Biological Anthropology and Ethics

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Biological Anthropology and Ethics

From Repatriation to Genetic Identity

Edited by

TRUDY R. TURNER

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In memory of my parents Harry and Fay Turner who survived a world where ethics were forgotten

Acknowledgments

In February 1999, nearly fifty people, including anthropologists, geneticists involved in studies of human diversity, ethicists and attorneys specializing in genetic and biomedical issues, and member of some of the involved communities participated in a workshop in Milwaukee entitled "Anthropology, Genetic Diversity and Ethics." The aim of the workshop was to discuss research on genetics in diverse, identified populations. Workshop participants engaged in frank discussions of the issues and were able to reach consensus on some of the practices that facilitate this type of research, including the need for trust between the researcher and the individuals in the study. All the participants in the workshop recognized that the steps we were taking at the workshop were necessary beginning steps. Discussions of ethics in both anthropological genetics and our discipline as a whole needed to be extended and expanded. This recognition led directly to a symposium at the 2001 American Association of Physical Anthropologists meetings on "Biological Anthropology and Ethics." The symposium would extend the discussion of ethics to all aspects of biological anthropology. The room the symposium was held in was filled to overflowing. Many people listened from the hall. Again, one of the themes that emerged was the continuing need for discussions on ethics in our profession. This book is a result of that symposium. Moreover, the participants of the symposium felt that this would be a way to continue the discussion. Our hope is that students and colleagues will use this book to help them engage in continuing discussion of ethics in our professional lives.

Participants in the symposium and in this volume employed a case study approach in their presentations. Each participant was asked to present material on an ethical situation that they had faced and to discuss how they had dealt with the issues. A discussion of the ethics of a situation that one faces is both courageous and daunting. Many of the participants remarked that it was much more difficult to write than any other type of paper. I am very grateful to the participants for allowing us some entry into the issues they confront in their professional lives.

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I am also indebted to the National Science Foundation for funding for the original symposium. I owe a special debt of gratitude to Mark Weiss for his continuing consultation. The reviewer's comments were helpful and are gratefully acknowledged. Michael Rinella, Diane Ganeles, and the editorial staff at SUNY Press have been helpful and gracious as they answered many question. I also thank Patricia Sloane-White and Jeffrey Nelson for their help with this project. My everlasting thanks go to Scott, David, and Micah for their patience and support.

Chapter 1

Introduction: Ethical Concerns in Biological Anthropology

Trudy R. Turner

For the past 20 years there has been an increasing emphasis on ethics in professional life. One indication of this increase is the expanding number of professional organizations codifying statements of professional ethics. The Center for the Study of Ethics in the Professions at the Illinois Institute of Technology collects professional codes of ethics. In 1981 there were 241 codes; there are currently over 850. New codes and revisions to older codes are a response to both advances in science and technology and to an intensified public awareness and scrutiny of professional life. Doctors and medical researchers confronted by the atrocities of World War II were subsequently required to confront life sustaining technologies and their implications. In the 1970s lawyers were required to confront Watergate; business people and engineers were confronted by a series of bribery scandals (Davis, 1999). In addition, during the past 20 years centers for the study of ethics in professional life, including the Hastings Center, the Ethics Resource Center in Washington, and Josephson Center in California were established to provide training in ethics. The International Society of Ethicists was founded in 1985 for consultation in the application of ethics (Davis, 1999, p. 10). Publications on ethics in the professions have also increased dramatically.

Practitioners of medicine, law, business, and engineering are most often thought of as facing ethical dilemmas. However, every discipline has its own history and its own ethical challenges. Anthropologists face a variety of issues as they engage in research with human and animal subjects. Numerous examples of ethical dilemmas can be found throughout the history of the discipline. Many dilemmas, including the ones that led to Franz Boas being stripped of his membership in the governing council of the American Anthropological Association (after he wrote of a letter to *The Nation* in 1919 accusing some anthropologists of spying for the U.S. government) and the accusation in the late 1960s of anthropologists engaged in counterinsurgency actions in Thailand, concern the possibility of covert activities by anthropologists in foreign countries. (Weaver, 1973) Some of these issues have much in common with those faced by sociologists and other social scientists; others, however, can be subsumed under the general term "bioethics."¹

Cultural anthropologists, archaeologists, and biological anthropologists working with modern or ancient human populations deal with many of the same issues. Who speaks for a group? If the group is nested within a larger group, who represents the original group? What is the relationship between expatriate communities and the community of origin? Does permission from the national government to conduct a project have meaning for the populations studied? How does one obtain informed consent from an individual or a group whose members have little understanding of the project or the risks involved? How can the culture of the population be taken into account in the design and implementation of the project? What are the implications concerning the disclosure of the identity of the group? Can consent be withdrawn sometime in the future? How? Can samples be withdrawn sometime in the future? How? Are there appropriate benefits for the population under study?

Many anthropologists currently regard their research as a collaborative effort between the researcher and the study population. They feel that trust between the researcher and the study population is a fundamental requirement for successful research collaborations. This trust implies a long-term relationship, agreements protecting the financial and health benefits of the participants, training and research opportunities for group members, and the recognition that specific historical and cultural contexts facilitate some research projects and preclude others. There remain many unresolved issues in this era of collaboration, including the ways to address the effects that research can have on a study population.

Biological Anthropology and Ethics

Anthropology can be defined as the study of humankind in all its aspects. Biological anthropology is one of the four fields of anthropology. Cultural anthropologists, archaeologists, and linguists approach the breadth of the study of the human experience from the touchstone of culture. Biological anthropologists concentrate on the biological basis of human behavior, diversity, and evolution using evolutionary theory as the major organizing principle. It is a particularly diverse field of inquiry. Practitioners of the field face an array of ethical issues as they confront their involvement and obligations to their research subjects, their discipline, society, and the environment. These issues

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are complex and often contentious. Many biological anthropologists are most familiar with the issues in their own particular subfield; they are not always aware of the similarities across subfields. The participants in this volume represent the major subfields of biological anthropology—primatology, genetics, human biology, paleontology, and skeletal biology. Each participant has confronted ethical challenges in his or her work and has reflected on the nature of ethical challenges and principles in the discipline. The underlying assumptions inherent in the ways we address these ethical issues provide the norms (or principles of action) of the discipline. A code of professional ethics, a common consensus, forms the framework for the ways members of our profession should act.

History of Professional Ethics

Professional ethics are considered to be a branch of normative or applied ethics based on either the late eighteenth century utilitarian theories of Jeremy Bentham and John Stuart Mill or the deontological theories of Immanuel Kant (Mappes & DeGrazia, 1996; Beauchamp & Childress, 1989). An ethical theory indicates an overall perspective that informs an ethical problem (Ridley, 1998) and provides moral principles or standards. Utilitarian theories are based on consequences. "Any ethical theory that claims the rightness and wrongness of human action is exclusively a function of the goodness and badness of the consequences resulting directly or indirectly from that action" is a utilitarian theory (Mappes & DeGrazia, 1996, p. 6) Act utilitarian theories suggest that a person should act in such a way as to produce the greatest balance of good over evil. The interests of everyone associated with the act should be weighed. An act that results in the greatest good for the greatest number is ethically good. "Rule" utilitarian theories state that a person should act in accordance with a rule that if generally followed would produce the greatest balance of good over evil, everyone considered. Act utilitarian theories are situational whereas rule utilitarian theories are not. Rule utilitarian theories envision a mediating step, the moral rule, between an individual action and an ethical principle. "According to the rule utilitarian, an individual action is morally right when it accords with the rules or moral code established on a utilitarian basis" (Mappes & DeGrazia 1996, p. 13). The foremost proponent of the deontological theory, Immanuel Kant, argued that the single fundamental ethical principle was not utility, but the categorical imperative. The first and second formulations of the categorical imperative state "Act only on that maxim through which you can at the same time will that it should become a universal law" and "Act in such a way that you always treat humanity, whether in your own person or in the person of any other, never simply as a means, but always at the same time as an end." (Mappes & DiGraza, 1996, p. 17). Particular duties and obligations are derived from these formulations and form the basis of deontological theory. Notable perfect duties, based on a respect for persons, include the duty not to kill an innocent person, the duty not to lie and the duty to keep promises (p. 18).³

Both utilitarian and deontological theories have been used as the basis for discussions of personal and professional life. Professions are characterized by the scientific competence of their members as well as a collective ideal of service and duties that the members share (Bayles, 1989). At the center of a profession is a collection of skills or competencies. Professional ethics are concerned with the rules and decisions concerning the practices, methods, policies, and research of various professions (Appelbaum & Lawton, 1990) and are derived from ethical theories and principles. The first code of professional ethics in the United States was that of the American Medical Association (1847). The first two decades of the twentieth century saw a "boom" in ethical codes when many professional societies organized and adopted their first statement of ethics. The past 25 years have witnessed a second boom in codes of ethics. In addition to an increase in the number of recognizable professions, many of the original codes have been reevaluated in light of new moral problems.

Bioethics

A special branch of applied ethics—bioethics—is concerned with human health and human subject research. Bioethics has a set of standards and principles that have become the model for work in medicine and research. Formal bioethics began after World War II (in the wake of Nazi experimentation on concentration camp inmates) with the Nuremberg Code. The 1947 Nuremberg Code emphasizes the centrality of voluntary consent and sets forth other criteria that must be met before any experiment using human beings as subjects can be judged morally acceptable.

The 1950s and 1960s saw the establishment of multiple codes of ethics for biological research and medicine. In 1953 the National Institutes of Health issued a policy for its clinical centers. This was the first code to establish protections for subjects in U.S. government facilities. In the early 1960s the U.S. Congress passed legislation regulating the drug industry in part as a result of the birth defects due to the use of thalidomide. The law required that researchers inform subjects of a drug's experimental nature and required that consent be obtained for participation in a clinical trial. In 1964 the World Medical Association formulated the Helsinki Code, which distinguishes be-

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tween therapeutic and non-therapeutic research. The Helsinki Code, was used by many other agencies as a model in establishing their own guidelines. In 1966 institutions receiving federal funding were required to provide peer review of research, that included the rights and welfare of subjects, the appropriateness of methods, and the balance of risks and benefits. However, the review was entrusted to local institutions and there was little oversight. Despite various codes, multiple infractions of bioethical principles continued. Congress acted in response to various allegations with Institutional Guidelines of the Department of Health, Education, and Welfare (1971) and the Patients' Bill of Rights (1972). (see Beecher, 1970; Gray, 1975; Faden & Beauchamp, 1986; Coughlin & Beauchamp, 1996; and Doyle & Tobias, 2001 for a fuller discussion of the history of bioethics)

Current generally accepted principles of bioethics emerged from the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, created by Congress in 1974. The commission was charged with developing guidelines for research involving human subjects. The existing codes, including the Nuremberg Code, the Helsinki guidelines, and the 1971 HEW Guidelines, were "inadequate, conflicting and difficult to apply" (Gert, Culver, and Clover 1997). A new set of guidelines, known as the Belmont Report, emerged from the commission and articulated three ethical principles—respect for persons, beneficence, and justice. These three principles form the basis of bioethics and are usually understood in terms of moral requirements and prohibitions, such as do no harm, apply the rules of justice and fair distribution, do not deprive persons of freedom, and help others.

The principle of respect for persons is often the most difficult for researchers and is one that anthropologists working with living individuals and populations often wrestle with. It is usually understood in terms of respect for autonomy and is implemented through informed consent. However, informed consent is often difficult to implement on an individual level. If the research is community- or population-based, the principle of respect for persons and informed consent becomes more complicated. The National Research Council (1997) recommends strategies for the implementation of respect for persons that may require that the population, not only the individual, give permission to pursue a research project.

Ethical theories are intended to provide a broad perspective on an ethical problem, ethical principles are intended to indicate a particular guideline or rule of thumb that one ought to follow in ethical reasoning. Some ethicists discuss autonomy, beneficience, and justice as prescriptive ethical principles, whereas others take agreed upon moral rules, such as do not kill, do not deceive, and keep your promises, and mesh these with the particular culture or profession to provide a particular ethical code. The results of both practices set forth ethical principles for the treatment of human subjects that are based on respect. The Belmont Report has been codified into federal regulations and is routinely used by Institute Review Boards in their analysis of research protocols. The National Research Council, the National Bioethics Advisory Commission (NBAC), which was created by presidential order in 1995 (charter expired in 2001) and the President's Council on Bioethics continued to examine these issues and prepared updated guidelines. Two relatively recent reports to emerge from the NBAC dealt with ethical issues in international research and research involving human biological materials (NBAC, 1999, 2000).

These are the issues that biological anthropologists dealing with genetics and human diversity must address. They are the same issues skeletal biologists and archaeologists working with local populations need to address. In the United States, skeletal biologists work within additional federal regulations stipulated by the Native American Graves Protection and Repatriation Act. NAGPRA, enacted by Congress in 1990, provides that the ownership of control of Native American cultural items and skeletal remains excavated or discovered on federal or tribal land after the enactment of the law should be given, in the following order, to: lineal descendents of the Native American, the Indian tribe on whose tribal land the objects or remains were discovered, the Indian tribe recognized as aboriginally occupying the land, or the Indian tribe with the strongest demonstrated relationship. Another section of the law addresses repatriation of remains and objects possessed or controlled by federal agencies and museums. Agencies and museums are required to return these objects at the request of a tribe with lineal descent. Inventories of remains held in museums and federal agencies are required. Additionally, if cultural affiliation can be demonstrated, the material must be returned to the requesting tribe. Outside the United States paleoanthropologists face additional questions relating to access and ownership of fossil material.

Primatologists also address the well being of their study subjects. And although they do not face issues of informed consent, they address the psychological and physical well-being of their subjects. Appropriate care for animals has also been codified by federal regulations, including the Animal Welfare Act of 1985. There is an ever-increasing literature on the ethical treatment of animals that addresses issues such as self awareness, the awareness of pain, and cognition. In addition, primatologists are often intimately involved in conservation issues in host countries.

Biological anthropologists adhere to the principles of the Belmont Report, the Animal Welfare Act, and NAGPRA in their work. During the past year the AAPA adopted its first code of professional ethics (see appendix II). It is based in large part on the code of ethics of the American Anthropological Association (AAA) (see appendix I). The current AAA code discusses research, teaching, and the application of anthropological research. The AAA

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recognizes that the anthropologists' first responsibility is to the people and animals with whom they work and whose lives and cultures they study. The code clearly states that its aim is to foster discussion and education. In line with these goals, the AAA Web site presents the most recent code of ethics, the charge to the committee to revise the older code, and chapters on the history of the discipline and the discipline's Committee on Ethics. The Committee on Ethics of the AAA does not adjudicate complaints. However, the Executive Board of the AAA can commission a task force to conduct an investigation of allegations, as it has recently done with the material presented in Patrick Tierney's book Darkness in El Dorado (2000). That inquiry was intended to contribute to the Committee on Ethics efforts to extend guidelines for field research. The AAA Web site also provides links to relevant codes of ethics for professional organizations, such as the Society for American Archaeology, the Animal Behavior Society, the Society for Applied Anthropology, the Society for Vertebrate Paleontology, and the Society of Toxicology. Some of these organizations credential members, others do not. Some can adjudicate alleged ethical violations, others do not. However, all these codes spell out the duties and responsibilities of members to their subjects or materials, science, and society.

Although professional codes provide a foundation for behavior, the application of this foundation to real situations is often problematic. Examples of these applications are usually examined through case studies. The AAA Web site provides a series of case studies for discussion and education. These case studies were provided by field researchers and present a series of ethical dilemmas faced by anthropologists. The technique of case study analysis is well established in the examination of ethics in various situations and is one that we have adopted here for volume. Case studies represent real situations, real dilemmas, and real solutions. They provide the basis of discussion because a single situation can have more than one solution, depending on the ethical theory, principle, or moral rule invoked. The nature of an ethical dilemma is that choices are presented.

In this volume each contributor was asked to describe an ethical situation they faced as they worked. The contributors are from all subfields of the discipline. In addition, other biological anthropologists have been asked to comment on the contributors' papers. In this volume, a series of papers or case studies are presented in a specific area of the discipline and these are then commented on by a member of the discipline.

Contributions to This Volume

The first section of the volume deals with primatology. Primate research takes place either in the laboratory or in the field. This research present unique situations for researchers. The first case, by Linda Wolfe, begins with a discussion of the ethics in science and field research and the ways in which this intersects with the study of nonhuman primates. Her chapter includes a detailed discussion of the difficulties faced by a field researcher and the types of behavior that are acceptable. Wolfe goes on to describe the work of several field researchers in various parts of the world, as well as her own work with a free ranging, habituated group of rhesus monkeys in Florida. She makes two important points: 1) researchers are obliged to conduct themselves in a way that will allow other researchers to continue to work in a given area and 2) researchers must conduct their work on nonhuman primates continually keeping the adage "do no harm" in mind.

Leanne Nash compares the similarities and differences in the study of primates in the field and in captivity. Nash begins her contribution with a review of attitudes toward primates as research subjects. She describes the utility of "critical anthropomorphism" and the "3Rs" (replacement, reduction, and refinement) to the use of primates as study subjects. Nash asks three critical questions: What ethical questions have researchers raised? Is there evidence of regulatory review? Do published papers show a concern with ethical issues? She reviewed articles from the *American Journal of Physical Anthropology* published directly after and 10 years after the implementation of the Animal Welfare Act. Although she found a marked increase in concern and review of studies of primates in captivity, this did not hold true for studies of primates in the wild.

Michele Goldsmith's contribution discusses the ethics of research on wild populations of gorillas. In her chapter she presents a history of habituation and the researcher's relationship to the animals they study. She suggests that researchers work to reduce the risks of habituation by minimizing stress and only habituating to the point of tolerance. Measures should also be taken to minimize the risk of disease transmission from human to animal. She argues that the habituation of long-lived animals, such as the great apes, necessitates a lifetime commitment.

Cathi Lehn discusses the uses of biological samples collected from animals maintained in zoological gardens. Samples collected from animals in zoos often involve less stress to the animal than samples collected in the wild. There are numerous ethical issues surrounding the curation of biological samples, including access to samples and the transfer of animals and samples. Lehn uses as an example the curation of samples at the Wildlife Conservation Society headquartered at the Bronx Zoo. Zoos have been instrumental in conservation programs working with Species Survival Plan (SSP) and the Taxon Advisory Group. Lehn shares the expertise and experience of the WCS in her discussion of tissue banking.

Jay Kaplan comments on the chapters and includes his own experience with primates in the laboratory and in the field. In the wild, habitat destruc-

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tion and the bush meat trade are the greatest threats to primate populations. However, the capture and transport of animals for research can also severely affect populations. Kaplan discusses his experiences with cynomologous monkeys imported from Indonesia. Kaplan was part of a group that forged an agreement between the government of Indonesia and academic institutions in the United States to establish a two-way transfer of resources. Macaques were imported into the United States; training and resources were provided to Indonesians.

A second subfield of biological anthropology deals with the skeletal biology of living and fossil humans and nonhuman primates. This section begins with a paper by Janet Monge and Alan Mann. They discuss the ethical dilemmas in the casting of fossil material. Because considerable research and teaching is based on casts of material, access and reproducibility are important considerations. Monge and Mann discuss the implications of the loss of anatomical detail that results from reproducing and handling fossil material. Access to casts is another issue that contrasts openness of access to conservation of resources. They use the casting program at the University of Pennsylvania as an example of an institution that deals with these issues.

The second chapter in the section is by Clark Spencer Larsen and Phillip Walker. They discuss the tensions that exist between scientists, who regard ancient human remains as objects with enormous research potential and the ability to tell us about the history of the human condition, and descendants of the people whose remains are found, who regard the remains as objects of veneration that need to be protected from indignity. They believe that human remains should be treated with dignity and respect, that descendants have authority over remains, and that if at all possible remains should be preserved so that they are available for study. Reaching and maintaining a balance between conflicting demands requires considerable effort. They describe a cooperative arrangement that was worked out with the Chumash Indians of Southern California. Remains were repatriated to a subterranean crypt where they are available to both native people and researchers.

Heather Walsh-Haney and Leslie Sue Lieberman discuss some of the ethical issues involved in forensic anthropology. Forensic anthropologists analyze skeletal material for legal and humanitarian purposes. They work within the legal system. Although much of their work is applied, they usually are associated with research institutions and are required to teach and publish. There are specific ethical questions that follow from this duel role. Some of the issues include the participation of students in formal investigations, harvesting tissues for the resolution of cases and consent, and the intricacies of consent with the families of deceased individuals.

Susan Antón discusses the papers in this section and includes additional discussion of some major issues in skeletal biology. In her discussion of the

claims and counterclaims regarding permit areas and fossil finds, she asks where such issues should be raised. Should they be raised at scholarly meetings or in some as yet unavailable international forum? Antón also discusses the ways in which the availability of casts helps shape thought on human evolution and the obligation to build infrastructure and train students in host countries.

Human biological variation and genetics are regarded as separate subfields of biological anthropology. However, they both face the same ethical questions, especially when dealing with genetic variation in human populations. Because of this similarity, the commentators were asked to discuss chapters in both sections and they are placed together in this volume. Sara Stinson's chapter discusses the nature of studies of human biological variation. This particular subfield deals with the relationship between biology and culture, and both biomedical and behavioral data are collected. When behavioral data are collected there exists the possibility of psychological harm to the subject. An individual may be embarrassed by questions, they may confront a loss of social status, face economic or legal problems, or they may be stigmatized by their social group. A group may also face the possibility of negative stereotypes. Stinson also discusses her work with children. Children have special status in research settings. They are considered to have diminished autonomy, especially with regard to informed consent.

Stacy Zamudio discusses the frustrations of a researcher engaged in a multi-institution research project. Every institution has its own IRB and requirements are not standardized. Zamudio gives several examples of the way in which this complexity has proved to be an impediment to research. She also discusses the ways in which IRBs in other countries differ from U.S. requirements. She suggests standardization of U.S. IRBs and also suggests ensuring culturally sensitive demands for international IRBs.

Trudy Turner and Jeffrey Nelson discuss the controversy generated by the publication of Patrick Tierney's *Darkness in El Dorado*. The book discusses James Neel, Napoleon Chagnon, and others who did research among the Yanomami of Venezuela. Tierney accused Neel of complicity in a measles epidemic in 1968. Turner and Nelson review the charges and find that Neel actually worked hard to save Yanomami lives. The controversy has, however, raised other ethical issues, including the long-term storage of biological samples and the changing nature of the consent process.

The chapter by Cynthia Winston and Rick Kittles discusses the African Ancestry Project. The project was designed to use genetic, historical, and cultural data to provide a bridge to the past and to answer the question of "who am I" for an American of African ancestry. DNA based testing is used to determine which of several indigenous African maternal and paternal lineages are present among African Americans. The project has a database of

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over 9,000 individuals available for comparison. Winston and Kittles discuss the ethical as well as the positive and negative psychological effects of this project. They conclude that benefit for the community and a significant contribution to science are requirements for individual participation in a research project In addition, researchers must ensure confidentiality, prevent discrimination, and fully disclose all risks.

Sloan Williams discusses the results of testing whether Thomas Jefferson fathered some of Sally Hemmings's children. This study is an example of historical genetics. In this type of study the risks to participants are usually psychological and social. Descendants of Jefferson and Hemmings were left with a sense of anger because they felt that some promises made to them were not kept. Williams emphasizes that trust between researchers and subjects can possibly mitigate the effects of results that are contrary to expectations. Her discussion focuses on the need to protect the privacy of individuals, the nature of group consent, and the conflicting aspects of peer review and scientific publication and the popular dissemination of information.

Frederika Kaestle and David G. Smith discuss the utility of the use of genetic evidence in assessing the cultural affiliations required by NAGPRA. They present the results of some of their analyses of ancient DNA from samples found in the Americas. Kaestle and Smith deal specifically with the Kennewick Man samples, which they worked on. They discuss the weight given to scientific and nonscientific evidence in determining affiliation.

Dennis O'Rourke, M. Geoffrey Hayes, and Shawn Carlyle discuss the legal, ethical, and social issues encountered when working with ancient DNA samples. These include access to samples, the consent process, a realistic assessment of the risks and benefits, results assessment issues, and NAGPRA. Their experiences include working with two Native American populations, those of the Great Salt Lake Fremont, and the Aleut of the Aleutian Islands. The Aleut project was successful and they discuss the methods they followed that helped insure this success.

Jeffrey Long and Jonathan Friedlaender are the two commentators on the human biology and genetics chapters. Friedlaender reaffirms the need for caution when working with individuals and groups where a large power differential exists. Group consent, an explanation of goals, and an assessment of outcomes is crucial when working outside the United States. Friedlaender also discusses his work in the Solomon Islands, Papua New Guinea, and Indonesia. He first went to the Solomon Islands over 30 years ago. He is able to trace the differing attitudes toward consent and research through his own experience and reminds us that the ways in which we do research can be time and place specific.

Jeffery Long also discusses the gap that can exist between the researcher and the subject. Currently researchers are responsible for the scientific design of projects, for monitoring participant rights and welfare during the project, and are also responsible for insuring that all personnel are trained and qualified. Long suggests that in order to ensure that researchers are able to meet these goals the biological anthropology community further its discussion of ethics with an annual workshop at the AAPA meetings.

Trudy Turner discusses the new technologies available for the sharing of data between colleagues around the world. The Internet and computer databases have allowed access to both genetic and fossil information. These new technologies are expanding the ways in which all researchers can participate in a global scientific community.

The authors hope this book will provide a basis for a continuing discussion of ethics in our discipline. All of the participants have at one time or another commented on how much more difficult it is to discuss ethics than it is to produce a data-based paper. The discussion of ethics in professional life is not easy, but it helps to clarify the relationship and responsibilities of individuals to each other.

Notes

1. For an account of the ethical issues anthropologists faced from 1900–1970, see Thomas Weaver (ed.) (1973). *To See Ourselves*, Scott Foresman, Glenview, IL.

