the participants. One might well ask why we should be privy to their thoughts about any number of private subjects while they are not privy to ours (Patai 1991; Fine 1993). Like other ethnographers, we use language and make speculations in our notes that we would not do in the presence of informants. Because many of those with whom we work are emotionally volatile and easily injured, we have for the present concluded that it is not in their best interests to reveal these notes. Whether and how these materials should be archived, and whether informants have the right to review them, remain troubling and unresolved issues.

Subjects and Subject Matter

Medical anthropology has enormous breadth, spreading across areas of study from population biology to analysis of healing ritual and symbol to the nutritional implications of social organization to the political economy of health. Medical anthropologists may be found tracking down the human pathways of an infectious disease, doing secondary epidemiological analysis of huge impersonal data sets, or interviewing persons labeled mentally ill or addicted to illegal drugs. Some engage in intensive ethnographic work with individuals and groups, while others gather tissue, bone, or blood samples. The wide expanse of the topics we cover generates data so diverse as to defy categorization and involves us with informants who range from those severely disabled by disease to clinicians and healers.

Does the *type* of information we gather and the special characteristics of our informants make a difference in how we think about preserving the information? In my view, it must. When informants have terminal or dread diseases like AIDS or schizophrenia, when they are weakened and vulnerable because they are infirm, and when their confidence is so hard won, many of us feel and indeed have special obligations to honor the stated and unstated agreements made about their privacy — ultimately about their autonomy and dignity. By recording their stories, by eliciting those details within the power-laden context of science, we become guardians of their biographies — our versions of their lives. Creating a text creates duties and obligations (Sanjek 1990). How do we fulfill the role of trusted guardian if the data are archived in a place that might, for example, be inhospitable or inaccessible to the informants? It is difficult to imagine that many of the people with whom I have worked over two decades would be able to get to a university library, much less feel comfortable once there, to view their own records. By archiving intensely personal information in academic space, we increase our claims to the data and diminish the ability of informants to exercise theirs. If we mean to participate in joint ownership of data with those whose lives comprise it, we have to consider where and how we store data.

In a recent essay, Price (1994) spells out some related questions from her group's work with persons who are HIV-positive and who use intravenous drugs, which require careful consideration and resolution.

Another issue concerns data storage and access. Ethnographic research data have a richness that makes us loathe to destroy them. But, even with identity disguised (ID numbers, pseudonyms) what ultimately should be done with, for instance, the life histories of heroin injectors? If the PIs [principal investigators] leave, do the transcripts then belong to the university (as our Internal Review Board once suggested)? Do they belong to the NIH, which funded the study? Do they belong to the anthropologists who directed the project? Do they belong to the ethnographic fieldworkers who put their personal integrity and reputations on the line to develop rapport and guarantee confidentiality to participants? Although an uneasy truce prevails, there is an underlying contradiction in AIDS and drug user research between the guarantee of continuing confidentiality and the rights of "public access" to data collected with public monies.

Indeed, one ought to add to Price's list of arguable "owners" of the data the informants themselves, complicating matters a great deal further (Estroff 1994; Stoller 1988; Liebow 1993). Nonetheless, her dilemmas make clear the inherent tensions incurred when we promise informants perhaps more privacy and confidentiality than we can deliver, and when there are legitimate contested claims of ownership of information.

Advocacy and Self-Help: Other Voices, Other Claims

Individuals with lifelong disabilities and illnesses have formed thousands of national and local self-help and advocacy organizations over the past decade. There is a group for almost every affliction one can imagine, from Manic Depressives Anonymous to the Spina Bifida Association. ACT-OUT, an organization for people with AIDS, is perhaps the best known of these groups, and one of the most outspoken and insistent in claims to equal partnership with clinicians and researchers. It is not coincidental that researchers and clinicians have given increasing attention to issues of informed consent, privacy, and data-ownership claims. One of the most celebrated recent disputes concerned the ownership of a strain of DNA, taken from a patient, that was used by researchers to develop new drugs from which they made a huge profit. The patient claimed that since his tissue was the ultimate source of the drugs, he should share in the bounty. He also claimed that he was not informed adequately about the use that was intended for his tissue.

While less dramatic, the claims of patients who are research participants and recipients of treatment to represent their own views are at unprecedented levels. Former and current psychiatric patients, or consumer/survivors as they prefer to be called, now sit on the editorial boards of scholarly journals and publish articles about themselves with researchers and clinicians (Everett and Nelson 1992; see also Frank 1984). Some biomedical psychiatric journals now publish "first person accounts" of illness. Within this context, questions about ownership and access to data loom ever larger (Fowler 1992). Medical anthropologists

working with informants who are articulate and informed about their rights as research subjects, and who are understandably sensitive about how they are represented by and to others, must consider these sensibilities when deciding what to do with records. As noted above, the place of storage should be user-friendly to subjects. Research participants arguably have the right to review, if not have a copy of, all materials about them in the possession of the researcher. Research informants should have the right to withdraw materials about them from archived records if they choose. While these provisions will no doubt complicate the records preservation process for many, disclosing what will be done with research materials at the end of a project and protecting the rights of informants to make choices about them fulfill the obligations created when we pledge to respect the wishes of those about and from whom we gather information.