2. The word "deontological" is derived from the Greek word *deon*, which means duty or obligation.

3. It is not the purpose of this chapter to review major philosophical theories. Any of the works listed in the bibliography can provide such a review with special reference to bioethics.

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Chapter 2

Field Primatologists: Duties, Rights, and Obligations

Linda D. Wolfe

Introduction

Early in the history of field primatology conducting research was relatively uncomplicated. Before leaving for the field, the primatologist obtained the necessary funds and permits to enter an area inhabited by the species to be studied. Upon arrival at the study site, the field primatologist expected to be allowed to carry out her research and publish her results unharmed and without interference. More recently, however, as rain forests and other areas inhabited by primates have shrunk in size, it has become increasingly difficult to find study sites that are free of problems that potentially disrupt research (e.g., see Oates, 1999). Field primatologists (and ethnographers) are now frequently faced with problems related to human and nonhuman primates being forced to live in smaller and smaller habitats and problems related to government authorities whose responsibility it is to manage natural parks and reserves.

For this chapter on the ethics of conducting and reporting the results of field research on nonhuman primates I have collected material from personal experience, journal articles, government documents, book chapters, and the ethics statements of professional organizations. Because field primatology is situated within the traditions of science, this chapter begins with a general discussion of the ethics of science as it intersects with the study of wild nonhuman primates. The discussion then moves to the ethics of field primatology per se, which will be presented from two viewpoints. First, the ethics of field research will be discussed from the viewpoint that researchers are obliged to conduct themselves in the field in a manner that will not result in other researchers being prohibited from running future research projects in the same geographical area. Second, researchers are expected to conduct their research on wild primates from the perspective of "*do no harm*."

Science and Ethics

As members of the scientific community, field primatogists are guided by the same general ethical principles as other scientists. For a brief overview of science and ethical principles see Jackson (1997), Ahearne (1999), and a National Academy Press document (1995). For more complex discussions, see Woodward and Goodstein (1996), Broad and Wade (1994), and Segerstrale (1994).

The guiding principles for members of the scientific community include:

- Avoid plagiarizing, fabricating, cooking, or falsifying data. According to an editorial in *Science*, the low-end estimate is that there is 1 case of fraud per 100,000 scientists per year (Marshall, 2000). The author of the editorial advocates ethics training for graduate students.
- Avoid carelessness when collecting data and the falsification of grant records.
- Avoid mistreating or discriminating against students, coworkers, or employees.
- Avoid giving professional advice on topics for which you are not qualified by professional training or experience.
- Avoid speaking for a professional organization unless its permission is obtained.
- Report professional activities when and where there is a conflict of interest. This has recently become more of an issue with the increase in university and private industry joint research ventures. Shulman (1999, p. 114) reports that in a review of the publications "of more than 1,000 scientists at universities in Massachusetts . . . more than a third of the these articles had one or more authors . . . [who] stood to make money from the results they were reporting." However, none "of the papers mentioned that the authors had a financial interest in the results." Science depends on truthfulness and openness, and all conflicts of interests should be openly reported.
- Be cautious when engaging in any research for which the results cannot be freely published. This is, of course, one of the more controversial issues currently under discussion in the scientific community. Much of the concern is focused on graduate students and postdoctoral fel-

lows who should not be expected to carry out secret research that will not be published as it may harm their future careers. For a history and discussion of the controversies relating to cultural anthropologists who engaged in clandestine research see Fluehr-Lobban (1991).

- Follow the rules of multiple authorships. The rules of multiple authored publications vary by discipline, professional organization, and journals. The interests of graduate students and postdoctoral fellows should be protected.
- · Be an objective peer reviewer. Honest, responsible, and forthright peer review of scientific publications and grant proposals is a cornerstone of good science. Whether written by a friend, foe, or stranger, a peer review of an article, book chapter, or grant proposal should be done objectively. Unfortunately, scientists "let personal biases interfere with peer review" (Steneck 2001). For example, Klopfer (1999, p. 118-119), an ethologist, reports that he had a grant proposal involving underwater observations turned down because a reviewer had written that the primary investigator (i.e., Klopfer) "cannot possibly supervise this research adequately as he cannot swim and is afraid of water." Klopfer reports that earlier in his career he was indeed afraid of water but had overcome his fears and became certified for SCUBA diving. However, the reviewer of the Klopfer proposal did not attempt to discover if his past memories were current realities. Similarly, I was turned down for a grant to study the rhesus monkeys of Jaipur, India, because a reviewer wrote, "she [referring to me] just wants to go to India to visit her in-laws." There was no attempt on the part of the reviewer to learn where my in-laws reside vis-à-vis my proposed research site (which happened to be on the other side of India from my proposed research site) nor did the reviewer offer a critique of the proposal per se. Klopfer eventually received his grant, and I was awarded the funds through another agency to carry out my project in India. Over the years, I have heard other primatologists tell of other mistreatments at the hands of reviewers.

The point of this discussion is that science depends on objective evaluations from reviewers who put aside their personal biases. Reviewers are not accountable for what they write and, therefore, have a particular responsibility to take the peer review system seriously and evaluate manuscripts and proposals without personal bias (see Ahearne, 1999, for a further discussion of peer review and Kennedy, 2001, for commentary).

 Avoid following the group; use critical, independent thinking. For example, Segerstrale (1994) warns scientists against the "jumping on a bandwagon and 'seeing' the same effects as their colleagues." The desire to report the same results as colleagues can unduly influence researchers and, as a consequence, predetermines the outcome of an experiment or field project. For example, although not rejecting the hypothesis that infanticide has influenced primate social behavior, it seems to me that evidence for infanticide as a causal agent of primate social behavior is often weak and its attribution seems more of the "jumping on the bandwagon" phenomenon than being based on solid data. For example, Sussman, Cheverod, and Bartlett (1994/95, p. 149) examine the evidence for infanticide as an evolutionary strategy among primates and conclude, "the use of the sexual selection hypothesis to explain infanticide has become a widespread, almost mythological belief, even in the popular literature" (but see Hrdy, Janson, & Van Schaik, 1994/95). Bartlett, Sussman, and Chevend (1993) come to a similar conclusion.

The sexual selection hypothesis states that:

An infanticidal male gains reproductive advantage by selectively killing the unweaned offspring of his male rivals. In addition to the relative gain in genetic representation, the infanticidal act terminates lactational amenorrhea, shortening the interbirth interval of the infant-deprived female. This ensures the earliest possible opportunity for the infanticidal male to mate with and inseminate the infant-deprived females. (Sussman et al. 1994/95, p. 149)

When Sussman et al. (1994/95, p. 149) reviewed the data on langurs (*Presbytis entellus*), for example, they found that "of the 48 cases [they examined] only 12.5% fit the requirement of the sexual selection hypothesis. In 87.5% of the observed infant killings, the context not compatible with this hypothesis." Dagg (1998, 2000) examined the evidence for the sexual selection hypothesis of infant killing among male lions and concluded "It is lamentable that the infanticide by male lions hypothesis disproven here has been so widely accepted (Dagg 1998, p. 947)" (but see Packer, 2000). I think we need to keep an open mind about the sexual selection hypothesis as an explanation of infanticide and, while not completely rejecting the hypothesis that males are a danger to females and their infants, carefully examine the evidence before jumping on the bandwagon of the sexual selection hypothesis of infant killing, or, for that matter, any other hypothesis that might be currently in vogue.

Ethical Guidelines and the Field Researcher

When starting a new research project in unfamiliar surroundings, the field researcher may experience culture shock and have a difficult time understanding the local language. There is, nevertheless, the expectation that field researchers will conduct themselves in a manner that preserves the integrity of the study of animal behavior (for more details see Animal Behavior Society, 1996). When conducting fieldwork, researchers should not engage in behaviors that will cause them to be removed from the research site by those in authority or make it difficult for others to obtain research permits in the future. It is also important that field primatologists obey local, national, and international laws that regulate the treatment and traffic in animals and animal body parts. Field researchers are expected to be honest about their activities with the local people and use any opportunity to educate people on the topics of concern to the investigator.

Field researchers are generally cautioned against becoming personally involved with the local people. I would venture to say, however, that field primatologists often become friendly with the local people. Although most of the time nothing untoward happens, there are circumstances where women field researchers have been raped. The rapes are associated with differences between the culture of the local men and the women researchers and with a misunderstanding of what it means to be a lone woman in public places who lacks an obvious male relative or husband in attendance. The professional career of the researcher is disrupted by these situations; also, future researchers, male or female, are likely to be denied research permits by those in authority.

It can be difficult to know how to handle situations when one is the recipient of troublesome behavior. There is the fear that unwelcome behaviors might escalate, but there is also the apprehension that if one makes a commotion, research permits might be withdrawn and future researchers denied research permits. In my case, while I was conducting research in India, no situation escalated to the point where I felt I had to involve the authorities. There were, however, bothersome incidents while I was observing monkeys. On several occasions men who apparently misunderstood my prolonged presence in public places offered me money to go with them to my hotel room. Several friends suggested that I hire an older boy to hang around me to keep such men away.

In much of the literature on the ethics of doing fieldwork, there is discussion of the problem of using research as a cover for spying (Fluehr-Lobban, 1991). The recommendation is that field workers avoid undertaking covert activity in the field because if they are caught it is likely that other researchers will not be granted access to that site or even into the country in the future. For example, at a research site in India I was forbidden to go near a state government office building as I followed the monkeys I was studying. The explanation I was given is that prior field researchers had been involved in spying. As far as I know, these charges were never substantiated, but they were believed to be true by the local police and university professionals. The accusations affected my research and the requests for research permits of other field researchers. In summary, field researchers need to conduct themselves in such a manner as to assure that they and future researchers will be granted research permits. They also should use every opportunity to communicate with the local people the importance of the research currently being conducted. It takes knowledge of the local culture and social skills to negotiate the fine line between friendliness and aloofness, both of which can lead to misunderstandings and future difficulties.

Ethical Treatment of Animals in the Field

Because there is a lack of consensus among scientists (or laypeople) as to the moral position of animals, an uncomplicated statement of the philosophical basis for the ethical treatment of primates or other animals is problematical, if not impossible at this point in time (for examples of the debate on this point see Dol, Kasanmoventalib, Lijmbach, Rivas and van den Bos, 1997; Erwin, Gendin and Kleiman, 1994; Oates Jamieson Mitchell, Thompson and Miles. 1997, and Agar, 2001). There is a wide spectrum of positions on the ethical treatment of animals. At one end of the spectrum is the opinion that invasive research on animals is necessary to improve the health and safety of humans, although that research often causes pain and suffering (e.g., see Cohen, 1994). At the other end of the spectrum are those who call for the complete elimination of experimentation on animals by finding alternatives to live animal research (Jamieson & Regan 1994).

Regardless of the lack of a consensus on the ethical treatment of animals, the ethics statements of the major animal behavior societies (e.g., American Society of Primatologists, 2000a; American Society of Mammalogists, 1998; Animal Behavior Society, 1996; and International Primatological Society, n.d.) are in agreement that the ethologist should *do no harm (or at least minimal harm)*. For example, in an introduction to the 1991 guidelines for the use of animals in research written by a committee of the Animal Behavior Society the following statement appears.

Observation of free-living animals in their natural habitats may involve disruption, particularly if feeding, capture or marking is involved. While the furthering of scientific knowledge is a proper aim, and may itself advance an awareness of human responsibility towards animal life, the investigator should always weigh any potential gain in knowledge against the adverse consequences for the animals used as subjects, and also for other animals in the care of field studies. (Dawkins & Gosling, 1991, p. 3)

Field research may call for a physical examination and/or the collection of tissue samples which require the trapping, shooting, holding, and releasing of animals. The American Society of Mammalogists publishes a document entitled "Guidelines for the Capture, Handling and Care of Mammals" (available on their website) in which field researchers are provided guiding principles for conducting field research in the least disruptive manner. Field researchers are expected to use as few animals in field experiments as possible (Cuthill 1991). When tranquilizing an animal in the field, an experienced shooter is needed to prevent undue harm to an animal. Because animals are particularly vulnerable when a tranquilizer is wearing off, the researcher must provide a safe place for the animal to recover. Karesh et al. (1998) have suggested that

The capture and handling of free-ranging primates is always accompanied by risk of injury or mortality. It is ethically important to maximize the amount of information gathered during these procedures. Furthermore, sharing the undesirable impacts with the scientific community enables informed decisions to be made during future project development. (p. 107)

As rain forests and other areas inhabited by primates shrink in size and logging roads open up forests facilitating access to new areas, field primatologists are now faced with problems that 20 years ago would have been unheard of. War, migration, and the presence of refugee camps have impacted primates and the ability of primatologists to pursue their studies. Field primatologists often find themselves caught between a desire to protect dwindling primate populations, compassion for local populations, and a sense of obligation to cooperate with the legal authorities.

Disease Transmission

As free-ranging Old World primates come into increasing contact with humans, the chances of diseases being passed between human and nonhuman primates increases. Measles, tuberculosis, influenza, chickenpox, polio, malaria, and a variety of parasites are some of the diseases for which there is reason to believed are capable of being transmitted from humans to other primates (Jones-Engel, Engel, Schillaci, Babo, and Froehlich 2001, and Wolfe, Escalante, Karesh, Kilbourne and Lal, 1998). The American Society of Primatologists recently passed a resolution recommending that field researchers and their assistants maintain health and sanitation standards to avoid the transfer of pathogens from human to nonhuman primates (see the American Society of Primatologists, 2000b, and also Wallis & Lee, 1999, on this problem).

Problems of Habituation

Field primatologists, in order to study a group of primates, must habituate those primates to their presence. Habituated primates are, however, an easy target for poachers and hunters and those who traffic in animals and animal body parts. If working in an area where there is heavy poaching or hunting pressure, the primatologist may decide it is unethical to habituate those primates unless it is to document the poaching. When faced with issues of possible disease transfer and the consequences of habituation, the primatologist should do whatever is in the best (preferable the long-term) interest of the primates. For example, an ecotourism project may be a short-term solution to poaching, but it may not be the best long-term solution to problems of maintaining primates in their natural habitat. Deciding what is in the best interests of a group of primates can be a difficult decision.

What Do Field Primatologists Owe Their Informants?

A question as old as anthropology is "what do anthropologists owe their informants?" It is generally accepted today that ethnographers owe their informants a copy of their reports and the maintenance of the confidentiality of the informants. There may also be situations in which the primatologist would not want to provide the location of the animals they studied in order to protect them from poaching.

There are also situations where primatologists accepted the responsibility of removing a group of primates out of harm's way. For example, Iqbal Malik, an Indian primatologist, moved two groups of rhesus monkeys away from areas where they were in danger of being extirpated and placed them in safer rural areas. She has also been a strong advocate for the translocation of city rhesus monkeys to other locations (Malik & Johnson, 1994). Similarly, U.S. primatologist Shirley Strum (1987) translocated 130 baboons from one site where they threatened agricultural crops to other sites where the baboons would not be bothering human activities, and in the process she saved their lives. These are examples of the actions taken by primatologists who asked the question "what do I owe my informants?" and decided to bear the responsibility of translocating monkeys who might otherwise find themselves in danger of extirpation.

Field Primatologists, Local People, and the Authorities

Primatologists also find themselves in situations were they are caught between the local people, the primates they are studying, and government authorities, all of whom have divergent interests. Ardith Eudey (2002), a primatologist with extensive research experience in Asia, has described the situation at a wildlife sanctuary in Thailand where she was challenged by the interplay between local ethnic hill folk and government officials from Bangkok. As might be expected, the local people and the government officials lacked respect for each other. The officials from Bangkok, however, had the power of the government behind them. Eventually the local people were relocated to a new inappropriate site. Eudey has continued to visit the people in their new village and to lobby the government on their behalf. She would like to see the people be allowed to return to their village near the sanctuary and hired as guards. Eudey provides a model for the primatologist who is concerned about the welfare of the local people and for the needs of the animals in the sanctuary to live their lives unmolested by humans.

I also found myself in a situation in which I was caught between my desire to see a population of free-ranging rhesus monkeys at a tourist site in north central Florida treated humanely and three groups of people, all of whom had different interests in the monkeys. The local people who wanted the monkeys to be left alone were one interest group, and the tourist park owners who used the monkeys to attract tourists but needed to be in compliance with the demands of the Florida Game and Fresh Water Fish Commission (FGFWFC) were another. Finally, the FGFWFC, a third interest group, wanted the monkeys removed by any methods and in any manner.

I supported the local people to try to prevent the removal of the monkeys by unqualified trappers. The monkeys were, unfortunately, an easy target for trappers because they were highly habituated. The local people did get legislation passed in the Florida House of Representative that would have allowed for the monkeys to be trapped, sterilized, and rereleased but the legislation failed in the Senate. As a State of Florida employee on a state salary, however, I felt obligated to report on my research to the FGFWFC. The FGFWFC used the information I supplied, of course, to trap monkeys. In 1994 I decided it was in the best interests of the monkeys if I stop my research so that the monkeys would become less habituated and, therefore, more difficult to trap or shoot. Also, I would have no further information on the numbers or whereabouts of the monkeys and thus it would become more difficult to find and trap the monkeys. I believe I made the best ethical decision to stop my research, but perhaps I should have concluded my research sooner than I did (Wolfe, 2002; Wolfe et al., 1991; Wolfe & Peters, 1987)

Conclusions

As scientists, primatologists need to follow the ethical guidelines established by the major scientific organizations. As field researchers, primatologists need to conduct themselves in a manner that will not prohibit future research by themselves or others. As primatologists they need to act in ways that take into account the best interests of the primates they study and support the people impacted by decisions that may adversely affect their lives. In this chapter I have also argued that the obligation of field primatologists is to conduct their research within the ethical traditions of science, collect and provide scientific information on the primates they study, assist those in authority to protect both people and primates from harm, and oversee the humanitarian treatment of nonhuman primates.

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Chapter 3

Studies of Primates in the Field and in Captivity: Similarities and Differences in Ethical Concerns

Leanne T. Nash

Introduction

This chapter will review some major changes in the last few decades in the environment within which primate, and all animal, research is undertaken. To determine the types of ethical issues raised by primatology within biological anthropology, I have surveyed papers published in 10 years of *American Journal of Physical Anthropology*. This survey forms the basis for presenting a list of ethical issues common to field and captive settings as well as issues pertinent to each of those setting.

Perspectives are shaped by one's unique experiences. I begin by describing my background and research experiences that have shaped my perspectives on the issue of ethics in biological anthropology, and more specifically primatology as practiced within biological anthropology. Although my graduate training was in biological anthropology, my undergraduate degree was in psychology. As a psychology major, I had considerable experience literally in "rat-running"-experimental work in rat behavior and neurobiology. I have since studied primate behavior in both the field and in captivity. In the field, my research has involved habituation and observation, as well as trap, mark, and release, radio tracking, and sedation of animals. I have both managed a small colony of galagos for 20 years that involved experimental and observational studies and worked closely on observational studies conducted by the Primate Foundation of Arizona, a federally funded chimpanzee research institution. My view of the care of captive primates has been shaped by having experienced and appreciated them in the wild (Janson, 1994; Snowdon, 1994).

My involvement with captive primate work spans pre- and post-1985. This is the date of the amendment to the Animal Welfare Act (AWA, 7 U.S. Code 2131-2157 (Agriculture) 9CFR Parts 1, 2, and 3), which required research institutions to "provide a physical environment adequate to promote the psychological well-being of primates". Those few words took several years to develop into appropriate and usable regulations—some of which are still debated. I have also been involved for many years in the animal research oversight committee at Arizona State University, which became the Institutional Animal Care and Use Committee (IACUC) due to the requirements of the 1985 amendment to the Public Health Service Act (Health Research Extension Act of 1985). I have also served as IACUC chair. Even when wearing a "regulator's hat," I tried to maintain the perspectives and values of a researcher. While maintaining oversight of animal research, it is possible to have the goal of helping the researchers do their work, but first keeping the welfare and well-being of the animals in mind.

Growing Debate on the Moral Status of Animals: Rights vs. Responsibilities

During my research career, spanning over 30 years, there has been a tremendous change in attitudes towards animal research, laws and regulations applied to it (especially in the United States, United Kingdom, and Europe), and the rise of the controversial issue of "animal rights" (Singer, 1975; Rollin, 1981; Regan, 1983; Phillips & Sechzer, 1989; Garner, 1993). A modest bibliography of writings on animal rights from the mid-1980s to the mid-1990s would easily exceed all the writings on the moral status of animals since the time of St. Thomas Aquinas (Regan, 1995). This is not the place for a detailed examination of the issue (nor have I the expertise to do so); however, Beckoff and Meaney (1998) provide a helpful overview of concepts in the rapidly expanding literature on animal welfare and rights. Monamy (2000) presents an excellent brief introduction to the various approaches to moral philosophy dealing with the moral position of humans, animals, and the wider environment as a whole.

Today, scientists working with animals cannot proceed without reference to the values and morals of the wider society, not just other scientists. As an example of the growth in public concern, see the cover story, "The Battle over Animal Rights: A Question of Suffering and Science," in *Newsweek* (Cowley et al., 1988). One ethical responsibility of animal researchers is to critically examine their own moral position and to become aware of at least the basics of the arguments for various views on the "moral status" of animals, for example, utilitarian, "animal interests," "animal rights," humanist (Monamy, 2000). Rollin (1981) points out that considerable gains in animal welfare can be made by adopting a more realistic strategy that weighs the "good" coming out of the research against the cost to the animal—without having to invoke animals as having "rights." A recent polling of primatologists who did and did not believe animals had rights found that there was little difference between them in the obligations they professed towards primate research subjects (Petto 1994). Whether or not one chooses to view animals as having rights, few researchers question the notion that animals, certainly primates, can experience pain and anxiety—can suffer.

In the last 30 years, there has been a major shift of emphasis from issues of physical welfare (mainly health) to issues of psychological and behavioral well-being (Phillips & Sechzer, 1989; Hunt, 1991). In the absence of any clear consensus among philosophers about the existence or identification of relevant differences between the moral status of humans and nonhumans (Leahy, 1991; Brinkman, 2001), a perspective that I personally find useful and appealing is based on Albert Schweitzer's notion of a "reverence for life" (Monamy, 2000). No matter our view of the moral status of animals, such reverence requires all who work with animals to become "moral stewards" of those animals.

"Only certain essential knowledge, rather than trivial information, should be justifiably sought at the expense of animal's suffering" (Fox, 1986, p. 185). However, weighing the costs and benefits has difficulties (Bateson, 1991; Stephenson, 1993). Sometimes we have to assess the probable utility of a study before it is done and we have the results (Leahy 1991). Given the uncertainties involved, it is valuable to have people of disparate interests debate this issue, as must now be done as research protocols are reviewed by an IACUC, see below. Another difficulty that primatologists often confront is balancing the interests of the individual animal against the interests of whole populations, species, and ecosystems (Cuthill, 1991; Lacy, 1995). Although there is no easy answer to this latter problem, sensible guidelines can be developed when reasonable people attempt to find a common ground (Norton, Hutchins, Stevens, & Maple, 1995).

Primatology as a Privilege

I have always viewed doing primate behavior research as a privilege. However, it is even more important from the ethical perspective to view it as a privilege, not a right. We can borrow the medical principle: "do no harm." However, even in medicine, harm is done: the surgeon cuts, medicines have side effects. This must be modified to "be only beneficent"—again, weigh costs and benefits. The costs are to the individual animal. The benefits usually are to science—not to the subjects of our study (Driscoll & Bateson, 1988; Hunt 1991; Martin & Bateson, 1993). However, benefits may also accrue to animals (though perhaps not our specific subjects)—for example, through improvements in conservation biology. Bekoff's (1998) personal journey of changes in his thinking about the privilege of doing animal research is a good exemplar of these issues. He notes that the arguments about animals' moral status or rights can be informed by philosophers knowing more about animal behavior, as well as by animal researchers knowing more philosophy. Because each researcher has to find for themselves where the boundary between the acceptable and unacceptable is, one of our major ethical responsibilities is to train our students to think about these issues. As a profession, we need to define what is "unequivocally inhumane" and thus clearly unethical.

The Paradox of Working with Primates

"The paradox that we face as researchers working with living nonhuman animals, especially nonhuman primates, is that we must see them as sufficiently similar to us to provide reasonably interesting answers to compelling issues of concern to humans today; yet, we must also regard them as sufficiently different so that we can use them as subjects in experiments that we would consider morally or ethically objectionable with human subjects" (Gareth Matthews, 1993, quoted in Petto, 1993, p. 119).

It is the phylogenetic affinity of nonhuman primates to ourselves that makes us readily conceive of and accept the notion that, like us, they have the ability to suffer physically, socially, and cognitively. When I was a graduate student at University of California, Berkeley in the late 1960s, Sherwood Washburn used to point out that with nonhuman primates we faced the biggest danger of anthropomorphism. However, given their anatomical, physiological, neurobiological, behavioral, and evolutionary similarity to ourselves, we were most likely to be right! When weighing costs and benefits of animal research, "critical anthropomorphism" has been suggested as an approach that can help us identify the basis of our empathetic responses to animals and even to seek evidence of their having empathy with each other (Petto & Russell, 1993). Petto suggests that in educating students and new animal care staff in ethics, it is helpful to begin with their empathetic response to animals. In addition, in dealing with captive primates, critical anthropomorphism can be used as a way to replace "additive" models of animal welfare (i.e., provide for basic physical health and then "add" enrichment via social and physical devices) with a "controlled deprivation" model. The latter concentrates on the specific perceptions the captive animal is missing which change its behavior from that found in the wild (Burghardt, 1998), and seeks to *reduce* that deprivation.

Anthropologists have a central role to play in providing information on the conflicting ideas about similarities and differences between human and nonhuman primates. Washburn always emphasized that anthropomorphism may be a good way to generate hypotheses, but not to test them. Decisions must be based on well-documented biological and behavioral similarities among species. However, we cannot resolve ethical issues by scientific research alone (Petto & Russell, 1993). We have to consider them within a professional ethical framework. This returns us to weighing costs and benefits. Leahy (1991) and Dawkins (1980) present contrasting views on the value of anthropomorphic-based empathy.

Minimizing Ethical Costs, the 3 Rs: Replacement, Reduction, and Refinement

Although originally developed with medical experiments in mind, the 3Rs of Russell and Burch—Replacement, Reduction, and Refinement—provide a helpful approach to minimizing the ethical costs of animal research (Russell & Burch, 1959; European Center for the Validation of Alternative Methods Workshop, 1996). Briefly, the concepts are: (1) replace the use of animals whenever possible, (2) reduce the numbers used to the minimum required for good science, and (3) refine study methods to minimize 'costs' to those animals that are used. These concepts are now routinely called for in work with captive animals, but also provide a framework for thinking about issues in fieldwork.

The 3Rs are at the foundation of some of the important changes in U.S. law that came with the 1985 amendments to the AWA (Johnson, Morin, Bayne, & Wolfle, 1995; Spinelli, 1997). A major effect of the AWA, and changes at that time in Public Health Service policy, was the requirement for an IACUC whose composition includes a veterinarian and a person unaffiliated with the research institution who represents public interests. A required IACUC role is to review animal research protocols (generally using the 3Rs principals) on both living and *dead* animals. Anatomists must also become aware of these requirements. This review is required of all captive research and of some, but not all field studies. Exempted are field studies "conducted on free-living wild animals in their natural habitat, which does not involve an invasive procedure, and which does not harm or materially alter the behavior of the animals under study" (9 CFR Part 1; Federal Register, August 31, 1989, vol. 54, no. 168, p. 36121). Many field studies by biological anthropologists would not be exempted from review. IACUC's have the difficult but important role of achieving consistency in weighing of costs and benefits of activities under differing scenarios and across differing institutions (Herzog, 1996)

One issue that primatologists, especially anthropologically trained ones, can address is the need for, but concomitant difficulties in achieving, international standards that implement the 3Rs approach to animal work in all countries. Ethically questionable research should not be "exported" to areas (often primate habitat countries) where laws and regulations are weaker (European Center for the Validation of Alternative Methods Workshop 1996; Homberger & Thomann, 1996; Matfield, 1996; Bayne & Miller, 2000).

Replacement of nonhuman primates in biological anthropology would be difficult, in many cases, because their phylogenetic similarity to humans is fundamental to our rationale for their study. Reduction in numbers is possible in some studies, but there are risks in using too few subjects and wasting all due to loss of statistical power (Still, 1982; Erb, 1990; McConway, 1992; Ruxton, 1998).

Refinement can take many forms, but in studies of captive primates, a form of refinement currently dominating the profession arose from the 1985 AWA requirement that the physical environment must "promote psychological well-being" (Kreger, 2000). This vague phrase was then and remains difficult to implement, as indicated by the five-year time span between the passage of the law and the publishing of the final regulations to implement the law (56FR 6495 February 15, 1991). The rule making process produced a major shift from "engineering standards" (e.g., cage size requirements) to "performance standards" based on behavioral criteria (Sackett, 1991). Critical anthropomorphism may be useful in helping us define psychological wellbeing (Rosenblum, 1991; Sackett, 1991). However, both trying to define psychological well-being and documenting ways to promote it in disparate primate species has generated a large literature (Novak & Suomi, 1988; Izard, 1991; Mason, 1991; Novak & Petto 1991a, 1991b; Novak & Suomi, 1991; Annelli & Mandrell, 1994; Novak, O'Neill, Beckley, and Suomi, 1994; Snowdon, 1994; Markowitz & Gavazzi, 1995; Rosenblum & Andrews 1995). See also the on-line bibliography on environmental enrichment in Laboratory Primate Newsletter (http://www/brown.edu/Research/Primate/enrich.html). Ethically, primatologists must both work within the regulations and provide the needed expertise to meet them. Problems with implementing the law remain; due to legal challenges to the notion of performance standards, additional proposed rules about how to develop plans to promote psychological wellbeing are still under discussion as of November, 2001 (FR Vol 64 No 135, July 15, 1999) (DeHaven 2000).

Primatology within Biological Anthropology—Are There Ethical Concerns?

It is easy to think about primatology, as practiced by medical researchers, or perhaps psychologists, as presenting ethical concerns (Cowley et al., 1988).

Many biological anthropologists, at least those who are not primatologists, might initially conclude that biological anthropology does not raise such issues. For example, in primate behavior studies, whether in the field or in captivity, biological anthropologists often observe the animals' behavior without interfering with it. Skeletal studies are usually based on collections made over many years, often over a century ago (not to forget that "collected" is a comfortable euphemism-usually for being shot!). Studies of primate cadavers are usually done on animals that were not specifically killed to acquire that cadaver. However, does the fact that the anatomist is helping to maximize the information gained from an animal that died eliminate the need to think about why the animal died? Although I recognize that these perspectives are something of "straw men," it is comfortable and easy to fall into them. Consequently, I surveyed two sets of sample years within the official journal of the American Association of Physical Anthropologists (AAPA), the American Journal of Physical Anthropology (AJPA), to see what ethical concerns were present in the papers published during those periods. Similar surveys have been done in animal behavior and in general science, but have not compared periods prior to and after the major AWA amendments in 1985 (Phillips & Sechzer, 1989; Cuthill, 1991).

Types of Ethical Concerns Raised in Research Published in the American Journal of Physical Anthropology

Rationale

Given the changes in attitudes about animal research over the last three decades, as well as the major changes in regulation of animal research in the mid-1980s (see above), some journals that routinely publish animal research have come to expect or require statements about the ethical concerns that the research might raise. Authors are instructed to address such issues (e.g., *Animal Behavior*, 2001, 61(5), ii–vi); *American Journal of Primatology*, every issue). See also a discussion of this need by Fox, (1986, p. 125). Currently, *AJPA* does not have such a requirement. I examined two time periods to see 1) what sorts of ethical issues arose in these papers, 2) how well ethical concerns in primate research and evidence of regulatory review had been expressed in the papers, and 3) if the proportion of papers showing concern or review had changed through time.

Methods of Scoring

Two five-year periods were examined: 1) 1985–1989, just subsequent to the major changes in law, during the development of the regulations implementing

the 1985 AWA amendments, but prior to their implementation, and 2) the last half of the next decade, 1995–1999. I expected to see fewer references to ethical or regulatory concerns in the former period. I reviewed all research papers that were published during these years—specifically, the abstract, methods section, and acknowledgements. Only papers presenting original data were scored. Those that exclusively reviewed or analyzed previously published data were excluded.

Only types of research that might raise ethical concerns in primatology, or other research involving live nonprimate mammals, were scored. The types of research were categorized as 1) research on captive living primates, 2) research on wild living primates, 3) work on primate cadavers, 4) work on primate museum specimens, and 5) work on other living nonprimate animals. Multiple papers might reference the same source material (e.g., animal colony, field site, museum collection), but each paper was scored separately.

In categorizing ethical issues that arose in a paper, my attitude was "if I were the IACUC member, before the work was done I would have wanted to review the protocol." Each paper was tallied only once, into it's "most severe" ethical issue within a "research type" (see Table 3.1). If several issues arose in a paper, it was scored into the one issue that I judged to cause the most "concern" or which was the most "invasive." For example, within the type "research on wild living primates," a paper scored in "radio-collaring" would imply "lesser," but necessarily included, concerns about capture methods, habituation, and the effects of observation on the animal. If more than one type of research appeared in a paper, again the one carrying the most "invasive" issue was where the paper was scored, for example, a study involving both cadaver dissection and observational work on positional behavior of captive primates was judged on the basis of the dissection. This implies a scaling of "invasiveness" that IACUC members must do routinely (Orlans, 1996). Clearly, others might differ from my judgment of what was "most invasive," for example, that an animal died to provide the cadaver or that some animals lived in captivity. Readers should consider their own ethical position on such scaling. Disagreements about these categories do not effect the scoring of what was said in the paper concerning ethics or regulatory review. Thus, the results here reflect the frequency of issues of strongest "concern," not the greater *cumulative* costs to the animals the research represents.

Lastly, statements in paper were scored, on a yes/no basis, to see whether there was 1) some expression of what I called "concern" about the ethical issues that the study might present, and 2) some mention of a review of the research protocol by something like an IACUC. The latter required a clear statement that the protocol had been reviewed prior to the work being done. In contrast, scoring a "yes" on "concern" was given as liberally as possible. I counted as a "yes" any statement that suggested to me that the researcher

		Time period	
Research Type	Specific Ethical Issue	1985–1989	1995–1999
captive	anethesia	6	5
	dental impression	1	0
	diet modification	2	0
	EMG	4	1
	euthanasia	1	1
	housing/husbandry	7	9
	social stress	3	0
	surgery	3	3
	tissue sample	15	10
	behavioral training	8	3
	x-ray	9	8
	captive subtotal	59	40
wild	anesthesia	0	3
	capure/mark	2	4
	dental impression	1	0
	habituation & observation	10	18
	provisioning	1	0
	radio collar	2	2
	tissue sample	$\frac{1}{2}$	4
	wild subtotal	18	31
cadaver	dissection	7	6
	source of specimens	1	3
	tissue	1	0
	cadaver subtotal	9	9
museum (all)	source of skeletons	30	30
other	dog, x-ray	1	0
	rats sacrificed	2	0
	rabbit or rat surgery	1	2
	rats stress, sacrifice	4	0
	rats surgery, sacrifice	1	0
	other subtotal	9	2
Total		125	112
Total papers reviewed		610	524

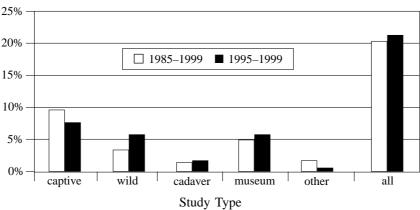
TABLE 3.1 By time period, counts of papers into their ethical issue of "greatest concern" (see text)

was aware that the research had an ethical cost to the animal. For example, a "yes" was scored for captive work that mentioned the facility was accredited, for museum specimens when the date of the collection was noted, and for mention that anesthesia was used during any procedure that might require it. In other journals, such a statement as that the research followed the ethical guidelines of the society associated with the journal would count—but we have as yet to have such guidelines for the AAPA.

Results

No mention will be made here of specific papers, as I know that many of the authors of these papers are concerned about these issues, even if the papers might not explicitly reflect their concern. A full list of the papers scored, and how I scored them, will be provided upon request. The general topics of research covered were not analyzed, but were not surprising. They included anatomy of living and fossil animals, genetics, behavior (social or positional), growth and development, dental microwear, physiology, and behavioral endocrinology.

For each time period, the aggregate of all the five types represented about 20% of all papers published in *AJPA* (Table 3.1, Figure 3.1). There also was not much change between time periods in the distribution of the types of research. The ratio of papers based on captivity vs. the wild was more extreme in the earlier time period than in the latter. Thus, in terms of setting, approximately the same kinds of research were reported in each time period.



AJPA: % Papers of Each Type

FIGURE 3.1 Within each time period, percentage of total American Journal of *Physical Anthropology* (AJPA) research papers found which were of each research type.

Varying sorts of ethical concerns were raised in each type of research (Table 3.1). Studies of primate behavior, whether in captivity or in the wild raised a wide range of issues. For all captive primates, minimally there are the issues of the effects of capture on wild source populations, the humaneness of capture and transport, and of whether or not the animals should be in captivity at all. Given the "psychological well-being" provision of the 1985 AWA, we must be concerned with balancing physical vs. psychosocial wellbeing. An animal in a single cage may be physically healthier on the surface, where it does not get bitten, scratched, or passed diseases from its fellows, but what is its psychological state (Rosenblum, 1991; Suomi & Novak, 1991)? There are immense differences in species-specific housing and husbandry needs between species ranging from tiny nocturnal mouse lemurs to gorillas. Within a species, differences in sex, age, and dominance influence what gives well-being. In addition to these concerns for all captive primates, some studies caused the animals to experience diet modifications (including restriction), social stress, behavioral training, or tissue sampling. More invasively, animals were anesthetized to have dental impressions or x-rays made, or electromyograpic electrodes implanted. The latter remain after the animal awakes. At the most invasive, animals may have surgery or be euthanized.

Studies on wild primates must minimally consider the potential negative effects of habituation and observing the animals; for example, there is the potential stress of being observed at all, habituation might make animals more vulnerable to poachers or human to animal disease transmission (Wallis & Lee, 1999). If food provisioning is done, it has similar harmful potentials, as well as disruption of normal nutrition. Other studies involved capture, for a variety of purposes, which has the potential of harming the animal and must be done in a humane fashion. Capture often also involves anesthesia (with its attendant risks) in order to take dental impressions, fit a radio-tracking device (which might cause the animal to get caught, or become too tight), mark the animal (which might make it more vulnerable to predators), and/or have tissue samples taken. If a few animals are to be captured, how do we balance the costs to the individual animal against what might benefit the whole population?

Although the other research types were less in my realm of experience, ethical issues appeared in all. In cadaver work, there was the issue of the source of the specimens being used. In museums, there was still some need to collect new specimens to document recently described species. Given that so many primates were collected in the past, it was also an ethical concern that existing specimens are properly curated and conserved. Research on nonprimate mammals (rats, rabbits, and dogs), although rare in AJPA, incorporated some of the most invasive work found in the survey (multiple physical stressors applied prior to death, multiple surgeries, and sacrifice of animals to provide skeletons and other tissues).

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Turning to how the papers presented recognition of "concern" or of regulation, in the earlier time period, the evidence of "concern" was never over 20% (Figure 3.2a). Concern was most often expressed in captive work, and not at all in work on other animals, though often this was invasive work (Table 3.1). Protocol review was found in only 1 paper of the 125 papers reviewed for that period. In the latter time period, there is a marked increase in evidences of "concern" (Figure 3.2b). There were also some increases in evidence of review. However, there was still no evidence of review of wild studies. This was despite the fact that in both time periods about one-third of the papers from wild studies involved something more than "just" habituation and observation, for example, capture-mark-release, radio-tracking, tissue collection.

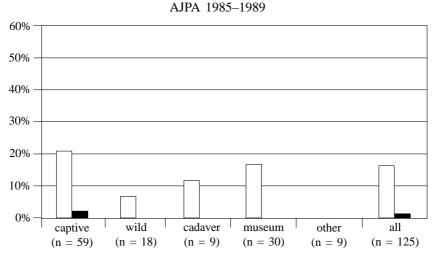
Finally, a quick review of *AJPA* in 2000 and 2001 revealed that there were some papers with invasive work published with no mention of any protocol review. Also, there are other sorts of concerns that primatology work can raise, which did not appear in the surveyed papers (Novak, West, Bayne, & Suomi, 1998). These include field experimentation that might cause harm (e.g., induced infanticide, aggression, or predation), conflicts in captivity between sanitation and regulation of naturalistic enclosures, potential costs and benefits of mixed species enclosures, and problems of observer and animal handling safety (Huntingford 1984; Elwood 1991; Gibbons, Wyers, Waters, & Menzel, 1994; O'Leary, 1994; Herzog, 1996; American Society of Mammalogists Animal Care and Use Committee, 1998; Hart, 1998; Vandenbergh, 1998; Guidelines, 2001).

Ethical Responsibilities of Primatologists within Biological Anthropology: Comparing Field-Based and Captive-Based Research

The foregoing survey and my personal experiences show that there clearly are ethical issues to be addressed. At first glance, the issues might seem different for researchers primarily working in field versus captive venues. However, the survey illustrates that in both settings research can present a continuum of more to less invasiveness and "cost" to the animals. As I see it, our responsibilities have more similarities between the venues, than differences.

Responsibilities of Researchers Working with Animals in Any Venue

- Each worker should think carefully about their own ethical stance regarding animal work, consider the philosophical underpinnings of their position, and find the balance of costs and benefits that they can accept in their own research.
- Our students should be educated to do the same thinking. In addition, we must ensure that our students understand the regulatory issues



Study Type



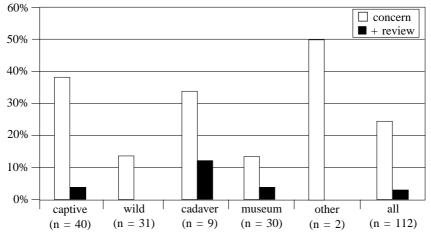




FIGURE 3.2a and 3.2b Within each time period (a: 1985–1989; b: 1995–1999), percentage of *AJPA* research papers within each research type (Ns specified), which show either 1) some sort of ethical "concern" as defined in the text (white bars), or 2) evidence of regulatory review (black bars).

concerning the privilege of working with animals (King, 1991; Shalev, 2000; Slauter, 2000). Students must receive appropriate training in all animal handling procedures that they will do (e.g., trapping, radio-collaring, tissue sampling, anesthesia, surgery).

- In our own work, and in our training of students, we must consider how we can implement the 3Rs in our research protocols and choose as noninvasive a method as possible (Snowdon, 1994). Part of this is to embrace the spirit as well as the letter of the regulations and accept, and even seek, review of our research protocols by others with divergent views. This will make us more sharply consider the reasons why we should do what we propose to do, and whether there are better ways to do it.
- We have a responsibility to help our home institutions embrace and teach the attitude of reverence for animals and, again, seek to meet the spirit, not just the letter, of regulations. We have a responsibility to our institutions to act in a responsible fashion, to play by the rules. As the ads say, just do it! This responsibility includes understanding all relevant regulations and being willing to serve on and lend our expertise to IACUCs. By meeting our obligations to our institutions, we can, in turn, expect our institutions to continue to support our ability to do work on living animals and cadavers in the face of regulatory burdens (Brinkman 2001).
- We have a responsibility to our profession, for example, AAPA, to ensure that it develops a set of ethical guidelines that incorporates animal research issues (Dodds, 1991; International Primatological Society Captive Care and Breeding Committee, 1993; American Society of Mammalogists Animal Care and Use Committee, 1998; American Society of Primatologists Research and Development Committee, 2000; Guidelines, 2001). Guidelines need to go beyond the statement in the American Anthropological Association ethics statement (Commission to Review the AAA Statements on Ethics, 1998), see: (http:// /www.aaanet.org/committees/ethics/ethcode.htm). In addition, AJPA, should have an editorial policy that incorporates concern about animal use, space for authors to show that protocol review has been done, and encourages reviewers to comment on ethical issues during the review process. In acknowledgements, we might expect to see a statement that animal use protocols had been reviewed, as is done in American Journal of Primatology (see Guidelines for Authors, http:// /www.interscience.wiley.com/jpages/0275-2565/authors.html). Foreign colleagues who publish in AJPA, but work in less-regulated societies, should also meet ethical standards of professional associations.

- We have a responsibility to the animals we work with to do what we can to promote their conservation. We must grapple with the problem of balancing costs to some individual animals and benefits to their population, species, or ecological community.
- We have a responsibility to those who work for us on animal research. We must be concerned with zoonoses (diseases communicable from animals to humans). Field workers must deal with those of differing ethical and cultural standards. We must deal with unease that some of our coworkers, whether in the lab or field, may have about procedures carried out on animals (Arluke, 1990; 1994; Walshaw, 1994; Ellenberger, 2001; Schub, 2001).
- We have a responsibility to the public. We need to do more to educate our community on the importance of animal research and how our work can help us understand both what humans share with other animals and how we, and they, are unique (King 1991). It is not uncommon for abolitionist or extremist groups to promulgate half truths or outright falsehoods about primate research (Novak & Petto, 1991b). Also, we need to show how what we do does not only benefit our sometimes arcane scientific interests, but that some of what we do benefits the animals themselves. Finally, we need to educate them that primates are not good pets.

Responsibilities of Researchers Working with Animals in the Field

- We must look at issues of habituation and capture and release in terms of their impacts on both the individual animals and the population to which they belong. Will habituation put the animals or local human populations in danger? How is capture and handling done safely and humanely?
- Field workers can lend their expertise to conservation efforts, but they have equally valuable abilities to inform decisions about captive care and husbandry. For example, the recent passage of the Chimpanzee Health Improvement, Maintenance, and Protection Act (HR 3514) involved work by both field workers and those involved with captive work (Brent, 2000; Shalev, 2001).
- Because many field workers are foreigners in the habitat country of the primates they study, we need to collaborate with local people and to help educate local students in conservation and ethical animal research. We have a responsibility to share with those in habitat countries *both* our research results and our ethical standards.

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Responsibilities of Researchers Working with Captive Animals

- We have a responsibility to consider the source of captive animals that we study. What was the impact of their acquisition on wild populations? Were capture and transport done in a humane manner? If animals were bred in captivity, what is the long-term support for their continued care?
- We have ethical and legal responsibilities for their captive care and husbandry. We have to grapple with the complex issues of defining "psychological well-being" and finding effective ways to enrich captive environments and thus promote it.

My goal in this chapter was to raise issues, especially to biological anthropologists who are *not* primatologists. I sincerely hope that for biological anthropologists that, like me, do primate research, this is all "old news"; for students and new professionals, I hope this is a helpful primer. I also wanted to compare field and captive work, given my experience in both. For field workers, Wolfe (in press) in this volume raises some issues that I have not touched upon. Even I was a bit surprised to find so few differences between the venues in the animal welfare and ethical issues that we researchers must confront.

Acknowledgments

Thanks to Trudy Turner for organizing the excellent symposium that led to this chapter and for making me think more about the topic than, perhaps, I had wanted to. Jeff Long most poignantly reminded me of an important issue I had overlooked. The manuscript was greatly improved by comments from L. Bidner, J. Fritz, S. Howell, S. Meredith, M. Schaefer, and L. Wolfe.

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Chapter 4

Habituating Primates for Field Study: Ethical Considerations for African Great Apes

Michele L. Goldsmith

Primatology, as a field of study within biological anthropology, is the science of understanding nonhuman primates with the goal of gaining insight into the human condition. To better examine and understand the behavioral intricacies of their study animals, primatologists usually rely on habituating their subjects to their presence. As defined by Tutin and Fernandez (1991), habituation is the acceptance by wild animals of a human observer as a neutral element in their environment. This is the progression to a state that allows the natural behavior of a species to be observed and documented. Although information from habituated primates has been instrumental in providing a wealth of information for both research and conservation, little attention has been given to the costs these animals bear when their fear of humans is removed.

As an introduction to this topic, I first briefly review the history of habituation within primatology. I then consider costs attributed to habituation, suggest ways to minimize the costs, and conclude with thoughts and considerations for the future. The focus of this essay is on African great apes (*Pan* and *Gorilla*), primarily gorillas, simply because this is where my experience lies, although I suggest the same arguments hold true for orangutans (*Pongo*). All great apes are listed as "endangered species" and some subspecies (e.g., *Gorilla gorilla beringei*) are "criticially endangered" (International Union for Conservation of Nature and Natural Resources, 2000). In this chapter, I voice my concerns about the detriments of habituation, especially to the livelihood of our subjects. Sometimes playing devil's advocate, I welcome the opportunity to turn this monologue into an active dialogue, which might improve the direction in which we are heading.

A History of Habituation in Field Primatology

For decades biological anthropologists have studied wild primates in their natural habitat. Researchers discovered early on that habituating their subjects to the presence of observers was an intricate part of study for a number of reasons. Field investigators needed to 1) increase the visibility of their subject animals (especially in forest habitats), 2) be able to identify individuals and their relationships with each other, and 3) reduce any effect observers might have on natural behavior.

The first long-term field study began in the early 1930s when Clarence Ray Carpenter studied howler monkeys on Barro Colorado Island (c.f., Carpenter, 1965 for review). Lack of visibility in forest conditions lead him to devise observation methods that primarily involved concealing himself in hides or blinds and behind trees. When more than just simple visibility of his subjects was necessary, such as when studying dominance or aggression behavior, identification of individuals and knowledge of their kinship became necessary. Carpenter then proceeded to habituate one group by following them daily over a one-month period.

Early baboon studies, attempting to model the evolution of early hominids, provide a good example of how habituation for recognition of individuals became important. Unlike howler monkeys, baboons live in open savannah, which is the easiest and most convenient place to see primates. In addition to their open habitat, baboons also have a long history of interacting with humans without harm (DeVore & Hall 1965). Both of these factors lead to the easy acclimation and habituation of baboons (Strum, 1987).

When habituation was difficult (e.g., in dense forest habitats), and hides or blinds did not work because groups were not localized to a specific area, food provisioning was often used. This was the most common method used by Japanese primatologists (e.g., macaques; see Kawamura, 1959; Imanishi, 1960). Interestingly, early attempts to habituate gorillas also involved provisioning (Osborn, 1957 and Baumgartel, 1960, cited in Schaller, 1963), but these attempts failed because the gorillas refused to eat the strange food items presented to them. Later habituation efforts by Schaller (1963) attempted to follow Carpenter's method of concealment, but Schaller soon found that this was logistically difficult because he was easily detected when trying to follow the group. Although concealment had worked to a certain degree in an earlier study of chimpanzees (Kortlandt, 1962), Goodall (1986) experienced the same difficulties as Schaller when she attempted to hide from her subjects. Schaller soon discovered that due to the apes' keen eyesight and heightened curiosity that they were much less excited when he presented himself out in the open than when he "deviously attempted to hide" (1963, p. 22).