Roles

Some medical anthropologists are practicing clinicians — nurses, physicians, psychotherapists — as well as researchers. The varied roles we play create a multitude of *types* of records of our research, as well as different obligations about the custody and use of those records (see Levine 1992). Clinician-researchers may generate data that are more intimate than other researchers', and therefore potentially more injurious if revealed. Consent may then be even more restricted than for other data, such as for the clinician's use only. In view of the highly charged and carefully guarded nature of clinician-client trust, some clinicians do not publish about their clients without their express approval. For example, Stoller (1988) gives his patients veto power up to the point of galley proofs.

Medical anthropologists who conduct research as clinicians face the same hazards of misuse of their power as do other clinician-researchers. They are also creating medical records that will be controlled differently from those of the non-clinician.

In the medical setting, collaborative work with a team of investigators is the norm. In the anthropological world, solo inquiry prevails. Medical anthropologists often work with clinicians whose ideas about data ownership and preservation may differ in orientation and tradition. As we work toward responsible archiving or disposal of data, we will have to come to some mutually acceptable agreement with our clinician colleagues. Similar issues arise when we receive funding from public sources like the NIH. Like Price, as noted above, we must meet the requirements of multiple constituencies when deciding what to do with our data. The NIH is oriented to the practices and principles of biomedical research. So far, their stance regarding the protection of research subjects has not been in conflict with that of anthropologists, but we do not know their position on data archiving beyond the three-year retention requirement.

Interim Steps

Many of the concerns raised in this paper would be the same if instead of patients we were describing research with an ethnic group or political organization. I have argued that the biomedical context and audience for much work in medical anthropology exaggerate these dilemmas, but I do not suggest that the issues are any less salient for work in other than biomedical settings. The potential harms of biomedical studies exceed those of most research in cultural anthropology, but we are no less obligated to preserve and protect privacy, autonomy, and dignity and to act with beneficence.

There are steps we might take to address some of these concerns. Most obvious would be to include in the consent process a discussion with informants about the destination of records created about them. We should let them know who will have access to the information during and after the research, how access will be regulated, and what rights they have to be informed about or to approve publication of information about them. These principles will be difficult to honor, particularly when the rights and obligations of the researcher to publish information conflict with the wishes of informants. Including records preservation issues in the consent process will certainly unduly alarm some informants, and may discourage others from participating in research at all. It may also make the consent discussion so detailed as to confuse and overwhelm the potential participant, thus undermining the capacity for *informed* consent. No doubt we will get better at it as time passes, but good-faith efforts have to begin.

We should archive records with accessibility for informants in mind. In choosing a locale, we may wish to consider informants' (carefully monitored) access to information about them, or we may make copies of items and publications available at no cost upon request. Cassell (1982) has suggested that information gained in research should be systematically communicated to the informants in ways that are compatible with their interests, abilities, and special characteristics. We would not, for example, try to present findings to any informant in our study when they were psychotic, but we would work with them individually so that they could review the information when able.

My colleagues and I are already engaged in a campaign to get our university to provide archival space that is acceptable and accessible to researchers and informants. No doubt this is a task that requires attention at many other universities. Because so many medical anthropologists work in applied and nonacademic settings, other arrangements for their materials will have to be explored. Applied medical anthropologists have the option of depositing their data in archives serving anthropology, but some may have conflicts with medical institutions that may claim ownership of the records.

I would strongly encourage the use of pledges of confidentiality and respect for informants when others use our data. Indeed, access to such materials in an archives might carry this requirement. Even if these pledges carry weight that is only moral, requiring that they be read and signed will remind users of the responsibilities they incur.

There may well be instances when our obligations to the discipline to preserve the records of our work are in conflict with the wishes or best interests of the informants with whom we have studied. Yet raising questions should not deter us from seeking solutions. What we decide about archiving is less important than confronting the questions. The first step is to make the issues problematic; the second is to work toward resolution. The only unacceptable move is no move at all.

Summary

- Medical anthropologists have a professional obligation to make considered decisions concerning the preservation of their records, taking account of the sensitive nature of some items and institutional policies governing human subjects.
- The process of obtaining informed consent should include provision for the disposition, preservation and use of data.
- Plans for the archiving of medical-anthropological records should consider, among other factors, arrangements for their accessibility to the individuals involved.
- Procedures should be established that require users of archived material to respect the terms of consent obtained by the original investigator.

Note

1. Unlike most of those involved in the preservation initiatives described in this book, I engaged with this topic with considerable skepticism about the "absolute good" of preserving records. I am now persuaded that regardless of what one decides to do with data and written materials generated in the process of research, deliberate and careful consideration must be given to the matter. Each of us has both the right and the obligation to decide how best to honor our commitments to informants and the discipline with regard to records. While I am not persuaded that each of us must preserve everything we gather or learn in the conduct of research, I am convinced that we must think about what to preserve *and* do something about it.