Food provisioning to increase visibility or to promote habituation of research groups has been a controversial issue within the field of primate behavior (see Fa & Southwick, 1988). Chimpanzee sites in Gombe (Goodall, 1986) and Mahale (Nishida, 1979), Tanzania, as well as the bonobo site in Wamba, Democratic Republic of Congo (Kano, 1992), all incorporated food provisions to increase visibility of their subject animals. In Wamba, sugar cane is still provided to some bonobo groups to coax individuals into open spaces for observation (note that due to warfare in the region this research site has been practically inactive since 1994), whereas in Gombe, bananas are also still used to medicate individuals. Although an intriguing topic, especially as to how it has contributed to our knowledge of social learning and cultural traditions in some primate species (e.g., Koshima Inlet macaques; see Kawamura, 1959) and how it may influence natural foraging and ranging behaviors, it will not be considered further in this essay.

Costs Associated with Habituation in Great Apes

Effects of the Habituation Process

A number of studies have specifically examined the responses of chimpanzees (Johns, 1996), bonobos (Krunkelsven, Dupain, & Elsacker, 1999) and gorillas (Tutin & Fernandez, 1991; Blom, Chloe, Brunsting, & Prins, 2001) to the presence of observers during the process of habituation. These studies demonstrate that animals show a variety of responses when investigators arrive, which appears to be related to their previous exposure to humans, the structure of the habitat, and the behavior of the species when faced with unfamiliar intruders into their environment (Tutin & Fernandez, 1991). Some populations, such as the Bwindi gorillas, can take as little as six months to habituate, whereas some western lowland gorillas can take more than 14 years in some cases (e.g., in Gabon). Similar variation in habituation has been observed among macaque populations (see Kawamura, 1959).

Initial reactions to habituation include fear behaviors such as vocalizations, increased aggression, and changes in daily ranging pattern (e.g., Blom et al., 2001). Fear behavior, in gorillas for example, is often associated with diarrhea (Butynski & Kalina, 1998) and is highly indicative of physiological stress (Habib et al., 2000). Increased stress levels over time may inhibit reproductive function, causing infertility (Moberg, 1985; Wasser, Sewall, & Soule, 1993), can damage the hippocampus (Sapolosky, Uno, Rebert, & Finch, 1990), and may weaken the immune system, leaving individuals vulnerable to disease (see below).

In gorillas, as they become more accustomed to your presence they begin to enter an intermediate stage of curiosity. At this point, individual animals may begin to challenge the observer. Bluff attacks and actual biting are common during this phase and are both frightening and dangerous to the habituators. For example, two people in the Central African Republic (CAR) were bitten during follows of gorilla groups under habituation and both were seriously hurt. One was bitten in the arm, the other in the leg. After the leg bite, the silverback stood over the researcher not allowing him to move or retreat for more than 30 minutes (A. Blom, personal communication). In the case of the arm bite, some evidence indicated that the group was going through "social upheavel" and that this might have heightened aggression (Blom et al., 2001). It is often only after the animals work through this stage, that they eventually begin to accept your presence.

Minimizing Effects of the Habituation Process

With regard to the habituation process, it is important to employ methods that minimize stress to the animals. Fear is kept to a minimum during the habituation process by maintaining a good distance between the researcher and the animals, keeping the number of observers small, not following the animals after they flee, and verbally notifying the animals that you are about to approach (as originally suggested by Schaller, 1963) (Johns, 1996). Most ape habituators follow these general guidelines. In Bai Hokou, CAR, researchers use tongue-clicking to alert gorillas to their presence (Blom et al., 2001), whereas in Bwindi, researchers generally use low stomach grunts (personal observation).

During the habituation process, Blom et al. (2001) found that a number of factors influenced the gorillas' first response after being contacted by observers. Gorillas were less fearful when they were contacted on a daily basis over many days, whereas multiple contacts during the same day did not seem to alleviate fear. The habitat in which first contact was made also influenced their response with gorillas tending to ignore observers when contacted in dense understory but often running away when contacted in more open habitat. Therefore, how, when, and where to approach animals is important in minimizing effects of the habituation process.

Another important tool is to monitor physiological stress during the habituation process so that approaches can be modified accordingly. Studies are now being planned and/or conducted using fecal corticoid steroid measures as an estimate of physiological stress during the habituation process in lowland gorillas (e.g., M. L. Goldsmith), and comparatively between habituated and unhabituated mountain gorillas (e.g., J. B. Nizeyi). Measurements based on fecal samples can provide a noninvasive way to collect and monitor information over time.

Long-Term Consequences of Habituation

Only a handful of studies have considered to some degree the long-term consequences of habituation on wild apes (McNeilage, 1996; Butynski &

Kalina, 1998; Wallis & Lee, 1999; Goldsmith, 2000, Butynski, 2001), but this is sure to change in the near future as this topic becomes more controversial. In this section, I concentrate on three main effects of habituation: 1) increased vulnerability to poachers, 2) changes in ecology and behavior, and 3) the introduction and transmission of disease.

EFFECTS OF POACHING

Individuals in habituated groups can be seen as "sacrificial lambs" because removing their fear of humans may make them more susceptible to both poaching (if left unprotected) and to disease (due to closer interactions with humans). I agree with Wrangham (2001) that our presence as researchers is a major means of protecting these animals from harm. Sometimes just the fact that we are there deters illegal activities such as hunting. Unfortunately, African great apes live within countries that are politically unstable and where wars are frequent. During these times, researchers along with their assistants and local field crew are often evacuated leaving the site without protectors. The fearless animals they leave behind become easy targets for the poacher's gun.

In the Tai Forest of the Ivory Coast, where chimpanzee and other primate research has been conducted since 1979, there is a clear divide between where the study area starts and where it ends. Due to intense hunting pressures, there are low primate densities immediately outside the study grid. Researcher presence in this area has certainly deterred hunting and has helped in protecting the primates within the study area. However, if due to political instability, this field site were to be evacuated, the habituated monkeys and apes left behind would be such easy targets for poachers that the whole site could be cleared in just one or two days (Scott McGraw, personal comment).

In addition, it is possible that over the past few decades some primate populations (perhaps those other than apes) may have been habituated by budding primatologists (e.g., Masters or Ph.D. students) and then discarded after completion of the study. Although I am unaware of actual cases, it would be interesting to investigate this and see what effect it has had on the vulnerability of the habituated individuals left behind.

Although our presence may help protect the animals we study, it may have another effect that has not been considered in the literature. While we are at field sites, deterring poachers, we also discourage natural predators from hunting their prey. By not weeding out the sick or weak, which might result in less fit animals reproducing, inferior genes may be passed on with a possible long-term consequence of weakening the gene pool (S. McGraw, personal comment). In addition, this protection from predators may also influence group demographics and population density. The effect of researchers on genetic viability and on behavioral changes of their subjects needs to be investigated. The suggestion that habituated animals are more susceptible to poaching is basically theoretical, because no data exist on the subject. The difficulty is in reporting. Officials are almost always aware when animals from monitored populations have been killed however it is often difficult to determine when illegal hunting has occurred in "wild" populations.

MINIMIZING IMPACTS ON POACHING

Our attendance may only be a temporary solution to protecting our habituated subjects, because it is difficult to guarantee our continued presence. When we set out to habituate animals we should be responsible for their well-being for the remainder of their lives. Researchers working in great ape sites that are not within protected national parks should take every initiative to promote a more protected environment. This means primatologists need to become savvy in the governmental and political arena. Infrastructure needs to be put in place that will protect the animals even in the absence of the researcher and their staff (i.e., protection that can withstand pressures of political instability).

Although researchers in Wamba and Lomako, Democratic Republic of Congo have been instrumental in protecting bonobos (few bonobos exist outside these areas), their absence due to political instability has led to bonobos falling victim to hunters for the bushmeat trade (Karl Amman, personal communication). Initiatives for well-protected parks should be a priority in these fragile areas.

EFFECTS ON ECOLOGY AND BEHAVIOR

Changes in ecology and behavior may result when apes lose their fear of humans. For example, in Bwindi, Uganda, gorillas living near the edge of the national park explore human inhabited areas outside the park boundary soon after becoming habituated (Goldsmith, 2000). Butynski (personal communication) observed gorillas in Bwindi from 1983 and 1993, prior to their habituation, and not once did he observe them to sleep outside of the forest. During a preliminary study following a habituated gorilla group in Bwindi, they were observed sleeping and ranging outside the park boundary (in and around agricultural fields) 35 of the 36 days they were followed. While outside the park, their diet varied and included items such as banana pith and eucalyptus bark, their foraging effort was greatly reduced, and individuals nested more cohesively and often in the same small area night after night (Goldsmith, 2000). These changes in behavioral ecology may influence the overall health of the group by increasing parasite load and promoting disease transmission. In addition, habituated gorillas become pests to local inhabitants and have direct conflict with farmers, which certainly hinders conservation efforts. At least one farmer was sent to the hospital after trying to coax a gorilla away from his crops (personal observation).

Another effect on behavior may be an artificial increase in group size. For gorillas, McNeilage (1996) found a greater number of immatures in monitored versus unmonitored groups in the Virunga Region of Rwanda. In addition, a group of some 44 animals now exist in one group in the Virungas (Vedder, personal communication), which is thought to be an artifact of habituation (mean gorilla group size across research sites is 10 individuals; Goldsmith, 1999).

Furthermore, Butynski (personal communication) reasons that unhabituated adult male gorillas that would normally challenge dominant males in habituated groups are, due to their fear of humans, either deterred from presenting a challenge, or are less successful in their challenge. This is expected to be particularly so where there is frequent or near constant human presence, which is often the case (Butynski, 2001). If this is happening, then this human-caused change in the behavior of unhabituated gorillas could serve to lengthen the tenures of dominant males in habituated groups, and also to reduce the rate of infanticide in those groups. Conversely, dominant males and infants in unhabituated groups would be expected to be under greater than normal pressure from males in search of groups to take over. Males in unhabituated groups would be expected to have shorter tenure lengths, and infants in these groups would be expected to suffer higher rates of infanticide. Butynski (personal communication) also suspects that habituated groups of gorillas, with humans "attached" to them, have essentially unchallenged access to food resources. If so, the behavioral and ecological repercussions both for the habituated and unhabituated groups might be numerous.

Another important dilemma that is not addressed in the literature is whether apes can ever truly be habituated in every sense of the word, since the definition states that the human observer should remain a "neutral" element in the environment. There are obvious instances where this has not been the case. For example, in the Virungas, one researcher was bitten (possibly as a show of power), when two silverback males were involved in a dominance struggle (Doran, personal communication). We don't really know what the long-term effects of close interactions between researchers and apes have had on the natural behavior of the animals. It may be that habituation of these highly intelligent creatures has permanently altered their behavior.

A final matter is controlling the number of animals that are habituated. Little consideration is given to the possibility that habituation may spread throughout the rest of the population. However, if we consider the life history and social structure of gorillas, both males and females emigrate from their natal group. In fact, females often transfer between groups more than once in their lifetime. Therefore, we have a situation where habituated individuals transfer to unhabituated groups, perhaps reducing the "wild" groups fear of humans. This is probably more of a factor for males, because they are the main protectors of the group and most members will follow their lead. In contrast, as wild animals enter habituated groups, they too may become habituated. As habituated groups increase in size or as males mature, they may fission to form two or more groups. Group fission, in addition to the transfer of individuals among groups, may increase the number of habituated individuals beyond what researchers and/or management originally planned.

It is disconcerting to think what affect this might have on small, fragmented populations (e.g., Virunga and Bwindi gorillas, Gombe chimpanzees). For example, in the Virungas at least 75% of the entire gorilla population is habituated for either research or tourism (Butynski, 2001). It could just be a matter of years before the entire population loses its fear towards humans, leaving the entire subspecies (or species) vulnerable. Although it is possible that a habituated animal, once removed from habituation, loses its habituated tendencies, there are no data as yet regarding the long-term effects of transfer of habituated animals.

MINIMIZING IMPACTS ON ECOLOGY AND BEHAVIOR

Perhaps the easiest way to minimize the effect of habituation on ape ecology and behavior is to simply not habituate them. For the past 15 years, studies of western lowland gorillas have provided a wealth of information about diet, foraging effort, and grouping patterns without habituation (see Doran and McNeilage, 1988, for review). For example, the fact that some western lowland gorilla groups in the wild temporarily fluctuate their group size in response to environmental variables was discovered using indirect observation techniques (such as nest sites, tracking, and dung remains) (e.g., Remis, 1994, Goldsmith, 1996, 1999). It would be interesting to compare the behavioral ecology of habituated versus unhabituated apes within the same area to see what influence it has on their behavior.

Because it is possible that the number of habituated animals within sites may increase naturally, we may want to consider habituating fewer animals than were intended. Most, if not all great ape sites, tourism and research are kept completely separate from one another (Gombe is an exception). Regulations at most sites restrict visitation of tourists to research groups (e.g., Bwindi). In addition, the rules governing groups habituated for tourism are usually so strict that visits by anyone beyond the one hour per day allotted for observation is forbidden (see International Gorilla Conservation Program). If tourist groups provided opportunities for researchers or vice-versa, we could greatly reduce the number of animals already being exploited. Some great ape research areas (such as Bai Hokou, CAR) that have become tourism sites no longer encourage scientific research in the region. This may have the unintended, negative effect of increasing the number of research sites being established, therefore increasing the number of animals habituated. Furthermore, to reduce possible influences our presence may have on the social dynamics of certain ape groups, we should consider habituating apes only up to where they tolerate our presence, but not to the point at which we are incorporated into the social group. Ultimately, whether humans can ever be a "neutral" element in the presence of great apes is truly debatable given their keen senses, intelligence, and curiosity.

EFFECTS ON HEALTH AND WELL-BEING

Perhaps the biggest threat to habituated great apes is disease. Although it has been known for decades that humans and apes share many of the same parasites and disease pathogens (see Benirschke & Adams, 1980), impacts of zoonoses are just now being highlighted (Butynski and Kalina, 1998; Wallis & Lee, 1999; Wallis et al., 2000; Woodford, Butynski, & Karesh, 2002). Both Wallis and Lee (1999) and Butynski (2001) review the history of diseases effecting apes among different sites within Africa. In summary, there are over 19 viruses and 18 parasites that are known to infect both great apes and humans. These diseases have been responsible for between 63 and 87 ape deaths in habituated groups (both research and tourist groups) in the Virungas, Bwindi, Mahale, Tai, and Gombe (as estimated from Butynski, 2001). Butynski notes that in Gombe over the past 32 years, 42 chimpanzees have died from what are presumed to be human induced illnesses (although chimpanzees outside the research community may be worse off; Wrangham personal communication). The Mitumba community in Gombe lost 11 individuals to a respiratory illness, leaving just one adult male, and this community will probably never recover (Wallis & Lee, 1999). In Bwindi, there have been numerous infections from the skin mite Sarcoptes scabiei, in both tourist and research groups which resulted in the death of one infant, (Graczyk, Mudakikwa, Cranfield & Eilenberger, 2001). In the Virungas, both measles and respiratory infections (Hastings, Kenny, Lowenstine, and & Foster, 1998) have caused gorilla deaths, and were thought to be human introduced (cf., Harcourt, 2003).

In Bwindi, as gorillas become habituated and begin to spend more time outside the park, they increase their direct and indirect interactions with humans. For example, there have been many times where I have witnessed gorillas walking through and inspecting human fecal remains. In one case the human feces contained a nematode parasite over three inches in length. Studies have shown that the prevalence of parasites such as *Crytopsporidium* and *Giardia* are more prevalent in habituated gorilla groups living near humans along the border of the park than wild ones living deeper within the forest (Nizeyi et al., 1999).

As these illness and injuries are introduced, we are faced with the dilemma of what to do with these animals, some of which may be our research subjects. The Mountain Gorilla Veterinary Project (MGVP) provides health care to gorillas in their natural habitat and their policy is to intervene only when the problem is human induced, such as a snare injury, or when the condition is life-threatening to the individual (Morris Animal Foundation, 2002). In 1988, six habituated Virunga gorillas died of a measle-like disease. Consequently, the MGVP vaccinated 65 animals within seven habituated groups, stopping the spread of the disease (Hastings et al., 1991).

However, veterinarians are also asked at times to intervene in situations that are not human induced. For example, a Ugandan veterinarian was asked by the Ugandan Wildlife Authority to intervene in two such cases (Kalema, 1999). The first was an older silverback badly injured as a result of continued assaults by a younger male in the group. Aware that this was the "normal" process within gorilla societies, the veterinarian did not intervene, even in the face of intense pressure to do so by park staff, and in this case, visiting tourists. The second case was a tourist gorilla with a rectal prolapse that was worsening and would have been fatal. In this case she intervened, stating that she did so for the welfare of the animal, to reduce visitor distress, because of political pressure by park management, and for research purposes to find out what causes rectal prolapse (i.e., welfare of the individual took priority over remaining a neutral element in the animal's environment).

MINIMIZING IMPACTS ON HEALTH AND WELL-BEING

To avoid human induced health problems in apes, stricter guidelines should exist. Although guidelines and regulations exist for tourists when they visit apes (as listed by Sleeman, 1998, p. 129) rarely do they apply to researchers (Woodford et al., 2002). On the other hand, apes in captivity and the scientists who research them have to adhere to strict rules and regulations enforced by the United States Department of Agriculture under the Animal Welfare Act (AWA) (1985), which often includes the monitoring of disease. For example, a negative Tuberculosis test is required for anyone visiting a primate laboratory in the United States (NRC, 1996). The same disease prevention regulations should also exist in the wild, where in many places researchers, assistants, and rangers, are in close daily contact with apes.

As researchers, we can decrease the likelihood of disease infection and other human induced factors by being more vigilant and making sure we and our staff keep a safe distance from our subjects (e.g., all contact should be forbidden). Daily monitoring of everyone's health should be conducted to insure that no sick humans visit study groups. Federal and/or international regulations (e.g., United Nations) should be put in place to provide guidelines for field primatologists. IACUCs (as mandated by the AWA) strictly guide research on animals in captivity in the United States, and although they also often consider the trapping, marking and euthanasia of wild animals in the field, they rarely consider the ethics of behavioral studies not requiring capture. We should not treat behavioral studies in the wild any differently from those in captivity when it comes to the health, care, comfort, and psychological well-being of our subjects. The solution may be that IACUCs include animals under field study to a greater extent than they do now, but the difficulty will be in enforcing approved research protocols.

The problem of apes coming out of the forest after habituation where they increase their risk of contracting human diseases is a difficult one to solve. For example, in Bwindi, after three years of chasing gorillas back into the park, they still spend a large percent of their time raiding crops and interacting directly and indirectly with humans (Goldsmith, 2000). Buffer zones or other attempts need to be made to restrict contact between local people and the local wildlife to reduce health risks to each.

Finally, we need to consider our intervention in the health of wild animals. Although I see the value in attending to injured or ill animals, especially when the number of apes remaining is so small, I also see this as a controversial issue. The controversy results from the fact that veterinarians may be interfering with natural selection and may be promoting the propagation of unfit genes within an already small and fragile population. This raises an ethical dilemma. Do we or do we not intervene? Although I see the vaccination of the Virunga mountain gorillas against measles as an important means of protection, I can not help but feel there is something inherently wrong with vaccinating wild animals. Perhaps we are at a point of no return and that this is the only way to assure their survival. I am still hopeful that if apes are able to remain wild and live without the presence of humans in their environment, we may not have to continue our interventions. The degree to which we provide medical attention largely depends on where one draws the ethical line.

Conclusions

I find it interesting that we are just now, in the twenty-first century, starting to consider the ethics of what we have been doing for the past 50 years. Long-term studies on apes in the field have highlighted how special they are and have heightened people's awareness of their plight and importance. Now that we have this information and understand their special place in the world, perhaps we should start focusing on letting them live in peace, concentrating our efforts on their long-term well-being without human observation or intervention.

Some researchers are still determined to habituate unstudied "wild" ape populations for the sake of biological anthropology investigation. Theses new research endeavors should be reconsidered and investigators should go to existing sites where great apes are already habituated. Although I appreciate some of the counter-arguments, such as that without their research endeavor loggers and/or bushmeat hunters would come through and devastate the ape community, I do not want us to confuse conservation with anthropological research. In other words, if the rationale behind starting a new research site is one of conservation, instead of research endeavors and habituation, should not the effort simply be to promote national park status or other forms of protection?

In addition, how might the desire for career promotion, funding, and recognition be driving such decisions (e.g., in recent years, researchers have been able to apply to large conservation NGOs for funding, which they had not had access to before). By synonymizing the name of the researcher with the name of the site, we suggest some sort of "right of ownership" to that person, prompting scientists to find and stake their own claim. Desire for ownership and funding are two motivators, besides research and conservation, which perhaps influence the number of study sites being established.

Although it is true that research sites may become national parks due to the involvement of the investigator in such issues (Wrangham, 2001), I think this is the backward way of going about conservation efforts. For example, Wright (1992) spent much time and effort in establishing the Ranomafana National Park Project in Madagascar before setting out to conduct her field studies on lemur ecology and behavior. She started from the bottom-up, first walking the entire area and speaking with elders and others in the community, learning how the local people would be affected by the Park and what they would need. After the Park was established and the safety of the primates in the region was secure, she was then able to begin the habituation of some groups. By involving and training many Malagasy people, she also insures the long-term protection of the park and its animals.

Habituation may not be an ape's salvation. It may not be the best means of conserving them. What would a world of habituated great apes really represent? I have highlighted the costs of habituation in field primatology knowing full well, as a great ape field primatologist, the benefits that have come out of this process. The debate is in weighing these costs and benefits. At this point I wonder if some aspects of the science of primatology in the field of biological anthropology (e.g., research for the sake of understanding humans) are still viable options. Perhaps primatologists should be relegated to study primates only when it directly benefits the welfare and conservation of the study animals, rather than our interest or curiosity in learning more about them or ourselves.

Ethical considerations are crucial as the numbers of great apes in the wild continue to dwindle. As primatologists, we have come to understand through our field studies just how intelligent, curious, and sentient these individuals are. Let us now use this information and direct our efforts to help conserve them and let them live the best possible life in highly protected areas free of human disturbance. Given the dire status of some primate popu-

lations in the wild, especially those of great apes, the issue is whether knowledge for humanity's sake is a valid reason for study, or whether this has become, in some form, exploitation.

Key points to minimizing the Risks of Habituation

- When habituating primates, use methods that minimize stress. Monitor stress by using noninvasive field techniques such as fecal corticoid steroids.
- Habituate only to the point where individuals tolerate your presence, and never to the point to which you are incorporated into the social group.
- Researchers working in great ape sites not within protected national parks should take every initiative to promote a more protected environment. Those within existing National Parks, should promote better protection.
- Lifetime commitments need to be made to habituated ape populations in the form of infrastructure that will withstand the pressures of political instability.
- As primatologists we need to decrease the likelihood of disease transmission by being vigilant and making sure we and our staff keep a safe distance from our subjects, with regular testing for Tuburculosis and other contagious diseases.
- Keep the number of habituated animals to a minimum by, in some cases, combining tourist and research groups, and by minimizing the creation of new sites for research.
- Instead of habituation for conservation, create protected areas or protected status for the animals within the region, perhaps by building Trust Funds (such as those in Bwindi, Uganda) that help with protection and development of the local communities.

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Chapter 5

Biological Samples in the Modern Zoological Park: A Case Study from the Bronx Zoo

Cathi Lehn

The American Association of Zoological Parks and Aquariums was first formed in 1924. Almost 80 years later, that same organization, now known as the American Zoo and Aquarium Association (AZA) is "dedicated to the advancement of zoos and aquariums in conservation, education, science, and recreation" (Kisling, 2001). In North America, over 200 zoos to date have met the high accreditation standards of the AZA.

Maple, McManamon, and Stevens (1995) define the "good zoo" as one that emphasizes humane health care for its animals, and includes science and education prominently in their mission and practice. The commitment of AZA zoos to research is evident in the current listing of contributions to conservation and research found in the latest AZA Annual Report on Conservation and Science (Lankard, 2001). Recent surveys of the AZA zoo community have found that within the last decade the percentage of zoos and aquariums conducting research has increased and that the types of research being conducted has expanded. Not surprisingly, applied research in the behavioral sciences and reproductive physiology are the most commonly reported types of research conducted within the zoos (Finlay & Maple, 1986; Stoinski, Lukas, and Maple, 1998). A similar trend was found by Wemmer, Rodden, and Pickett (1997) for publications occurring in the journal Zoo Biology. However, in a more extensive review of publications submitted by zoos, Hutchins, Paul, and Bowdoin (1996) found that a majority of articles contributed by zoos were in veterinary science, followed by research articles in behavior and reproductive biology.

Veterinary science has had a long history in zoo research, however not always as an applied science. The prosector, or the predecessor of our present

day veterinarians and pathologists, was interested in basic research in the areas of taxonomy and anatomy and conducted his research on the zoological materials of animals. Pure, or basic, research represented the primary mode of research conducted by zoos in the nineteenth century (Wemmer & Thompson, 1995). The prosector knew the value of zoological materials, as did the universities and museums of that century, and these materials are no less important to modern research practices. The focus of this discussion, the collection and curation of biomaterials, is one manner in which zoological parks make a significant contribution to research in the basic and applied sciences.

Biomaterials, or biological samples, may be defined as any organic piece or derivative of an animal, for example, tissue, urine, feces, gametes, hair, feathers, and DNA. Biomaterials from animals housed in zoological parks provide an invaluable resource to the scientific community. Biological samples are used in many disciplines, including taxonomy and systematics, population genetics, reproduction, nutrition, pathology, endocrinology, education, toxicology and veterinary medicine.

Within the zoo setting there are many opportunities for veterinarians, pathologists, and animal managers to collect biomaterials noninvasively, or in a minimally invasive manner, from the animals housed in the collection. For example, in the event that an animal in the zoo dies, a veterinarian or pathologist has an opportunity during necropsy to collect tissue samples. Tissues may be taken and placed in formalin for further histological analysis in order to determine the cause of death of an animal and/or to collect baseline information from an endangered species (McNamara, 1999). Duplicate samples of these tissues may also be stored in an ultracold freezer for use in future studies (Benirschke, 1996; Sheldon & Dittmann, 1997). Furthermore, after necropsy, as an alternative to destroying the carcass it may be donated to an educational program or to a natural history museum (Kitchener, 1997). In addition, in the course of routine veterinary procedures, blood may be collected and that portion of the sample not used for diagnostics may be stored for future research. Opportunities to collect samples noninvasively may also be found in routine husbandry procedures at the zoo. For instance, animal keepers may collect biological samples for research, for example, feces or urine, from an animal while performing their daily routine (Ding, Zhang, & Ryder 1998; Fujita, Mitsunaga, Sugiura, & Shimizu, 2001; Graham & Brown, 1996; Brown & Loskutoff, 1998; Asa Bauman, Houston, Fischer, Reid, et al., 2001). In addition DNA may be extracted from many samples collected noninvasively throughout the zoo, for example, feathers, shed snake skin, and hair (Fetzner, 1999; Kuehn, Schwab, Schroeder, & Rottmann, 2000; Russello & Amato, 2001) In some instances in fact the collection of samples in the zoo setting is less stressful to the animals than if those same samples were to be collected from animals in the field (Hutchins, Dresser, & Wemmer, 1995). Many additional examples of the uses of biomaterials collected from zoo animals may be found in the journal *Zoo Biology*. The diversity of animals found in zoos, and the relative ease of accessibility to sample collection, make the zoological parks an attractive resource for researchers.

The following discussion outlines the biomaterial collection program at the Wildlife Conservation Society's Bronx Zoo. The Bronx Zoo's policies and protocols will serve to summarize how one AZA organization is addressing the issues involved with biological samples in the zoological park. Issues which are addressed in the biomaterial program at the Bronx Zoo include:

- · protocols for the collection of samples
- the transfer of animal records associated with requested samples
- the ownership of the animal and its biological samples
- · access to samples by the research community
- · the review process for biomaterial requests
- the responsible use of samples by the researcher
- the curation of samples after collection.

Wildlife Conservation Society/Bronx Zoo

The Wildlife Conservation Society (WCS), founded in 1895 as the New York Zoological Society, is a nonprofit conservation organization headquartered at the Bronx Zoo. The WCS is composed of two divisions, the Living Institutions and International Programs. Within the Living Institutions division are five parks located within New York City, these are the Bronx Zoo, the Prospect Park Zoo, the Queens Zoo, the Central Park Zoo, and the New York Aquarium. Also included within the Living Institutions division is St. Catherines Island Wildlife Survival Center, a breeding center located off the coast of Georgia. The International Programs division has five regional programs in addition to several cross-cutting programs worldwide. This discussion will focus solely on examples from the WCS Bronx Zoo.

A review of the biomaterials collection program at WCS in the early 1990s has been summarized by Hutchins (1988, 1990). This discussion will update the reader on that program and outline the goals for the future.

A staff position within the WCS Science Resource Center has been assigned the responsibilities of coordinating the collection of biological samples within the Society. This conservation biologist also chairs the Biomaterials Committee, a subgroup of the Animal Management Committee, composed of

veterinarians and pathologists, curators, facility directors, researchers and the registrar. This committee reviews the protocols and policies of WCS with regard to the collection, disposition, and utilization of biological samples, in addition to reviewing biomaterial requests from researchers.

Within the Living Institutions, WCS employs clinical veterinarians, pathologists, a nutritionist, and field veterinarians in addition to veterinary technicians, laboratory and hospital supervisors. The clinical veterinarians are centralized in order that regular visits are made to all WCS facilities in the city. The Wildlife Health Center (WHC) is a 23,000-square-foot medical and applied research facility located on the grounds of the Bronx Zoo. The WHC houses specialized areas for the performance of pathology exams as well as suites for surgery and medical imaging. In addition, a 750-square-foot room adjacent to the necropsy lab has been designated as the frozen biomaterials library with the capacity for 25 ultracold freezers and a computer station. Storage of formalin and paraffin blocks is maintained at three stations of 300 square feet each within the WHC. Each of the city facilities has a full time veterinary technician and its own clinical facilities on site where biological samples may be archived.

Critical to the success of any biomaterials collection program is communication with, and cooperation from, the veterinary and pathology staff. Therefore, communication practices are continually being reviewed for improvement. Once a week, a Science Resource Center staff member attends the morning WHC meetings in order to meet with the veterinary staff, to learn which animals are currently scheduled for procedures in the WHC or in quarantine, and to inform the staff of approved biomaterial requests on file. All approved research requests are compiled by the Science Resource Center in easily accessible notebooks for review by the veterinary staff before a procedure begins.

Collection of Samples

Every animal that dies in the WCS collection is submitted to the WHC for a routine necropsy performed by a pathologist. Only under certain circumstances is a submitted carcass not evaluated, for example, colony rodents and some species of bats. During necropsy, pathologists take samples from every organ and place these in 10% formalin. The samples are then placed in paraffin blocks and a histological analysis is conducted. Tissues are also taken from the major organs, including liver, kidney, heart, skeletal, spleen, and brain, from animals indicated as a priority for future research needs, as determined by necropsy, or as requested from approved researchers (see below). These samples are then stored in an ultracold freezer. Routine veterinary procedures may also require that whole blood be collected from animals in the collection and sent to a diagnostic lab; the unused portion of this sample is then frozen for future use.

Biomaterials may also be collected by the animal management staff in the completion of their daily routine. Feces, urine, and feathers may be easily collected by the keeper staff. For example, gelada baboon (*Theropithecus* gelada) and gorilla (*Gorilla gorilla gorilla*) urine samples are collected routinely from the females for pregnancy testing. In addition, elephant handlers have trained their charges to allow blood to be drawn for future diagnostics.

Transfer of Records to Accompany Samples

The transfer of biological samples to a repository or to a researcher is also accompanied by the transfer of specimen records. All historical and behavioral information on an animal is maintained by the zoo registrar and is compiled from the daily records kept by animal keepers and veterinary staff, from records following an animal from another institution, and from the studbook keeper. It is the responsibility of the SRC and the WHC to ensure that all requested information is transferred, including a voucher specimen. A voucher specimen is also ideally transferred with each biological sample and is validation for the taxonomic identity assigned to the animal (Lee, Bell, & Sutton, 1982). Traditionally, a voucher specimen is thought of as a skin, skeleton, or skull deposited in a curated collection, such as a natural history museum. A voucher specimen is also needed, although not available in the traditional sense, from samples collected from the living animal, for example, blood, feathers. An alternative to a skin or skull is a digital photo image of the animal, or evoucher (Monk & Baker, 2001). The future of the WCS biomaterials program will investigate the feasibility of documenting each taxon in the collection with a digital photo to accompany the biological sample. Critical to the development of evouchers however is the determination of and the proper documentation of the diagnostic characters needed for proper identification of each taxon.

Ownership

Before a biological sample may be collected for an approved research request, it must be verified that the animal is owned by WCS or that approval has been obtained from the owner of the animal. For example, another AZA zoo may loan an animal to WCS for the purpose of establishing a breeding pair, this is called a breeding loan (Block & Perkins, 1996). In these cases, although the owner of the animal does not physically hold the animal, they

still retain responsibility for decisions regarding its well-being and disposition. In addition, an animal may be owned by the country of provenance of the founders in the captive population. For instance, golden lion tamarins (*Leontopithecus rosalia*) held by AZA institutions are owned by the Brazilian government and all transactions must be agreed upon by that government.

Researcher Request Form

All researchers requesting biological samples are required to complete a WCS biomaterials request form. The form is reviewed by the animal department holding the animal, the Biomaterials Committee, and final approval is given by the Animal Management Committee. Requests must be submitted by all researchers including WCS staff and their collaborators, as well as outside researchers including those associated with AZA conservation programs.

In order for each committee to adequately review a proposal the researcher must provide information outlining the research to be completed, their qualifications to complete the work, and the anticipated outcome of the research. Also, in order for the proper materials to be collected, the researcher is requested to specify what samples should be collected, how they are to be stored and shipped, and what information from the animal's records should accompany the sample. To satisfy legal requirements, the researcher must provide evidence that, if required, all permits are in order. For animal welfare concerns to be addressed IACUC approval is requested from the researcher's institution, if needed (see below). Samples are provided only for the research specified in the proposal therefore after completion of the intended use of the sample it is to be destroyed or placed in a curated collection. A timeline for completion of the study and for the collection of samples is also requested. Lastly, an account number for shipping by express carrier is requested.

Assistance in the genetic and demographic management of captive animal populations and in the establishment of research and field conservation priorities is provided by the Species Survival Plans (SSPs) and the Taxon Advisory Groups (TAGs) (Hutchins & Wiese, 1991). In order that taxon specific research within the AZA may be documented, the WCS request form asks that the SSP Coordinator be informed of the research being conducted and the materials being requested from WCS. This step in the process may also help the researcher locate additional samples from other AZA institutions.

Material Transfer Agreement

In addition to the request form, researchers are asked to submit a signed material transfer agreement. In contrast to the previous WCS agreement

(Hutchins, 1990), the investigator's institution is not asked to sign a material transfer agreement. The transfer agreement is a legal document outlining the responsibilities of the researcher. Listed among the researcher's responsibilities are:

- · no commercial use or third party transfer of material
- · responsible use of and disposal of material after use
- indemnity for WCS employees and trustees against all legal claims resulting from the use of the material
- · to secure all necessary permits
- to acknowledge WCS in publications resulting from the use of the sample
- to pay shipping and handling charges associated with the transfer of material.

The revised transfer agreement is currently under review for legal consideration. When the revisions are complete, the request form and transfer agreement will both be available on the WCS website.

Review Process

The WCS research mission recognizes the importance of both basic and applied research and encourages both types of research at its facilities. Highest priority however is given to research proposals that are likely to have a demonstrable impact on captive and wild animal management and breeding or other aspects of conservation biology. In addition, WCS does not engage in or support research that compromises the health or well-being of its animal collection (Koontz, 1996).

As Hutchins, Dresser, and Wermer (1995) states the best case scenario for research utilizing zoo animals is that the suffering to the animal is negligible, the research potential of the project is high, and the benefit from the research is certain. However this is usually not the case for each proposal and therefore each one must be critically reviewed. The WCS Research Manual (Koontz, 1996) outlines some of the criteria used when evaluating a proposal and include:

- Does the project have important implications for captive management or conservation of the species?
- Is the species selected classified as a WCS priority for conservation research?

- Are the proposed methods scientifically valid?
- Is the project feasible?
- Does the investigator have the necessary experience?
- Does the cost of the project outweigh the benefits?
- Does the project overlap with other research currently being conducted and if so, is there a possibility of collaboration?
- Does the project conform to WCS rules and regulations concerning research?

If there are any questions or concerns from the committee, the researcher is contacted and given the opportunity to modify the proposal or explain the details more fully.

The scenarios above refer to the noninvasive and opportunistic collection of biological samples, however, in the case of an invasive or potentially controversial procedure, a separate review process has been established. The Animal Welfare Act (AWA) requires that facilities which receive federal funds for research have an Institutional Animal Care and Use Committee (IACUC). This committee at WCS is composed of senior animal management staff including a veterinarian and an outside delegate. The IACUC is charged with the responsibility of reviewing research protocols that propose invasive research not covered under routine veterinary or husbandry procedures The IACUC's function is to assure that the research meets all requirements set by the AWA for appropriate care and use of animals (Kohn, 1996; Kohn & Monfort, 1997). A thorough discussion of animal rights and welfare concerns in zoo animal research may be found in the literature (Jamieson, Geist, Rowan, & Maple, 1992; Hutchins, Dresser, and Wemmer, 1995; Burghardt, Bielitzki, Boyce, & Schaeffer, 1996; Lindburgh, 1999).

Proper Curation of Collected Samples

Once biological samples have been collected by the veterinary or animal staff in the zoological park it is critical that they are properly curated for the long term. Curation includes the appropriate storage of samples and their associated data, the retrieval of samples and data in an efficient manner, and the employment of qualified personnel for sample acquisition, maintenance, and disposition. In order to ensure proper curation of samples collected at the Bronx Zoo and to facilitate the transfer of samples to the research community a formal partnership has been established with the American Museum of Natural History (AMNH) vertebrate divisions and frozen tissue collection. Vertebrate departmental curators within the AMNH have reviewed WCS animal inventory lists and have indicated taxa for which specimens are desired for their collections. In the event that an animal on this priority list dies, every effort will be made for the completion of a cosmetic necropsy in order that specimens may be donated to AMNH. In the case of extremely rare animals, and especially large mammals, within the zoo, it is advised that AMNH and WCS staff meet to discuss the specifics of the disposition protocol in order that a more efficient necropsy may be performed at the time of death and to ensure that all parties receive the appropriate notification and materials.

The AMNH Ambrose Monell Tissue Collection is housed in a 2,000square-foot laboratory in the basement of the Museum and holds a total of up to twelve liquid nitrogen cryovats. The staff at the Tissue Collection consists of a curator, associate curator, lab manager, and several laboratory technicians. Sample vials are maintained above a liquid nitrogen layer in the vats and kept at temperatures of -155°C to prevent the tissue from degrading. A computer database tracks each bar-coded vial, noting where the specimen was collected, by whom, and how many times it has been thawed and refrozen. Biological safety cabinets have also been installed in this facility to ensure the safe handling of all samples. It is envisaged for the future of this partnership that tissue samples from major organs will be regularly sent to the AMNH tissue collection from WCS. Researchers requesting standard tissue samples from WCS animals will then be referred to the AMNH curators. For some animals, especially highly endangered species or the taxonomically unique, duplicate tissue samples will be maintained at WCS in ultracold freezers in the frozen biomaterials library. Currently being drafted is a legal material transfer agreement with the AMNH collections. This document as in the case of the agreement with the individual researcher, outlines the responsibilities of both parties in the transfer of samples.

Summary and Conclusion

The recently revised WCS acquisition and disposition policy includes an extensive section dedicated solely to the disposition of biomaterials from living and dead animals in the WCS animal collections. This section outlines the responsibilities of the Biomaterials Committee and the process by which research requests are reviewed and approved. The policy also summarizes many of the points discussed above, including:

- priority is given to research that is of direct benefit to wild animals
- all mandatory restrictions upon the disposition of biomaterials from living or dead animals must be observed

- a sample taken from a living animal in the collection must be obtainable without causing harm or undue stress to the animal
- approval from the Institutional Animal Care and Use Committee must be sought for any invasive procedures that are not part of routine husbandry or veterinary procedures
- maximum scientific and educational utilization shall be made of the remains of animals that die in WCS's collections after the remains have been examined and assessed by a WCS Veterinary Pathologist
- SSP and TAG necropsy protocols are to be accommodated insofar as possible
- after the needs of WCS are met and all approved requests have been filled, priority should be given to placing a dead specimen in a curated museum collection or biological repository.

As it becomes increasingly difficult to obtain samples from animals in the wild, the animals held in the Bronx Zoo and other AZA institutions may provide the scientific community with resources which otherwise might be unobtainable. The biomaterials program at the Bronx Zoo is designed to uphold the AZA directives of conservation and research, both pure and applied, while still recognizing its responsibility to identify quality research but never compromising the care of the animals held in its collection.

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Chapter 6

Commentary: Ethical Issues Surrounding the Use of Nonhuman Primates in Biomedical Research

Jay Kaplan

Introduction

The following paragraphs focus on some of the ethical issues raised by studies of nonhuman primates. These issues will be considered from a biomedical perspective. It should be noted that biomedical research differs fundamentally from other kinds of research in both rationale and conduct. Hence, biomedical investigators generally use monkeys and apes to model physiological or pathological processes relevant to human health. As a result, benefits to animal health or well-being are usually only incidental. Furthermore, this research is often invasive, involving surgical procedures and sometimes requiring postmortem evaluation. Because monkeys and apes closely resemble humans in behavior, emotional expression, and appearance, such research often provokes intense moral and ethical objections. By and large, however, government granting agencies and the public believe that the human benefits derived from biomedical research outweigh the costs to the animals. In any event, this commentary will not consider the propriety of using primates in biomedical research; copious discussion of the issue can be found elsewhere and is briefly reviewed by Nash (this volume). Instead, the intention is to discuss two major ethical issues common to all primate research, whether done in the field or laboratory: 1) does our research activity threaten wild populations? and 2) are we treating the animals humanely? Where appropriate, case studies are used to examine these issues.

The Regulation of Primate Research: Laboratory and Field

Notably, federal and private organizations have addressed many of the ethical concerns relating to the humane use and care of research primates. For example, all aspects (acquisition, transportation, housing, handling) of primate research conducted in the United States are regulated by the U.S. Department of Agriculture (USDA) as mandated by the Animal Welfare Act and described in Title 9 of the Code of Federal Regulations (Animals and Animal Products) (Animal Welfare Act, 1985). This act covers all research facilities as well as zoos, carnivals, circuses, and roadside attractions. Institutions deriving support from the Public Health Service (for example, the National Institutes of Health [NIH]) are subject to additional requirements, consistent with the recommendations of the National Research Council (NRC) as published in the Guide for the care and use of laboratory animals (NRC, 1996). Finally, many research institutions subscribe to a voluntary accreditation organization, the American Association for the Accreditation of Laboratory Animal Care (AAALAC). The USDA (unannounced) and AAALAC (announced) routinely inspect research facilities, although the Public Health Service does not.

The situation with field studies is less clear. As most investigators are now aware, the USDA mandates that every research facility establish an institutional animal care and use committee (IACUC) to review all animal research and inspect all relevant facilities. However, animals living in the wild are specifically exempted from inspection. Furthermore, the regulations exempt from review any field studies that are not invasive and do no harm to the subject animals. Federal regulations imply, but do not categorically state, that protocols involving invasive procedures of wild-living animals living in their natural habitats are subject to review.

Together, logistical difficulties and regulatory uncertainties result in a relative lack of oversight in field studies in comparison to those done in research facilities subjected to direct USDA, IACUC, and AAALAC inspection and review. It is unclear whether this disparity has lead to ethical abuses. Nash (this volume) has performed a useful service for physical anthropologists by quantifying the degree to which field and laboratory studies using primates and published in the *American Journal of Physical Anthropology* (AJPA) acknowledge ethical concerns or regulatory approval. Her data suggest that such acknowledgement is more common after the development of federal regulations mandated by passage of the 1985 version of the Animal Welfare Act. However, recognition of ethical concerns occurs in relatively few wild studies. More surprisingly, no wild studies and less than 5% of captive studies mention protocol review regardless of whether they were published before or after the USDA and Public Health Service required such review. As Nash points out, it is not possible to determine whether the latter

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studies were conducted without IACUC approval (and thus contrary to USDA regulations) or whether such statements are missing simply because the *Journal* does not require them. Nash is clearly correct in suggesting that the AJPA join other major journals in accepting for publications only those studies stating that they were conducted in accordance with federal regulations and with IACUC approval.

Impact of Research on Primates in their Natural Habitats

A Case Study: the Rhesus Monkey Debacle

It is generally conceded that habitat destruction and bush-meat hunting pose the greatest threats to wild primate populations. The capture and transport of wild monkeys for biomedical and other research can also have a devastating impact, particularly in combination with habitat destruction. For example, the United States imported upwards of 25,000 rhesus monkeys (Macaca mulatta) per year from India in the years leading up to the 1978 export ban imposed by that country's government (Gray-Schofield & Chandler, 1983; Southwick & Lindberg, 1986). This number probably underestimates considerably the impact on local populations because primitive capture and handling techniques often resulted in large losses prior to and during the export process (Southwick & Lindberg, 1986). There seems little doubt that this degree of exploitation contributed to a rapid decline in the Indian rhesus population (Southwick & Lindberg, 1986). The importation of monkeys into the United States for research has dropped dramatically since the Indian export ban. Not only have rhesus monkeys become largely unavailable, but also the USDA and the Centers for Disease Control have restricted the use and importation of monkeys. Large price increases for all species have accompanied these changes. As a result, the United States currently imports approximately 12,500 monkeys per year for research, with the majority comprised of cynomolgus macaques (M. fascicularis) from southeast Asia (AESOP-PROJECT, 2001; Animal and Plant Health Inspection Service, 2000).

The havoc wrought on Indian rhesus monkeys by the U.S. biomedical research community was both morally indefensible and scientifically shortsighted. During the time when large numbers of rhesus monkeys were being imported to the United States, few scientists argued the need for conservation or stewardship of this resource. The monkeys were treated as a commodity, and a relatively cheap one at that. The failure to respect and conserve this resource has come back to haunt the biomedical research community, as rhesus monkeys are almost impossible to obtain from their countries of origin and domestic breeding colonies cannot nearly meet the current research demand (Institute for Laboratory Animal Research, 2002; National Center for Research Resources, 2002). This means that research originally based on the rhesus monkey as a model cannot be easily extended or duplicated. The scope of this problem can perhaps be understood by noting that between 1980 and 2002, more than 17,000 biomedical studies were published based on rhesus monkeys. This is more than twice the number reported for any other Old World monkey and more than 10 times the number of studies using the most common New World monkeys. The AIDS epidemic has exacerbated the current rhesus monkey shortage, as many researchers believe that Indian origin rhesus monkeys (including those from Nepal and Bangladesh) provide the most useful model for AIDS-related research (Institute for Laboratory Animal Research, 2002; National Center for Research Resources, 2002).

A Case Study: Crabeating Macaques in Indonesia

Could it have turned out otherwise with respect to rhesus monkeys? The answer is probably yes, as evidenced by the success of the Indonesia-U.S. Cooperative Program in Primate Medicine and Biology. This program had its origins in a series of collaborative interactions taking place beginning in 1970 between individuals from the Washington Regional Primate Research Center (WRPRC) and the Republic of Indonesia. In 1985, and with the help of contacts established by the WRPRC, this author was privileged to have an audience with His Excellency, Dr. Emil Salim, Minister of State for Population and the Environment. During this visit, Minister Salim (who received his degree in economics from the University of California, Berkeley) emphasized that he viewed the export of monkeys for biomedical research as representing an inherently unfair transfer of resources because nothing of lasting value was returned to the Indonesia. He used the term "technological imperialist" to describe individuals (like myself) who engaged in such activities. Minister Salim emphasized that the end users of monkeys have the moral obligation to cooperate with countries of origin, like Indonesia, to insure that biomedical and economic benefits go in both directions. In particular, he wanted Indonesians to be trained to conduct biomedical research beneficial to Indonesia. He termed this activity "software development." Finally, Minister Salim expressed dissatisfaction with complete reliance on wild-caught monkeys as a long-term strategy for satisfying research needs.

Partly in response to these statements, a group consisting of representatives of the Washington and Oregon Regional Primate Research Centers (now National Primate Research Centers) and the Bowman Gray School of Medicine (now Wake Forest University School of Medicine) met in late 1985 and decided to form a "Primate Centers Consortium." The objectives were to sponsor the education of Indonesian postdoctoral fellows in primate biology

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and medicine, to initiate a natural habitat breeding program in Indonesia, and to foster research collaborations between scientists in Indonesia and the United States. A joint U.S.-Indonesian committee (now termed the Indonesian-American Steering Committee, IASC) was established to facilitate these activities.

In late 1986, Indonesian and U.S. representatives signed a memorandum of understanding describing the foregoing objectives and identifying the U.S. Primate Centers Consortium and the Institut Pertanian Bogor (IPB, also referred to as Bogor University) as partners in the plan. The collaborative program continues to this day and has resulted in a number of specific accomplishments. First among these was the establishment of the Tinjil Island breeding facility, a 600-hectare island approximately 8 km off the southern coast of Java. In June of 1987, the Washington Regional Primate Research Center (WRPRC) obtained Federal funding to support the development and maintenance of a simian immunodeficiency- and retrovirus-free colony of cynomolgus monkeys at Tinjil Island. This natural habitat breeding facility, which is a model for large scale breeding in protected reserves, is now capable of supplying several hundred virus free monkeys per year for research in the United States (Kyes, 1993).

Beginning in 1988, U.S. scientists, particularly from WRPRC and Bowman Gray, began teaching a series of short courses in primate biology and medicine to Indonesian Students at IPB. This program has expanded considerably, largely through initiatives put forth by the University of Washington. Coincident with the start of the short course program in Indonesia, veterinarians and primatology students from IPB began receiving postgraduate training in the University of Washington. As a result of these efforts, four Indonesian students have received Ph.D.s and nine others have obtained nondegree advanced training in research. The previous and current trainees provide the "software" cadre identified by Minister Salem in 1985 as a major objective of the cooperative program between the Republic of Indonesia and the University and the University and the Republic of Indonesia and the University States.

As the veterinarians trained in primate biology returned to Indonesia, IPB was able to establish a primatology program to train indigenous students and professionals in all areas of primate management and care. Simultaneously, and largely with the support of the WRPRC and Bowman Gray School of Medicine, IPB constructed breeding and quarantine facilities, and the laboratories necessary to conduct primate research. Institut Pertanian Bogor also created elaborate holding and staging facilities on the mainland opposite Tinjil Island, in southern Java. Finally, in late 1991, the IPB Primate Research Center—Pusat Studi Satwa Primata—was formally established with Dr. Dondin Sajuthi as Director. Dr. Sajuthi had been trained in the United States, receiving his Ph.D. in Molecular and Cellular Pathobiology from the Bowman Gray School of Medicine. Another recent trainee—Yasmina Paramastri—is eligible

for certification by the American College of Laboratory Animal Medicine (ACLAM). Certification by ACLAM, in turn, makes possible continued NIH approval of the primate center facilities at IPB.

The Primate Research Center at Bogor has become a national resource for Indonesia, accumulating a large number of trained personnel, research laboratories and primate colonies. As part of its outreach program, the Center also supplies monkeys for biomedical research to collaborating academic institutions in the United States. This approach allows these universities in the United States to bypass commercial dealers in obtaining animals for research. More importantly, this arrangement provides considerable income to IPB, spurring the growth of its research and conservation programs. Though this activity does not represent the only effort to develop primate biology and medicine in Indonesia, the success and visibility of the IPB training and breeding initiative has helped encourage the sustainable research use of monkeys (particularly *M. fascicularis* and *M. nemestrina*) and the conservation of their habitats. It should be recognized that the relative success of this program relates in part to the high priority that the biomedical research community and funding agencies place on macaque species. However, insofar as the program increases public awareness of the need for habitat and wildlife conservation generally, its benefits may extend to species that are not used in research.

Could such an approach (i.e., an international arrangement between governments and academic institutions) be applied elsewhere to mitigate the effects of research or to encourage conservation and sustainable use of primate resources? If so, where? Recently, this author had the opportunity to visit Zambia, where several subspecies of baboon (*Papio hamadryas*) exist in relatively large numbers. Conversations with government officials, park rangers, and local inhabitants suggest that baboons are considered vermin in most locations in Zambia. In contrast, the baboon is a biomedically useful species, with almost 600 imported to the United States in 1999 alone (Howard & Jones, 2000). If a collaboration analogous to that created in Indonesia were established in Zambia, it is possible that baboons would be viewed, not as vermin, but as a renewable resource capable of generating funds for research development and conservation

Field Studies: Problems with Habituation, Disease, and Interactions with Locals

Compared to the widespread effects of habitat destruction, hunting, and trapping for export, it could be argued that most primate field studies affect relatively few animals and locations. Such studies can, nonetheless, cause problems. For example, observational studies generally require some degree of habituation so that the investigator can accurately describe the number, age, sex, and behavior of the species under study. Goldsmith (this volume)

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reviews the issue of habituation and points out that it can cause both shortand long-term problems to the subject populations. In the short run, attempts at habituation can stress animals, resulting in adverse physiological and behavioral responses. Observers themselves are at risk during such situations, as animals may lash out in self-defense and frustration. In the long run, habituated animals may cause the population as a whole to reduce its fear of humans and thus become more vulnerable to poachers and diseases of human contact. Of course, disease transmission can go in two directions, as clearly demonstrated by yellow fever, malaria, the simian herpes virus ("Herpes B Virus"), and—albeit more controversially—immunodeficiency viruses. Provisioning, which is frequently used as a habituation strategy, is also problematic as it can alter patterns of social interaction and habitat usage. Finally, humans generally supplant natural predators, thus altering the selective pressure on primate populations.

The foregoing problems are magnified for the great apes, which generally live in small, fragmented populations and in countries characterized historically by considerable political instability. According to Goldsmith, the adverse impact of habituation is often under appreciated and not explicitly addressed in primate field studies. Many observers seem to assume that, following habituation, they become a "neutral" part of the environment. Goldsmith and others would suggest that the observer is never really considered neutral by the animals. My own experience indicates that even wellhabituated monkeys frequently attempt to manipulate observers in the context of ongoing social interactions. Sometimes these episodes end in injury to the observer, other times animals will obtain access to social or food resources (e.g., the mother's nipple) they otherwise would not have.

Field studies not only can interfere with the lives of the subject animals, but may also affect local human populations. Wolfe (this volume) reviews this issue with respect to free-living populations in both this country (i.e., feral rhesus monkeys) and in countries of origin. She relates a number of instances where primatologists have become embroiled in local political squabbles relating to the study or removal of animals. Her review suggests that primatologists generally are best served by a low political profile, reducing their likelihood of becoming the focus of controversy. Wolfe also reminds us that personal interactions with local individuals can create a variety of problems, some of which put observers at risk of bodily harm. Although Diane Fossey probably represents the best known and substantiated instance of tragedy in the field, one hears stories of other deaths and many reports of rapes and near rapes among primatologists working in field situations.

Clearly, there are numerous ethical issues associated with fieldwork. Generally, however, such investigations involve few primatologists and do not have a major impact on study populations or human inhabitants. Studies with great apes may provide a partial exception to this statement. Nonetheless, the number of animals (and researchers) affected by field studies pales in comparison to the number of primates used in captivity, particularly in the United States. This essay now turns to the ethical issues raised by latter situation.

Primates in Captivity

Research Facilities: Regulatory Oversight and the Numbers of Primates Used

The USDA mandates that all primates used in research, without exception, be assigned to protocols that are reviewed and approved by each institution's animal care and use committee. The Animal Welfare Act and the USDA require that the IACUCs have community and nonscientific representation and that they act to reduce or replace animal use, and insure that pain and distress are minimized. Furthermore, when animals must be euthanized for health or experimental reasons, approved and humane procedures must be used. The USDA conducts unannounced inspections, generally done annually, to guarantee enforcement of all of its regulations relating to the care and use of animals in research.

The most recent USDA Animal Welfare Report (APHIS 41-35-071) indicates that approximately 57,000 nonhuman primates (all species) were used in research during fiscal year 2000 (APHIS, 2000). Although the USDA reports annually on the total number of animals used in research, statistics relating to specifically to terminal experimentation are harder to find. These numbers are not reported separately in any easily available, official publication. One way to estimate the extent of terminal experimentation is to compare the number of animals in approved protocols from year to year with the number of new animals imported. The number of animals imported annually into the United States has averaged approximately 12,000 (mostly M. fascicularis) over the past decade (Howard & Jones, 2000). Similarly, the number of animals assigned to research protocols has been relatively constant over the past few years, averaging 55,000 tp 60,000. Comparing these two numbers suggests that approximately 12,000 primates are used in terminal experiments or otherwise die in captivity each year. This number probably reflects an underestimate, as it does not account for the several thousand primates derived annually from domestic breeding colonies.

Pain, Distress, and Psychological Well-Being in the Biomedical Setting

Biomedical research is frequently invasive, sometimes involving pain and distress and terminal manipulations. As part of the IACUC protocol review

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process, all investigations using nonhuman primates must describe the degree of pain and distress involved and the methods used for relief. These statistics are reported to the USDA. In fiscal year 2000, approximately 31,000 primates were used in protocols involving no pain or distress, and therefore requiring no drugs for relief (APHIS, 2000). An additional 25,000 were used in protocols that involved more than the momentary pain that might result from an injection or other minor procedure; drugs for relief were used in these protocols. The remaining 900 primates were used in protocols involving more than momentary pain, but were not given drugs for relief. By USDA regulation, these latter protocols must contain adequate scientific justification for the proposed manipulation. The IACUCs in turn must review and approve the justification before the proposed research can be conducted. In summary, the majority of research using nonhuman primates involves no pain or distress. Where pain and distress occur, adequate relief is provided in more than 95% of instances. The remainder is exempted for scientific reasons.

The conduct of research involving nonhuman primates is governed by the policies and decisions of the USDA, the NIH, accrediting bodies (AAALAC), and each institution's IACUC. Research environments, however, usually differ markedly from the native environments of most nonhuman primates. This dissonance creates the possibility for psychological distress. In recognition of this potential problem, Congress amended the Animal Welfare Act in 1985. This amendment instructed the Secretary of Agriculture to promulgate regulations ensuring that research facilities provide "a physical environment adequate to promote the psychological well-being of primates." The USDA responded with an extensive set of regulations. These regulations require, in part, that each research facility have in place an environmental enrichment plan to promote the psychological well-being of any primates used in research.

Not surprisingly, considerable debate surrounds the interpretation of the phrase "psychological well being" and the USDA's regulations relating to this phrase. In an attempt to clarify the issue, the National Research Council convened an expert panel (Committee on Well-Being of Nonhuman Primates) and commissioned a report designed to provide standards that could be followed by research facilities to assure compliance with this aspect of the Animal Welfare Act. The report, *The Psychological Well-Being of Primates,* was published in 1998 (NRC, 1998). The USDA has said that its final policy regarding interpretation of the psychological well-being regulations will "complement the National Research Council's 1998 publication" (APHIS 2000). Unfortunately, this policy has not yet been released, leading to continued uncertainty in the research community as well as among USDA inspectors. Nonetheless, although there has been some confusion over the precise interpretation of the regulations, the USDA has insisted that every research

facility prepare and implement a detailed plan in support of primate psychological well-being. As with other USDA regulations, compliance is enforced through unannounced inspections and the threat of research suspension for the entire institution.

Primate Research in Zoological Parks and Related Venues

Habitat destruction and hunting have markedly depleted natural populations of nonhuman primates making it difficult or impossible to conduct reearch in the wild. Cathi Lehn (this volume) suggests that Zoological Parks provide significant opportunities to primate investigators in relation to basic and applied research, as well as species conservation. Such research, however, cannot be undertaken lightly. Her article identifies potential problems associated with obtaining biological samples, data, or specimens from zoos. Among these are issues with animal welfare (including any pain or distress associated with in vivo sampling), research access, and ownership of sampled material. Zoos, like research facilities, are subject to the USDA regulations associated with the Animal Welfare Act. Furthermore, international agreements such as the Convention on Biological Diversity (1992) can restrict access to and place limits on ownership of some biological materials held or collected in zoos. Another potential problem is that many zoos have restricted staff time and expertise and therefore cannot offer meaningful research support to investigators. Finally, even after samples are obtained, there are potential controversies relating to ownership, preservation, and utilization that must be resolved.

Lehn argues that research can be conducted successfully in a zoo setting despite the foregoing challenges. A case study from the Wildlife Conservation Society and Bronx Zoo illustrates a comprehensive approach to sample collection and research as undertaken by a well-staffed and equipped institution. What about those zoos and related institutions that have limited research expertise or resources? Lehn suggests that special Scientific Advisory Groups be established within the American Zoo and Aquarium Association to aid such facilities in the development of research policies and activities. Although Lehn specifically focuses her discussion on zoos, her comments could be extended to other contexts, such as wildlife refuges and commercial exhibits.

Concluding Comment

This essay considered whether research primates are treated humanely and whether primate research threatens wild populations. Regulatory (USDA, NIH) and accrediting (AAALAC) entities insure, with a reasonable amount of certainty, that primate research in the U.S. is conducted humanely. The situ-

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ation regarding wild primates in their countries of origin is less clear. In the absence of universal regulations and inspection, there appears to be almost no way to determine whether humane practices are followed in research conducted in the wild. One modest way to begin addressing this problem would be for all journals to require from their contributors a statement that field research was done in compliance with applicable USDA and NIH regulations and with IACUC approval.

Despite the lack of regulation and inspection, inhumane research treatment is probably not a significant problem for wild primates. The threat posed by research relates, instead, to the requirement for relatively large numbers of individuals to stock breeding colonies or to be used directly in experiments. Although the species in demand are usually plentiful (from the genera Macaca, Papio, Cercopithecus, Callithrix, Saguinus, Saimiri), the experience with rhesus monkeys demonstrates amply that no species is immune to a trapping-potentiated decline. This is particularly true given the ongoing destruction of primate habitats due to agricultural and industrial expansion in many developing countries. One potential way to reduce pressure on natural populations is to require that all primates destined for research be purpose bred and not taken from the wild. This solution is not without problems, however, in that breeding colonies must be stocked and genetically enriched from the wild. Further, it is possible to argue that trapping at a sustainable level from the wild can provide a financial incentive to maintain primate habitats, particularly in areas that are only marginally valuable for agricultural or industrial exploitation. The removal of this incentive could further hasten the destruction of such habitats.

What then should be the charge to primate researchers? We should continue to do what most of us are already doing. That is, we can work against habitat destruction, the bush meat trade, and the pet business. Just as important, we can work for the continued humane treatment of primates in research and for sustainable means of obtaining primates for future research. Beyond this, we can hope that national governments will more actively support wildlife and habitat conservation.

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Chapter 7

Ethical Issues in the Molding and Casting of Fossil Specimens

Janet M. Monge and Alan E. Mann

Introduction

The use of casts of fossil bones and teeth has a long history in paleoanthropology. Indeed, it is difficult to imagine human evolutionary studies as a comparative science without these replicas. Yet, little attention has been directed to the molding and casting techniques that produce these models or to the consequences to the original fossils that result from the molding process. In this chapter, we will address these issues; they raise broad ethical questions as well as concerns about future strategic planning. Two comparatively recent developments have led to the need to explore these matters. The last several decades have witnessed a dramatic expansion of the number of professional scholars involved in the study of human evolution (Johnston & Mann, 1997: p. 1078). This has resulted in an unprecedented increase in the number of researchers examining original fossil specimens. A related trend has been the heightened need for casts of fossil bones for teaching and comparative research. Both of these developments have serious implications for the original fossils as well as for the future of molding and casting projects.

Molding and Casting in Paleoanthropology

Although casts of fossil hominids¹ were routinely fabricated in the nineteenth Century on specimens such as those from the Neander Valley and Trinil, little is known about the molding and casting techniques employed to make these replicas. Surviving casts from this period, for example, of the Neandertal calotte, are made from relatively soft plaster ("plaster of Paris") that preserved little detail beyond general features of shape and size. One advantage of plaster, then as now, is that it is dimensionally stable, a quality not always present on modern casting resins, though they reproduce far greater levels of surface detail. Presumably, these early casts were made using much the same methods that were utilized by the celebrated mold maker at the British Museum of Natural History, F. O. Barlow (Grigson 1988).

Barlow worked through the early part of the twentieth-century, retiring just after World War II, when he sold his sizable collection of molds to the Wenner-Gren Foundation. These have subsequently been given to the Casting Program of the University of Pennsylvania Museum which curates them for both their scientific and historic value.²

Barlow's molding techniques, also employed by most other mold makers of the time, were elaborate, complicated, and time consuming. Molds were made using keyed wedges of plaster of paris that were built piece by piece around a fossil. Plaster was poured directly onto the highly waxed surface of the fossil (waxed to prevent the wet plaster from adhering to the bone). The sides of each plaster wedge were contoured and notched to precisely and tightly fit with adjoining wedges. Once completed, each wedge was waxed to insure that the plaster pieces remained separate (Mann & Monge, 1987; Goodwin & Chaney, 1995). Large molds, of the La Chapelle-aux-Saints skull illustrated in Figure 7.1, for example, might be composed of hundreds of these wedges, each reproducing a small section of the surface of the bone. Considering the materials employed, casts made from these molds often captured a surprising amount of detail.

In the 1930s, flexible materials, like natural latex rubber, replaced plaster as the molding material. Latex proved to be a practical molding medium in some respects: it was relatively easy to use and produced molds with greater amounts of detail than earlier media. However, it often had serious shrinkage problems that resulted in distorted casts when dimensional changes were more marked in one direction than another. Casts continued to be made from plaster, but with the use of finer grained dental impression plasters, there was an improvement in the amount of detail present on the casts. Although latex continues to be available today, it has a distinct disadvantage when employed with modern casting resins. Because these materials will bond to the latex mold, heavy applications of a releasing agent are required for successful unmolding.

Room temperature vulcanization (RTV) silicone rubbers became the molding materials of choice in the late 1950s. These had been developed for the tool and die industry and because they possess excellent flow characteristics, have the capability of capturing extremely fine detail. At about the same time, the use of rigid plastic resins such as polyester and epoxy became



FIGURE 7.1 Original Plaster-of-Paris mold of the La Chapelle-aux-Saints Neandertal skull, made by F. O. Barlow in the early part of the 20th Century. In this photograph, the mold has been taken apart to illustrate the number of small wedges that compose the mold. The inset illustrates two small wedges that make up a part of the palate. Heavy layers of wax separator were applied to allow the sections to separate from each other when the bone or a cast was unmolded.

common casting materials. The combination of these modern molding and casting media provide the basis for the fabrication of highly accurate and stable replicas that can reproduce even microstructural details. The quality of the casts produced by these materials, however, is not without serious problems associated with their use. Because of the flow characteristics, which produce molds of such high resolution, RTV silicones will penetrate surface foramina on a bone. When the mold is peeled off the fossil, many of these will break off and remain in the holes, thereby permanently modifying the surface anatomy of the bone. These materials also leave various chemical residues on the fossil, some of which will penetrate into the bone. The casting materials also have their problems. Polyester resins, the overwhelming choice for most fossil casts, cure by the evaporation of a solvent; unless a tempering agent, like fiberglass or talc, is applied to the resin during the casting process, shrinkage of as much as 10% or more can be expected, often accompanied by some distortion brought about by varying thicknesses of the resin (Figure 7.2). In contrast, because they cure through chemical changes when the epoxy and its curing agent are mixed, this particular resin produces dimensionally stable replicas. However, the epoxy curing process releases byproduct chemicals which penetrate the silicone mold, degrading it and ultimately destroying its elasticity. Epoxy resins are also expensive. Polyurethanes are another casting material; they produce casts that are dimensionally stable, possessing the same level of shrinkage as epoxy. However, polyurethanes require the application of a releasing agent between the mold and the resin to prevent bonding and this reduces the quality of surface detail captured in the cast.

Quick set silicone molding materials like polyvinylsiloxane are increasingly being employed on small sections of fossil bones and teeth to produce resin casts for studies of histological structures. These materials have their own particular hazards to the original fossil materials and their use should be carefully monitored (see below).

The Problem

There is a pressing need for the paleoanthropological community to weigh the long term implications of the loss of anatomical detail and data that results from the continued employment of these replication methods in conjunction with the low level destruction that will inevitably come from the increased amount of handling of the fossil specimens if high quality casts are unavailable.

At the core of the issue is the fossil evidence for human evolution. These specimens are the database of paleoanthropology and nothing can replace the study and analysis of these original specimens. With several exceptions, notably the Skhul materials at the Harvard Peabody Museum, the Tabun I, Kabwe (Broken Hill) and Gibraltar specimens at the British Museum of Natural History, and a few australopithecine fossils found earlier in the century (i.e., the 'Garusi' maxillary fragment housed in Tübingen, Germany and the isolated canine also from Laetoli in the British Museum) hominid fossils are generally curated in the country where they were found. In the past, access to these fossil specimens has been somewhat uneven, although in general, due to the generosity of the vast majority of curators, scholars have usually been

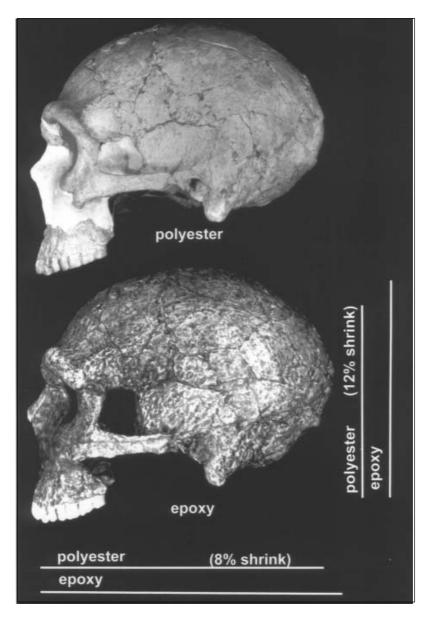


FIGURE 7.2 A comparison of two replicas of the skull of Wadi Amud 1. The upper cast was produced in polyester; the lower in epoxy. The epoxy cast retains the dimensions of the original specimen, while the polyester cast has an average decrease in size in the horizontal dimension (based on a maximum length measurement: glabella to opisthocranion) of 8%. In the vertical dimension, the decrease in size was more than 12%.

granted permission to examine the materials. There have been exceptions to this record; sometimes they relate to scholarly differences of opinion or personality conflicts, but most often they involve situations of political instability or where newly discovered fossils are in the process of original description.

However, this openness is now coming into conflict with the increasingly serious problem of long-term conservation. This is an issue confronting virtually all anthropological and natural history repositories in the world: How are the artifacts and bones representing the ancient and more recent past of human history to be preserved?

The losses, major and minor, that have occurred to the human fossil record bear ample testimony to the serious need to address this issue. Nowhere is this clearer than the disappearance or destruction during World War II of the samples from the Lower and Upper Caves of Zhoukoudian and from Předmostì. In this context, the beautifully made casts of virtually all the Zhoukoudian specimens (Mann, 1981) represent an extremely valuable resource for the study of these fossils. Unfortunately, the Předmostì fossils, with the exception of Předmostì III, were not molded, and the lack of suitable replicas of the remaining sample has resulted in these fossils being only rarely considered in discussions of the origins of modern Europeans.

Many hominid fossils are housed in parts of the world that have been involved in armed conflicts or are politically unstable. A decade ago, artillery rounds fell within 100 meters of the Croatian Natural History Museum where the unique Krapina Neandertal collection is housed. Another unique Neandertal sample, that from Shanidar Cave, is curated in Baghdad and for more than a decade has not been examined by anyone in the worldwide paleoanthropological community.

Other sorts of loss and damage to the fossil evidence take place more or less continuously, albeit in a less dramatic fashion. One of our graduate students at the University of Pennsylvania recently remarked after a trip to various European capitals to analyze a sample of Neandertal specimens that it did not take a great deal of expertise to measure fossils because the various anatomical landmarks were permanently dimpled or grooved on the bones. As a result, with each generation, these measurements become a little bit smaller. Apparently, even with the development of sophisticated biomedical technology the traditional methods of data collection using hand-held calipers on the fossils remain in use. Human evolutionary studies continues to require graduate students to view the same fossils and measure the conventional anatomical points as a necessary part of the process of becoming a professional scholar.

Further, there is the minute damage inflicted on fossils by constant handling. Tiny fragments can be lost during even the most careful handling, especially on poorly mineralized specimens; over the decades this can amount to a visible alteration in the form of a fossil. Senior researchers have often remarked that many fossils have changed their appearance from the first time they examined them.

Of course, every fossil specimen has undergone modification from the time the individual died until its discovery and this can result in missing parts, dramatic distortions to shape as well as chemical and genetic contamination. It is crucial, however, to maintain the fossil in as close to its discovered condition as possible, if only because future technologies may be able to amass much more data than is currently retrievable concerning, for example, its taphonomic history and original environmental context.

The Need for Reproductions

Thus, apart from issues of access to the original materials, one major reason for the fabrication of high-quality replicas is to reduce damage to original fossils from excessive handling. Just as importantly is the location of the fossil evidence. Because fossil finds have been made virtually all over the Old World with the specimens remaining in the country of discovery, casts are essential for the comparative studies that are at the core of much of paleoanthropological research. Thus, it is frequently necessary for institutions where original fossil specimens are curated to also possess sizable cast sets. In addition, research and training institutions throughout the world also require cast collections to enable scholars to design research strategies that may be later tested on the original fossils. Further, graduate student instruction necessitates cast series as training aids.

Finally, casts are used in undergraduate classroom instruction to provide students with an object that can be handled and often represents that touch of reality that drives home the reality of human evolution. In sum, many would argue that casts are essential to the practice of paleoanthropology.

Unfortunately, the molding process invariably results in damage to the original fossils. This is a reality of the molding process. Regardless of how carefully the initial preparation is performed, molding and set-up media infiltrate the surface of bones and teeth and subtly alter the form of fossils. Though it is commonly assumed that molding is noninvasive and nondestructive, this is clearly not the case.

Traditionally, molding has been used to fabricate casts of an entire fossil specimen for the analysis of gross morphological detail. Beginning in the late 1970s and 1980s, quick-set molding materials, developed primarily for use by dentists, have been increasingly applied to fossils to produce casts of limited surfaces of bones or teeth. Used with various sorts of epoxy resins, these casts are used principally in scanning electron microscopy (SEM) to examine histological features such as perikymata, resorptive developmental bone surfaces and cut marks (e.g., Beynon, 1987; Bromage, 1984a, 1984b, 1989; Rose, 1983; Ryan & Johanson, 1989; Scott, 1981; Shipman, 1981; Shipman & Rose, 1983; see more recent versions in Pickering, White and Toth, 2000). The molding materials most often employed in this work have been quick-set silicones like polyvinylsiloxane (brand names: Exaflex[®], Coltene Affinis[®], Reprosil[®], 3M ESPE Express[®]). These are all addition-cure dental impression materials that undergo only minute amounts of shrinkage during cure. In contrast, another widely employed molding material, Xantopren, is a condensation-cure material and sustains considerable shrinkage during cure. A more traditional dental impression material is alginate hydrocolloid (brand name: Jeltrate[®]). Although this material is reasonable in price, it produces molds that are dimensionally unstable and fragile; it also has the disadvantage of being difficult to remove from a specimen. It has no place in modern molding procedures.

As a result of the ease of application of the polyvinylsiloxane, the use of these molding materials has flourished. It is rare for anyone to discuss the serious limitations associated with their use (see Gordon, 1988; Monge, 1991). All silicones leave remnants on bone; small bits of silicone adhere to porous places especially in cancellous bone; residues of silicone also frequently dye the bone and leach oily residues into even compact bone areas (Figure 7.3). In virtually all situations, these are impossible to fully remove. This is especially true of fragile bones like those from many Neandertals that are not well mineralized. Further, many fossils have been molded numerous times and these often deposit enough residues so that subsequent molding episodes are actually replicating the damaged and rubber coated surfaces from previous molding attempts.

Less frequently, molding involves the replication of a complete fossil specimen. Although molding and casting have often been viewed by academic scholars as merely a technical skill, in addition to the detailed technical expertise there is also much anthropological and anatomical knowledge required for the tasks. For this process to be completed with minimum damage to the original specimen and to produce a mold that has captured maximum detail, a considerable amount of time and effort must be expended. Some molding media require the use of elaborate equipment like high-efficiency vacuum pumps.

Proper set-up of a fossil for molding requires experience with the process as well as a detailed knowledge of the materials to be employed (Mann & Monge, 1987; Goodwin & Chaney, 1995; Smith & Latimer, 1989). Liquid plastic, including B72 and Polyvinyl acetate (PVA) in solution of acetone at a proper viscosity (1–5%), can be applied by spray or brush to protect the bone surface without obscuring microscopic and macroscopic detail. One

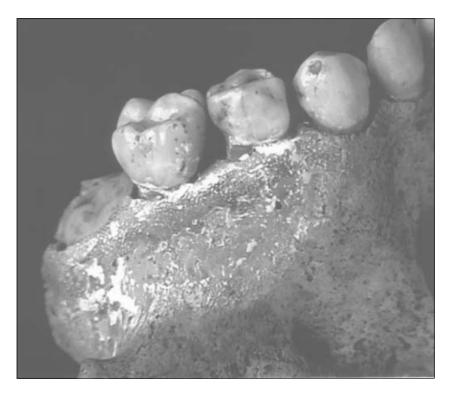


FIGURE 7.3 A maxillary fragment from an immature individual from the Iranian Iron Age site of Hasanlu. Note the silicone rubber residues on the bone surface and teeth.

advantage of the use of these plastics is that after the completion of the molding process, they can be removed, along with other molding residues. The fossil specimen must be evaluated for fragility and jigs are often designed and built to support the specimen in the correct position for successful application of the molding media (Figure 7.4). The evaluation process also includes a consideration of how much detail can be obtained on the mold: an astute balance between protecting the fossil and maximizing detail. A well-made mold in platinum based RTV silicone rubber (for example, Shin Etsu 1310ST) in combination with high-viscosity epoxy, for example, has the ability of producing a cast with significant microstructural detail to about 5,000X magnification (Figure 7.5).

In the end, however, no one can be sure of the level of chemical and structural damage to the surface of a fossil. It is also possible that these

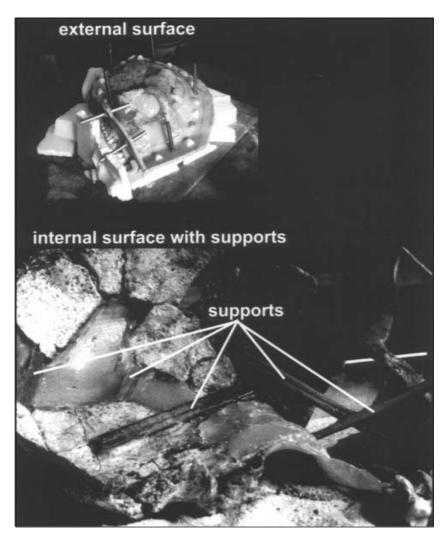


FIGURE 7.4 The partial skull of the late Neandertal from St. Cesaire, southwest France shown in the process of being molded (at the Université de Bordeaux I in 1992). The upper illustration shows the fossil at the completion of the initial preparation just before the application of molding silicone rubber. The lower photo shows the internal surface near the temporal bone. Because of the fragility of the fossil, contour-fit aluminum supports were used to reinforce the bone. After the conclusion of molding, the supports were removed.

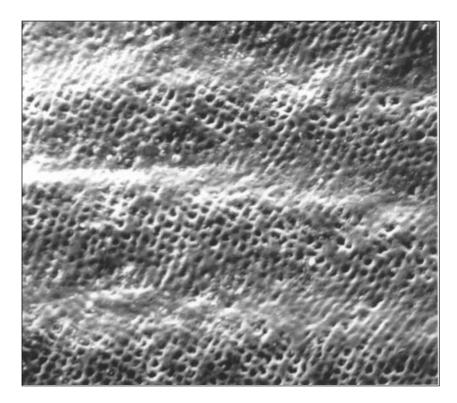


FIGURE 7.5 SEM micrograph at 600X of an epoxy cast of the labial surface of the crown of a just erupted lower incisor. The cast was made in a polyvinylsiloxane mold and shows undulations of perikymata with enamel rod ends clearly visible.

introduced chemicals will alter the results of other analytic procedures such as isotope analyses and DNA extraction and analysis. In some cases, because of the potential for damage to the originals, curators have elected not to mold fossils with especially rich surface detail, for example the hundreds of fossils from the Sima de los Huesos at Atapuerca (Arsuaga, personal communication).

Recently, White, in his general observations of the state of human evolutionary studies as it crosses into the new millennium, made a number of general recommendations to students in paleoanthropology, among which were the following: "In the laboratory, do not attempt to clean or mold a hominid fossil unless you are experienced and qualified. This is difficult, because you usually don't know when you're *not* qualified" (2000, p. 291) (emphasis in original). Once the molding process has been completed, what is the obligation of the mold maker and the curators who curate the fossil materials? Keep in mind that when a fossil specimen is molded, that mold is a unique representation of the fossil at that point in time. Because the process is partially destructive, subsequent molds will not reproduce the same exact fossil but a structurally modified version of it. Thus, it is a crucial matter that the original mold, or an equally accurate facsimile, be as carefully maintained as possible, along with a detailed record of the procedure, the materials applied to the fossil and any damage to the bone. Obviously, the number of times a specimen is molded becomes a matter of importance for the fidelity of subsequent molds as well as for the long term survival of the fossil.

Who is entitled to receive casts? This has been a matter of often fierce debate in the paleoanthropological community for more than thirty years (Cartmill & Hylander, 1974). Generally, casts and their distribution are controlled by the curators and primary researchers of the fossils; often casts are given to a small and select number of scholars. In the past, this has led to accusations of favoritism with a number of scientists claiming to have been denied access to both the originals and to casts.

To help mitigate this problem, the Wenner-Gren Foundation for Anthropological Research in the 1960s and early 1970s organized a facility for the molding and casting of hominid fossil bones and, just as importantly, for the even-handed distribution of the resultant casts (Cartmill & Hylander, 1974). The director of research of the Foundation at the time, Lita Osmundsen, concluded a series of agreements with institutions in Africa, Asia, and Europe to allow trained mold makers, employing a carefully worked out molding technique, to mold the fossil bones in their care. She also established a production facility (known as AnthroCast) to produce large numbers of epoxy casts. The procedures developed by the Foundation included the collection of detailed information on the molding procedure, the chemicals employed and the damage that might have been suffered by the original fossil. The casts produced under the auspices of the Wenner-Gren Foundation were required to be accurate to within measurement error of the original fossils. Although these remain the only replicas ever fabricated in paleoanthropology whose dimensions were guaranteed to be virtually identical to the original, this sort of control proved to be extremely expensive and the program ceased production in 1976.

Eventually, the molds made by the Wenner-Gren Foundation Casting Program were entrusted to the Casting Program at the University of Pennsylvania Museum, which continues to produce casts from these molds.

The molding and casting process developed by the Wenner-Gren Foundation, as well as the procedures for the long-term maintenance of replicas, was a remarkable system that has been maintained by the University of Pennsylvania Casting Program. The technical details involved in the molding process are elaborate and will not be described here. What is essential is to review the process by which the details captured by a silicone rubber mold, which is fragile and has a definite lifespan before it loses its elasticity, are permanently safeguarded. The Foundation developed the concept of a "pattern" in which mold sections, cast in epoxy, conform to the exact mold set-up employed on the original fossil. These templates ensure that without sacrificing the detail captured by the original mold, nor subjecting the fossil to additional molding episodes, many generations of molds can be produced from a pattern (Figures 7.6 and 7.7). The use of a stable and rigid material

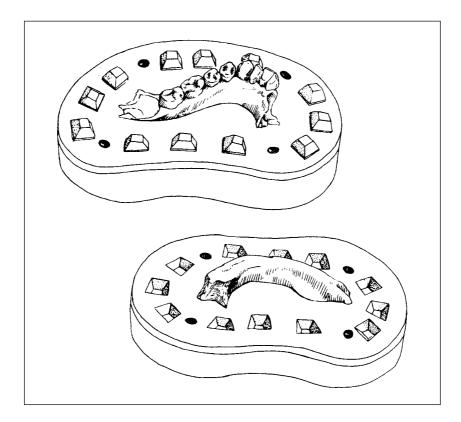


FIGURE 7.6 Line drawing of a pattern of a Neandertal mandible (#55, molded in Croatia 1988) from the Krapina site. Note that the two parts of the mold have been cast separately to make the two patterns of this specimen. Silicone molding rubber can be applied to each one of these templates or patterns and casts made from the resultant molds. This mold making process can be repeated many times without loss of detail or damage to the pattern. Bolt holes for bolts and the pyramids that surround the fossil are used to align the mold halves during the casting process.

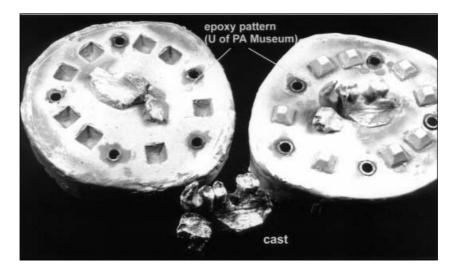


FIGURE 7.7 The cast of a maxillary fragment from the Miocene of Hungary (Molded in Budapest in 1988). The cast, in the foreground, was produced from a mold made from the pattern, the two halves of which are shown in the background.

like epoxy, which is capable of preserving the details of a mold over long periods of time, has proven to be a practical means to archive the form of a fossil. At the University of Pennsylvania Museum, through the support of the National Science Foundation, a pattern storage repository has been established as part of the Museum's Casting Program. Over 3,000 patterns are currently in the archive. They are used both as the basis for the fabrication of molds to produce casts, as an archive to ensure that an accurate and documented record of a fossil's form is preserved in case the original is lost or destroyed; they can also serve as a study collection. If permission to make casts of a fossil has been obtained from the curating institution, the pattern is used as a template for mold production. When permission has not been granted by curators for the general production of casts to the paleoanthropological community, the Casting Program respects this prohibition. However, researchers can request the production of a single cast from the appropriate curator. Occasionally, this is not possible and other avenues must be explored. For example, a mold was made of the relatively complete skull of the Shanidar I fossil in 1973. At the time, no permission had been granted to the Wenner-Gren Foundation by the Baghdad Museum authorities to produce casts and there has been no communication with a

curator for the last several decades. Because a number of researchers have requested casts of this singular specimen, in this special situation, the Wenner-Gren Foundation has granted the Casting Program permission to fabricate casts. Often, however, due to the complex nature of granting permission, many specimens preserved in the archive in the form of patterns cannot be cast. In this situation, it is possible for scholars to visit the archive in Philadelphia to study the patterns.

Although the catalog of patterns housed in the archive for study is available at the Casting Program Web site (www.sas.upenn.edu/~jmonge), it is obvious that information must be made more widely available. To aid in the dissemination of information about mold and cast availability, the Casting Program will purchase a Web site with a database containing detailed information on all 3,000 or so molds and patterns at the University of Pennsylvania. Ultimately, it is hoped that this database will also contain information about the availability of molds and replicas at other institutions.

Unfortunately, there are presently a number of organizations that are producing and selling casts without permission. Molds and resultant casts of fossils are protected by the 1976 Copyright Act of the United States. This applies internationally to those countries that are signers of international copyright treaties and conventions with the United States (see http:// www.loc.gov/copyright). Often, reproductions are being made by private businesses and not individual researchers or academic organizations. Many of these clearly infringe on copyright laws. These illegally produced casts have been copied from casts originally produced by the AnthroCast facility, the University of Pennsylvania Museum Casting Program, and the Kenya National Museums (and perhaps from casts from other institutions as well). When confronted, many of these businesses claim that the casts are sculpted from purchased casts. Sometimes, the cast is scaled down in size. Scaled down and sculpted versions of casts are not infringements of copyright laws although they are useless for any scholarly research. Clearly, these casts are useful for teaching purposes only and are sometimes deceptively advertised. Often, these pirated reproductions have modified the original casts in one way or another. For example, the part line (the place where the two halves of the mold come together) is sometimes moved or ground away to produce a smooth appearance. For a cast to be scientifically useful, the position of the part line should be obvious so that the researcher is aware of where distortion is likely to be present on the cast. Further, smoothing off the part line destroys all of the detail surrounding this area of the fossil, introducing additional areas of inaccuracy on the cast. Researchers and teachers ought to be aware of the illegal and unethical duplication of casts and prior to the purchase of any reproductions should ascertain just what the origins of the materials are.

Present Alternatives to Molding and Casting

It is clear that reproductions are a necessary part of human evolutionary studies, but current molding procedures are obviously hazardous to the original materials; are there any currently available alternatives? One option are computer-generated images that can be viewed in three dimensions. Minimally, surface representation of the fossil can be obtained. When the original fossil specimens are used in the image recording, results can be obtained that are useful in a number of comparative and other studies of the fossil evidence. Many textbooks in physical anthropology already incorporate these sorts of images on CDs included with the text, sometimes with interactive formats. Unfortunately, these are often photographs of casts rather than of the original fossils.

A more satisfactory alternative, but more costly and taking up greater amounts of computer memory, are the three dimensional images generated from the 1 mm slices produced and then reconstructed using computerized tomography (CT) technologies.

There are several constraints to the use of CT scanning, including the limited distribution of scanning instruments. Many fossils are housed in countries with little or no access to CT technology or to instruments that can be employed on nonmedical subjects. Further, CT images are generally composites of 1 mm slices. Thus, microstructural detail at less than this level is not preserved as in RTV molded fossils. Images are generated from computer generated models and viewed on computer screens. For some, the examination of images in this fashion is of limited value with the inability to directly handle the specimen a major handicap, especially when dealing with comparative features associated with scale. The distinct advantage is the visualization of internal structures and dimensions not available on gross examination of the specimens.

Laser stereolithographic impressions of photosensitive composite resins can be generated from these computer slices. Although these reproductions possess the form of the fossil, because of the scanning patterns involved, they lack the specific details found on more traditional casts. Furthermore, these reproductions are prohibitively expensive to produce and for the moment, it is not practical to consider them as a substitute for regular casts (Zollikofer, Ponce deLeon, & Martin, 1998; Ponce de Leon & Zollikofer, 1999; Zollikofer, Ponce deLeon, Martin, & Stucki, 1995). However, scanning instruments capable of slices much smaller than 1mm are in the process of introduction and if the cost of manufacturing these reproductions can be significantly reduced, these developments can have a profound effect on the future need to subject original fossils to the hazards of direct molding.

Conclusions

This review has examined some of the issues that face the paleoanthropological community as it deals with its primary database, the fossil record. Amongst the questions that need to be addressed are:

- 1. There are very real possibilities for permanent damage to unique fossil specimens during the molding process; what are the ethical issues involved in the decision to mold a particular fossil? Because of the amount of surface detail preserved on some fossils, should these never be molded? Who makes these sorts of decisions?
- 2. Because of the clear hazards involved in molding procedures, every effort must be made to limit the number of molding episodes performed on individual fossils. Molding should be conducted by qualified scholars and elaborate notes should be compiled regarding the whole process. Where possible, the use of patterns, or other such devices, should be employed to preserve the quality of the original mold.

The use of dental impression materials should be carefully monitored and the resin casts produced from vinyl polysiloxane molds should be returned to the original institution housing the fossils, to become part of the permanent record for that specimen and to eliminate the need for future molding episodes.

- 3. Although nonmolding methods of reproducing the form of the fossils for research and teaching, such as three-dimensional imaging and laser stereolithographic reproductions, are available, they have a number of limitations and do not, at the present time, represent a viable alternative to casts made from molds applied directly to the original fossils.
- 4. However, if it appears reasonable that techniques may be introduced in the near future that will produce high-quality replicas, but with significantly less, or no, damage to the fossils, should current casting activities be suspended until these less-destructive techniques are introduced?
- 5. Finally, although it is outside the topic of this paper, it is vitally necessary to initiate general discussions about the long-term preservation of the fossils and how their future safety can be reconciled with the need for an increasingly large number of researchers to carry on their research on the original fossil data base. It is recommended that an international forum be convened to deal with this matter.

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We would like to express our thanks to Professor Trudy Turner for the invitation to participate in the Symposium in which this paper was initially presented. We also wish to acknowledge our sincere gratitude and appreciation to the late Lita Osmundsen, under whose direction the Wenner-Gren Foundation developed the molding and casting procedures whose use will ensure the long-term preservation of major portions of the human evolutionary record. We believe that the discipline as a whole is also markedly in her debt.

Notes

1. There is much current debate about the precise taxonomic terms to be used in describing groupings that include living and extinct humans, the African and Asian apes and extinct forms with uncertain affinities to these living animals (i.e., Mann & Weiss, 1996). In this paper, for the sake of clarity, we use the term hominid to refer to members of the human lineage and hominiod to refer to all apes and humans.

2. For example, many fossils have undergone a series of reconstructions over the years, and morphological details as well as dimensions have often changed, sometimes dramatically (i.e., Frayer, 1992 and Heim, 1989 on the various reconstructions of the la Chapelle-aux-Saints skull). Molds made at these times preserve these now lost recreations of the fossils and allow scholars to more fully comprehend what earlier researchers were examining.

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Chapter 8

The Ethics of Bioarchaeology Clark Spencer Larsen and Phillip L. Walker

Introduction

The United States and other developed nations have taken enormous strides towards the advancement of human equality and protection of the basic human rights of all citizens over the last several decades. A direct outgrowth of this highly desirable development is the increasing weight given to belief systems of native and other minority or nondominant cultures. At last, many previously disenfranchised groups are gaining the political and economic power necessary to control the circumstances of their lives in ways unimaginable just a generation ago. Herein lies a crucial ethical issue for bioarchaeologists: The traditional perspective of scientists who study ancient remains has been to consider human remains as valuable objects full of research potential. Many descendants of the people whose remains bioarchaeologists study, in contrast, view ancestral remains as objects of veneration that should be protected from what they see as the indignity of examination by scientists whose motivations they consider suspect at best and immoral at worst. Because of the strength of such beliefs, newly empowered groups that previously were disenfranchised by mainstream American culture now demand-at least in some areasthat they be given the authority to make decisions as to disposition of ancestral remains they identify in museum repositories.

Over the last several decades, bioarchaeologists have been forced to grapple with the fact that they no longer have sole control of or access to the remains of ancient native populations in the United States, Canada, Australia, New Zealand, Israel, and elsewhere. In the United States, compromises between scientific and native concerns have been implemented through various state laws (Ubelaker & Grant, 1989; Price, 1991). However, it was the passage of the federal Native American Graves Protection and Repatriation Act (NAGPRA) of 1990 that coalesced a variety of efforts across the United

States to speak to both native and nonnative concerns in a comprehensive fashion. The law has three key provisions: 1) it protects native graves on federal and tribal properties; 2) it recognizes tribal authority on these lands; and most importantly for bioarchaeologists, 3) it requires that all Native American skeletal remains and funerary objects be inventoried, and that culturally-affiliated or potentially culturally-affiliated groups will be consulted concerning the ownership and disposition of the remains (see Rose, Green, & Green, 1996). Under NAGPRA, if a federally recognized tribe demonstrates a relationship of "shared group identity" with human remains curated by a museum, the tribe is given the authority to determine the disposition of those remains. In the more than 10 years since the enactment of the law, these provisions of NAGPRA have resulted in sweeping changes in the way scientists deal with Native American remains and how research on these remains is carried out.

From our perspective, the impact of NAGPRA on both Native Americans and scientists has been both positive and negative. A wonderful outcome in many regions has been increased communication between scientists and native peoples. At many academic institutions, the new dialogue between scientists and Indians has forged new relationships and mutual understandings. From a purely scientific perspective, the legislation has also been beneficial; it has required museums and other institutions to examine, at least in a cursory fashion, archaeological collections that had never previously been studied.

On the other hand, problems both anticipated and unanticipated with NAGPRA continue. These problems have a number of sources, but one of the primary causes is the failure of the law to deal adequately with some fundamental issues, such as the disposition of culturally unaffiliated remains and procedures for determining cultural affiliation and shared group identity. The law was intended to address the rights of descendant groups. However, a number of groups would prefer to see universal repatriation, even though most remains (primarily from prehistoric contexts) are not affiliated with any of the federally recognized tribes identified by the Bureau of Indians Affairs. Misunderstanding of the intent of the law by a variety of groups, including some of the federal officials responsible for its implimentation, has added no small amount of confusion to the issue. These ambiguities have resulted in lengthy disputes and legal challenges. For example, the Kennewick skeleton found in the State of Washington in the summer of 1996, dating to some 9,000 years ago, was formally culturally affiliated by the U.S. Department of the Interior (Babbit, 2000) to four federally recognized tribes and one nonfederally recognized group living in the region today that were likely not even in existence as cultural entities more than nine millennia ago. This decision has served to prolong an acrimonious legal battle between scientists interested in studying the remains and Native Americans who claim the skeleton based on the relationship of shared group identity they feel they have with this person.

Motivations and Ethical Responsibilities

Should bioarchaeologists study ancient remains when there are objections very strong at times—to such work by the members of a modern group that claims an ancestral relationship to those remains? One ethical perspective on this question focuses on the value studies of human remains have for understanding the history of our species. The study of ancient remains is not motivated by idle scientific curiosity. Rather, professional bioarchaeologists, skeletal biologists, paleopathologists, and others who study ancient remains believe that the information contained in the skeletons of our ancestors is of great potential significance to living people. Human remains are a repository of a person's individual life history and collectively tell the story of the population that individual belonged to (reviewed in Larsen, 1997). They are a unique source of historical information on genetic relationships and humanenvironmental interactions. Skeletal data are thus critical to our understanding of the adaptive history of our species.

The knowledge we have about the past is based, in part, upon information from products of human cultural activity, such as artifacts and literary sources. Cultural products, especially the written records that document our recent past, are symbolic constructs. As any good postmodernist will tell you, this means that they can be interpreted in many different, sometimes contradictory, ways. This problem of cultural contingency is especially acute when we attempt to interpret historical documents, which often tell us more about the cultural context of their authors than they do about what actually happened in the past. Certainly, skeletal data are also subject to biases and problems of interpretation, but these are different from those that make interpreting documents difficult. This is what makes skeletal remains of such great value as sources of historical evidence. They encode information on genetic relationships and physiological process relating to growth, development, and disease that are a unique record of life and death in the past (Walker, 2000).

Outside of physical anthropology there is little appreciation for such esoteric arguments regarding the value of human remains. Indeed, most people worldwide view skeletal remains in a different light, ranging from objects of morbid curiosity, an unpleasant reminder of their own impending death, to spiritual vehicles capable of actively interacting with those still living. Many focus on the ghoulishness of remains, not their potential scientific interest.

Given this minority status of our bioarchaeological perspective on the value of human remains, what are the ethical responsibilities of scientists who

study ancient human remains? We believe that there are three ethical principles that many people, world-wide, of diverse cultural backgrounds would agree upon: 1) human remains should be treated with dignity and respect; 2) descendants should have the authority to control the disposition of their relatives' remains; and 3) because of the importance of human remains for the understanding of our common past, human remains need to be preserved when possible so that they are available for scientific research (Walker, 2000).

The first of these ethical responsibilities is an outgrowth of the principle that all humans are to be treated with respect and dignity. But respectful treatment of the deceased is a subjective, culturally contingent, notion. Viewed from a global perspective, temporally and geographically, human beings have invented an amazing variety of ways to respect the dead. For example, some people place their dead relatives on special structures so that birds of prey can pick at the corpse; this is considered a sign of respect (Fathers, 2000). In other cultures, the same thing is done with the bodies of enemies as a sign of disrespect and social domination. In other cultures, remains of the deceased are stored in charnel structures until the soft tissue is fully decomposed and then placed in large pits. For the scientist, respectful treatment of the human remains we are entrusted with consists of treating them in a way that preserves the information they contain and allows us to learn as much as possible about the person's life and death. We believe that these different types of respect can be accommodated.

Strength of the relationship between the modern group and the skeletal remains being claimed is another key answer to the above question of why remains are studied. Dealing with the disputes that erupt over the control and disposition of human remains force bioarchaeologists to confront many fundamental ethical issues. The belief that immediate relatives should determine the disposition of the remains of the recently deceased is, with a few minor exceptions, a cultural universal. The crucial ethical dilemma, therefore, is not the question of whether or not close relatives should have the right to control the disposition of the remains of their close kin; we all agree that they do. Ethical dilemmas do arise, however, when we consider who has or is given authority to determine disposition when the remains in questions are those of individuals distantly related to the living people who claim them. How should this authority be determined when there is a distance of hundreds, thousands, or even millions of years between the living and the dead? And if links are made, who specifically should be granted the authority? Implicit in acknowledging the authority to control the disposition of remains is the assumption that some entity or entities have the right to own human remains (see Simms & Raymond, 1999).

In the United States, the issue of control has been dealt with at two levels. Issues surrounding control over the bodies of close kin are resolved

according a rigid hierarchy of relationships: control by spouses supersedes that of parents; control by parents supersedes that of siblings, and so on. At the other extreme, decisions concerning the control over ancient Native American remains in the United States are based upon the legal concept of cultural affiliation: by the definition presented in the NAGPRA legislation, a relationship of cultural affiliation can be said to exist if there is a relationship of "shared group identity" between an ancient individual and a modern federally recognized tribe. Demonstrating such a relationship involves evaluation of a range of information from sources as diverse as the expert opinion of traditional religious leaders, folklore, and physical anthropological data. Predictably, problems have emerged in establishing cultural links: If a person "believes" they share a cultural identity with a deceased person, then by definition isn't this a valid link? An example of the kind of ethical problem that could conceivably arise with this kind of definition concerns the intrusion of the so-called "New Age" movement into the cultural identify of Native Americans. Many Native Americans see this as an appropriation of spiritual traditions by outsiders. Is it ethical for someone who is clearly not culturally affiliated from a biological standpoint to become so because they sincerely believe that they are culturally affiliated? Probably not.

Some argue that NAGPRA adequately addresses the meaning of cultural affiliation and the allocation of rights of disposition. In some ways, this legislation has addressed the issue. However, major flaws-which we regard as having clear ethical implications-are present. Foremost in our minds is the fact that, NAGPRA empowers only *federally* recognized tribes when a direct ancestor-descendant relationship cannot be clearly demonstrated. Although NAGPRA has increased communication between federally recognized tribes and anthropologists, it has alienated many groups of descendents that are not federally recognized, yet are very much Native American tribal entities in every other meaningful respect. Indeed, most states have tribal groups that are state recognized, but not federally recognized. In many areas, there are tribal entities that individuals identify with as their group, and have done so for generations. Some of these entities are not even state recognized. Thus, these groups are denied any access to the provisions of NAGPRA, and have no claim to authority of disposition, in the strict legal sense. Thus, it is puzzling to us how the highest levels of the U.S. Department of Interior have affiliated the Kennewick skeleton to a group of tribes one of which is not even federally recognized.

Finally, bioarchaeologists overwhelmingly accept the ethical principle that, owing to the value of the information they contain for understanding the history of our species, whenever possible, human remains should be preserved. Skeletal remains are a unique source of information about the human past and provide the only means with which we can fully understand the lives of our ancestors. Why is having access to this evidence about the lives and deaths of our ancestors important enough to override the sanctions some cultures have against the study of human remains? We believe that having the substantive information about what happened in the past that human remains provide is essential as a defense against the pernicious effect of historical revisionism. This is one of the favorite tools politicians use to propagate racist theories that undermine human equality and basic human rights.

Both the American Association of Physical Anthropologists and the Society for American Archaeology have offered resolutions to the effect that human remains should be preserved for future generations and that the importance of research on human remains should be communicated to appropriate groups. It is only by preserving collections that we will be able to correct inaccuracies of present and past researchers in the future. It is this self-correcting principle that allows us to understand the past as we develop new theory and method and revisit old problems. Indeed, it is because of restudy of skeletal collections due to NAGPRA and other developments in analytical techniques that there has been a recent rapid increase in the self-correcting process.

We believe that a balance should be sought between the concerns of descendant group and those of the scientific community. Indeed, it was NAGPRA that set out to create this balance. Unfortunately, maintaining such a balance is a precarious process that has been disrupted in some key areas where perhaps it shouldn't have been, such as in the Kennewick case. In the current context where the legal system may not provide an appropriate setting for reaching ethical solutions to difficult decisions, how should we go about seeking a balance between the conflicting ethical principles of preservation and descendent control?

Crucial in the discussion is the fact that there are no *inherent* conflicts between the keeping of skeletal collections and respect for the dead (and see Walker, 2000). In a number of settings, for example, native societies have adopted new rituals that are consistent with old practices. The Chumash Indians of Southern California, for example, have worked with Walker in developing a cooperative arrangement involving repatriation from museums and universities to a subterranean ossuary at the University of California, Santa Barbara. As it turns out, this is a desirable arrangement with the Chumash, owing to the fact that the university is in the heart of ancestral lands. The ossuary serves dual purposes, including spiritual needs and access to remains by tribal people and to provide access to research by anthropologists under the supervision of the tribe.

Another important example of how mutual agreements about the disposition of archaeological human remains is from the Stillwater Marsh of Western Nevada. In the mid-1980s, record snowfalls in the Sierra Nevada Mountains to the west resulted in a huge outflow of water to the Great Basin. The increase in water resulted in erosion of the surface of the wetlands, exposing dozens of archaeological sites and hundreds of skeletons. Within short order, unscrupulous collectors began to pick up artifacts and bones from the surface and continued erosion led to additional destruction of human remains.

Within days, there was a unified response on the part of local, state, and federal authorities, archaeologists, and the nearby Fallon Paiute-Shoshone tribe (see Larsen & Kelly, 1995; Simms & Raymond, 1999). Under the direction of archaeologists from the Nevada State Museum, a heroic effort was undertaken to salvage the skeletal remains. From the outset of the recovery operation, a clear goal of all of this work was to include Native Americans in the mitigation of sites and study of remains. All parties agreed that the remains should be repatriated following study. Opinions varied on what repatriation should involved, but most argued that in addition to their sacred and emotional significance, there is educational and scientific significance. As a result of discussion involving all parties, it was agreed that a concrete subterranean burial chamber should be constructed to house the remains. This arrangement allowed for long-term interment, but also access for future studies. The issue in this setting was never about ownership, but rather about mutual respect and the sense of a common goal.

These and other similar arrangements have grown from personal contacts and relationships, mutual understanding and respect, and importantly, the recognition of common interests and respect for the dead. There are situations where compromise is not possible, and many tend to focus on the instances where collaboration between various interests is not occurring. But in our experience once the veil of mystery and misunderstanding is removed, it is often the case that mutual agreements can be forged. Out of such cooperation can grow increased understanding of the collective human past; this is something that will be beneficial to all people, not just anthropologists or Indians (and see Simms & Raymond, 1999).

Conclusion

Physical anthropologists have an ethical responsibility, we believe, to record for posterity the information that skeletons provide about the history of the human condition. This perspective runs counter to the assumption by some that anthropologists are simply interested in furthering their careers. Mihesuah (2000, p. 97), for example, suggests that anthropologists have a monetary interest in American Indians remains and that they "serve as the focal points of many anthropologists' careers. The fact that Indians exist allows these people—as well as historians—to secure jobs, tenure, promotion, merit increases, fellowships, notoriety, and scholarly identity. . . . Millions of dollars, hundreds of jobs, and numerous journals would be at stake if anthropologists could no longer study remains and their burial items." To be sure, if the motivation for studying Native American remains was career development, this would be unethical. However, most bioarchaeologists study these remains in order to understand the past and the history of humanity generally and not as a means of developing their careers.

The misperceptions about the motivation for the study of remains clearly reflect the conflict that emerges when two systems of ethics conflict (see Goldstein & Kintigh, 1990). Many have drawn the conclusion that one set of ethics is right and one is wrong. Ethics, however, are a cultural construct, and one set of ethics cannot (usually) be labeled as right or wrong. We believe that compromise is the key to reaching an ethical solution to skeletal studies of ancient ancestors. Compromise can be legislated, as was intended for NAGPRA. A key part of the legislation was to establish a seven-member committee that would advise on individual repatriation cases. This panel was intended to represent a compromise that balanced the scientific and nonscientific (native) perspectives. Thus, it was established that three members of the panel would be drawn from the Native American community, three from the museum community, and one to be determined by the Secretary of the Interior. Ten years later, the balance and compromise that formed the foundation of NAGPRA is clearly endangered: there has been a perceptible shift in the balance of power toward extremist native perspectives on repatriation. In reflecting back on the history of repatriation, compromise is developed when there is trust between two parties who have invested time and effort in reaching solutions that may not be perfect, but nonetheless attempt to competing interests of different groups.

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Chapter 9

Ethical Concerns in Forensic Anthropology Heather Walsh-Haney and Leslie S. Lieberman

Introduction

Practitioners of biological anthropology have been concerned with ethics and social policy since the emergence of the discipline in the mid-1800's (Wax, 1987). Forensic anthropology, as a more recently defined branch of anthropology, is directly involved in the interface of ethics and social policy as it is codified in law and applied to the definition of personhood and the fundamental issue of death (Fluehr-Lobban, 1991; 1998; Wax, 1987).

Forensic anthropology is an applied branch of biological anthropology whose scientists analyze skeletal remains for both legal and humanitarian purposes. Therefore, forensic anthropologists have unique relationships with a broad range of interested individuals or stakeholders: families of the deceased, accused murderers, victims, other forensic scientists (e.g., toxicologists, medical entomologists, odontologists, medical examiners), police, lawyers, judges, international human rights organizations and other NGOs, foreign governments, and undergraduate and graduate students. With these myriad stakeholders, forensic anthropologists must be vigilant in their adherence to the three major ethical tenets delineated by anthropological ethicist Carolyn Fluehr-Lobban (Fluehr-Lobban, 1998).

- 1. Try to do no harm or wrong. It is the duty of anthropologists to weigh the kinds, degrees, duration, and probability of good and bad outcomes.
- 2. Avoid deception and misrepresentation in the course of field research, data collection, and in the presentation and publication of research.
- 3. Act impartially so that all persons affected by the research are treated in an equal manner.

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This chapter fills a gap in the literature concerning the ethical implications of using human remains for research and training in forensic anthropology. We shed light on the need for analysis of ethical issues within the field of forensic anthropology by providing a glimpse into common ethical issues faced by its practitioners: Should forensic anthropologists be able to harvest tissues for the resolution of a forensic case from corpses without consent from next of kin? Is consent necessary for both passive (noninvasive) and active (invasive) anatomical research? If forensic anthropologists do not collect data from forensic cases are they doing a disservice to the resolution of future cases? Should undergraduate and graduate students train through the participation in ongoing forensic investigations? Can forensic anthropology be recognized as a science if no current data from contemporary individuals are collected? As stakeholders in these decisions, the rights of the individual (or victim who most would consider the ultimate stakeholder), next of kin, researchers, and students are discussed.

Qualifications and Certification

The American Board of Forensic Anthropology (ABFA), the regulatory and certifying organization for the profession, has stringent certification and oversight procedures (further information may be obtained via the internet at www.csuchico.edu/anth/ABFA/). Founded in 1977, the ABFA stated objectives are: 1) to encourage study and practice of forensic anthropology, establish scientific standards, and advance the science of forensic anthropology; 2) to promote a high standard of ethics and professional conduct; 3) to issue certificates to eligible individuals; 4) to inform government and private agencies of the activities of the ABFA and its certified members; and 5) to maintain lists of individuals who are ABFA certified and available for professional employment (Reichs, 1995).

The diplomate certification process is based on a candidate's personal and professional record of education (a Ph. D. is required) and training, experience, and achievement as well as a formal written and practical examination (Reichs, 1995). The process is analogous to procedures in many other medical and scientific fields. Upon meeting these qualifications and passing the diplomate's examination, an individual is issued a certificate of qualification in forensic anthropology and becomes a diplomate of the Board of Forensic Anthropology (DABFA). Certification is renewed each year according to specific standards and criteria established by the ABFA (Reichs, 1995).

Increasingly the federal government, most often through administrative agencies of the executive branch, has become involved in the legislation, policing, and education of students and established researchers with respect to biomedical ethical issues. For example, the National Institutes of Health and other federal agencies require researchers to be trained and certified in ethics. Institutional Review Boards (IRBs) also oversee compliance, especially for federally funded research.

Although the ABFA and the American Academy of Forensic Sciences (AAFS) mission supports the active training of undergraduate and graduate students in all fields of forensics, including forensic anthropology, apprehension concerning student participation in ongoing forensic cases is apparent. When one author (Walsh-Haney) began an internship at the C.A. Pound Human Identification Laboratory while a junior at the University of Florida she participated in the recovery and collection of hundreds of forensic cases with her mentor Dr. William Maples. While students, both undergraduate and graduate, were under Maples's constant supervision, Maples had mentioned that student participation in any forensic cases could prove a "legal achilles heel" of sorts. To paraphrase his words to the author, Maples had said that when a case goes to trial a line of questioning always advanced by both defense counsel and the prosecution involved "chain of custody" and who had access to the remains and associated physical evidence. When students had access to the evidence, questions concerning proper handling and training were always brought up. Although stringent training and Maples's eagle eye were on the one or two students that frequently accompanied him, in the eyes of a jury such students may be seen, in general, as unknowledgeable and incompetent. They may serve to discredit the anthropologist as an expert witness and ultimately affect the outcome of a trial.

During the AAFS meetings in 1995, Maples had also asked the author what she thought about a debate within the physical anthropology section to prohibit undergraduates from participating in forensic cases (whether in the laboratory or in the field). The author's opinion then and now remains the same and falls within ethical precepts and the mission of the DABFA and AAFS, to wit: Undergraduate participation in forensic anthropology cases is an important teaching tool and should continue both in the field and the laboratory so long as the student is properly trained and supervised. In this regard, the numbers of students to accompany the forensic anthropologist in the field or work in the laboratory must be kept to a minimum to ensure proper supervision, mentoring, and training. These issues of training and credibility facing students of forensic anthropology and their mentors brings to light the notion that forensic anthropologists are caught between two paradigms: those of academia, medicine, and the legal system.

Multiple Roles of Forensic Anthropologists

Forensic anthropologists are experts in the identification of age, sex, ancestry, and stature of skeletal remains. They are also trained in additional aspects of

identifying types of antemortem and perimortem injuries and their putative causes, skeletal pathology, and taphonomy. Forensic anthropologists' primarily work within the context of criminal cases but they are also involved in identification of persons in military conflicts (a specialty of the joint POW/ MIA Accounting Command in Hawaii—JPAC), plane accidents, and natural and human made disasters, such as the attacks on September 11, 2001.

Typically, forensic anthropologists acquire cases from a medical examiner or coroner seeking expert advice in the determination of a victim's identification or manner of death (i.e., accident, homicide, and suicide). Nevertheless, forensic anthropologists are also called upon to use their skills in analyzing prehistoric and historic skeletal remains. According to the ABFA, nearly 25% of forensic anthropology cases are comprised of skeletal remains from prehistoric or historic unmarked burials (Reichs, 1995). The forensic anthropologist's expedient and accurate determination of whether the skeletal remains in question are prehistoric or historic is imperative because such a determination allows the investigating agency to direct resources to cases that are forensically significant.

However, social policy dictates the form and manner in which the forensic anthropologist approaches the analysis of nonforensic cases. Pursuant to Florida's Legislative Statute 872.05, unmarked human burials, skeletal remains, associated burial artifacts, or land suspected of being a burial ground are "accorded equal treatment and respect based upon common human dignity." The human skeletal analyst, having spent at least one year in a laboratory assisting in the analysis and reconstruction of human skeletal remains, must examine the remains and reporting any findings to both the state archaeologist and medical examiner within 15 days. Thus, Florida state law implicitly requires that training in human osteology occur in an operating laboratory with access to remains of contemporary, as well as historic, significance.

This legislative mandate often comes into play when the forensic anthropologist assists the state archaeologist in determining whether remains are of scientific importance. In 2000, one author (Walsh-Haney) aided the state in the recovery and analysis of remains from a Civil War cemetery from downtown Jacksonville, Florida. The cemetery was discovered while work crews were digging trenches for water, gas, and electricity lines for a luxury, high rise condominium. The skeletal remains were friable, stained and fragmented with most of the bone being broken into thousands of pieces that were less than 1 cm in diameter. This degree of fragmentation was typical of prehistoric and historic burials that are accidentally unearthed by large equipment. Archival information about the cemetery location and time of use (but not who was buried in the cemetery), associated physical evidence, and the skeletal analysis of the remains supported the presumption that the burials were historic or historic remains are discovered the state archaeologist must determine whether the remains are of scientific importance requiring additional study. In this instance, it was up to the forensic anthropologist to make that determination because the remains were terribly fragmented and no information concerning the biological profiles of those in the burials was available. Ultimately, a decision to rebury the remains rather than archive them for additional scientific study was made.

Thus, there exists a necessity for the forensic anthropologist to train with real human bone in order to also assist in the analysis and recovery of prehistoric and historic cases as well as achieving diplomate status. Such laboratory training often occurs in forensic anthropology laboratories, of which there are 14 in the United States and Canada. Just as medical doctors receive their early training in biology laboratories or study in hospitals with living patients under the watchful eye of a mentor, graduate (and undergraduate) students of forensic anthropology must also be afforded an opportunity to hone their skills in such a fashion.

However, whereas medical doctors may spend their careers outside of academia with an emphasis on the application of learned techniques to immediate, single-patient outcomes, most forensic anthropologists (save those working for the federal government) work within academia where primary research is conducted to establish the scientific foundations for these and future techniques. Thus, there is a need to collect data from large samples in order to elucidate statistically significant trends. Forensic anthropologists associated with universities conducting primary research and training graduate students arguably have an ethical obligation to the betterment of their discipline and the appropriate training of their students to incorporate data (and possibly bone samples) from their casework into the broader research questions that need to be addressed. This obligation may at times be at odds with the interests of the next of kin. Resolving this dilemma has been the source of much discussion and legislation as we will see below.

Rights of the Individual, Next of Kin, and Science

The U.S. legal system implicitly recognizes that each individual has the right to say what will happen to his/her body after death. As such, the Uniform Anatomical Gift Act clearly stipulates that prior consent must be obtained from the *donor* before bone, organs, or other tissues can be harvested (Lamb, 1990; Nelkin & Andrews, 1998). If the decedent's wishes are not known, then the next of kin may consent to organ donation. However, if documentation outlining the decedent's wishes is available and contrary to the next of kin's wishes, the decedent's wishes should be followed. Yet some scientists and organ procurement organizations (OPOs) proceed in harvesting tissues under the assumption of presumed consent. Because a dead person is not considered to be a human subject, federally mandated consent rules are not applicable (Fluehr-Lobban, 1998). Instead, an individual's rights and rights of next of kin to control postmortem investigations have become a matter of state law (*Crocker v. Pleasant*, 1999; Nelkin & Andrews, 1998). Within this framework, a frequent source of conflict exists between the need of the medical examiner, and in many cases the forensic anthropologist, to dissect the corpse in order to analyze bones and tissues and the family's need to maintain the integrity of corpse. This essential ethical issue has led to numerous legal disputes on the state level.

In a Florida case, for example, the medical examiner removed the badly decomposed head from a homicide victim so that an osteological analysis of identification and trauma could be conducted by a forensic anthropologist. The victim's family sued the medical examiner for failure to obtain informed consent before removing the body parts. However, Florida Statute 406.11 provides that it is the responsibility of the medical examiner to perform autopsies and investigations into certain types of death; those deaths associated with criminal violence, police custody, gunshot injury, prison, poisoning, suspected sudden infant death syndrome, and when ordered by the state attorney. In addition, it is within the medical examiner's legal and ethical responsibility to seek the help of experts from other fields where necessary, including forensic anthropology. Therefore, the trial court determined that the statute excused the medical examiner from obtaining next of kin consent when he/she is conducting an official investigation and the case was ultimately dismissed. Nevertheless, although the medical examiner fulfilled his legal responsibility in the determination of the victim's identification and the cause and manner of death by seeking expert advice and exhausting the most current methods of scientific inquiry, this conduct, as permitted under state law, clearly conflicted with the final wishes of the family.

The courts have endeavored to reconcile the apparently conflicting value systems between the utilitarian and moral importance of the decedent by acknowledging that scientific study and clinical training conducted on human remains benefits society as a whole while at the same time creating state statutes and organ donation laws that ensure that the living will have a say in what happens to their property and their bodies after death (Nelkin & Andrews, 1998; Crocker et al. 2001; Walker, 2000). One issue confounding a clear-cut analysis of how a corpse must be treated revolves around how the law classifies remains. State and federal courts repeatedly face the question of how to strictly define a corpse. Rather than treating remains as pure "property," the courts often relegate the corpse to the level of "quasi property" (*Crocker v. Pleasant*, 1999; Nelkin & Andrews, 1998). This question arises most often in the context of disputes over the constitutional status of the corpse in relation to the due process protection of the 14th Amendment to the

U.S. Constitution. In this context, a corpse is defined as quasi-property, giving medical examiners and scientists the legal right to bone (and other tissues) without consent from the decedent's next of kin.

Our nation's legal system uniformly gives the medical examiner or coroner authority over the postmortem examination. The degree of authority of next of kin varies from state to state (see Crocker v. Pleasant, 1999; Nelkin & Andrews, 1998). Yet, the specific rules stipulating the disposition of tissues, organs, or bone after the completion of research are vague. For the most part, the courts have proclaimed that tissues held for research after the body has been released to the family may be buried, released to an educational institution, permanently archived, or cremated in an appropriate manner (Sec. 130A-413 N.C. Gen. Stat. [2003]). The medical examiner may retain or dispose of the organs, tissues, or unidentified remains in any of the aforementioned ways, unless the body parts are "claimed by the person responsible for burial" (i.e., next of kin; Sec. 611 RSA [2003]). Most family members are ignorant of the postmortem harvesting of tissues that occurs during a standard autopsy; and therefore, will not present a written request to the medical examiner for internment. Because the tissues are collected as a standard procedure during autopsy there is no need for the family's consent. Once the medical examiner has determined the cause and manner of death, the harvested organs, bones, and tissues can be disposed of in the manners outlined above. Of import, however, is that many of these harvested bones serve as much needed teaching materials for students of forensic anthropology.

Many forensic anthropologists stake claim to the right to conduct research on the dead because the interests of the living, as they see it, outweigh those of the dead (Walker, 2000; Hibbert, 1999). For forensic anthropologists, progress and accuracy in identification techniques, analysis of traumatic injury, and data collected on the establishment of the postmortem interval used in the analysis of skeletal remains depends on the continued availability of bone garnered from autopsy, the donation of unclaimed bodies, and access to Native American remains. To these researchers, corpses and skeletons have a utilitarian value because such analysis makes the science of forensic anthropology better and helps to ensure that future victims and perpetrators of crimes can be correctly identified.

Illustrating this issue is the experience of one author (Walsh-Haney) who participated in the analysis and identification of juvenile victims from the 1996 ValuJet air tragedy in Florida. Antemortem information concerning each victim's age, sex, and ancestry was collected, as well as radiographic and gross data from all of the juvenile remains in order to positively identify the victims and bring closure to the families. However, it was also the author's responsibility to publish the methodology and results used in the identifications in order to help anthropologists in the identification process should tragedy 128

happen again (Warren, Smith, Stubblefield, Martin, Walsh Haney, & Maples, 2000). No families or next of kin were contacted about the scientific publication. Rather, data were codified so that individuals could not be identified and the emphasis of the paper was on methodology. On the surface, some would argue against the publication of data gleaned from such a tragedy for purely academic pursuits. However, having worked with pathologists, odontologists, and radiologists who were unaware of the specific methodology and radiographic atlases necessary to efficiently process and identify the victims, we would have been remiss had we not informed other scientists on how to handle such a disaster.

Recommendations for the Forensic Anthropologist

The use of human remains for research purposes has been the source of much dispute because the scientific benefits that can be gained from the utilitarian use of the dead for the betterment of society conflicts with the religious value it has to the individual and the family (Nelkin & Andrews 1998; Hibbert, 1999). The perspective that we have presented serves to highlight specific instances wherein scientists have juggled the ethics of solving forensic cases and collecting data from the dead while taking into account the wishes of the individual, the next of kin, and the universal principle of respect for the dead. The use of human remains in forensic anthropology research has potent emotional effects on the next of kin, society, the scientists, and their students. When considering the ethical implications of scientific research on the dead forensic anthropologists understand and take to heart the tenet of "do no harm." However, because ethical choices are not clear cut and "doing no harm" comes in many forms and degrees, the forensic anthropologist must make tough decisions on a case by case basis.

On a daily basis, forensic anthropologists find themselves poised to collect convenient data because of their close working relationship with medical examiners and coroners. Indeed, both passive and active research have gone unfettered for decades because the medical examiner has been permitted to harvest bone at autopsy in order to facilitate the determination of cause and manner of death. If a forensic anthropologist then proceeded to conduct research on the parts that were harvested, he or she was within the bounds of the law to proceed with data collection without adherence or deference to laws governing consent. Additionally, if the family does not ask the medical examiner for the return of all tissues or body parts within 48 hours of autopsy, the remains may be disposed of by the medical examiner via permanent curation, cremation, burial, or donation to a teaching institution. The Florida Supreme Court recently added some clarity to these issues when the Court held that the state and its agents may be liable for civil rights violations if proper procedure is not adhered to in the disposition of human remains (*Crocker v. Pleasant*). In finding that the next of kin has a quasiproperty right in the remains of the deceased, the Court decided that the due process dictates of the 14th Amendment might be implicated in such situations (Nelkin & Andrews, 1998). Thus, where the next of kin is not given proper notice and opportunity to render a decision on disposition, a suit may be maintained pursuant to 42 U.S.C Sec. 1983. By analogy, it is logical to assume that the *Crocker* rationale is equally applicable to private rights of action and may give rise to liability in tort against the individual scientist. As such, forensic anthropologists should be conscious of their role and proceed with their analysis carefully and with an attentive eye focused on any stated desires of the deceased or their next of kin.

Ethical precepts and legal statutes form the core of an argument for implementing a standard operating procedure whereby the medical examiner notify the next of kin regarding the disposition of *all* of the decedent's remains. The roadmap for the implementation of such procedures already exists in the ethical and legal standards governing medical research. Failing to provide proper notice and obtain consent regarding active research is a violation of the individual's and next of kin's right to burial or other lawful disposition and results in undue emotional distress (Sec. 611 RSA [2003]); Nelkin & Andrews, 1998). When an autopsy is legitimately undertaken to determine if a crime has been committed, to identify the individual or to determine the cause and manner of death, the body must not be subjected to any additional active, invasive research unless the informed consent of the individual or family member has been obtained.

As anthropologists, forensic anthropologists, in particular, should be wellschooled in asking the tough questions (Bernard, 2000). If forensic anthropologists want to conduct research on autopsy corpses outside the realm of a normal forensic anthropological investigation, under most circumstances they must approach the next of kin for permission and acquire informed consent. This process will establish a more thoughtful and ethical research protocol. Properly done, such a request may result in the family's donation of the entire corpse, thereby contributing to scientific research and the growth of teaching collections. By way of contrast, if permission is not obtained then bone collected at autopsy should be returned to the body after analysis and properly interred.

The evolution of ethical standards, both in the legal context and in cultural norms is not a hurdle to overcome but insurance that forensic anthropologists will conduct good, ethical science. The American Anthropological Association already mandates that all graduate students in anthropology take a course in ethics. DABFA members who are involved in training forensic anthropology graduate students should be proactively teaching the ethical issues of medicolegal death investigation (Galloway & Simmons, 1997) and NAGPRA. A recent survey conducted by Galloway and Simmons revealed that forensic anthropologists are committed to the use of real skeletal material, rather than casts or computer simulations, for instruction. There is no doubt of the need for such collections to grow and be maintained so that future generations of students may acquire their skills by looking at "real bone." In expanding the population of teaching material and improving the training of new scientists, forensic anthropologists must adhere to their legal, moral, and ethical obligations as governed by the rules of their profession and existing law, as well as proceeding with the knowledge that improper actions are likely to adversely affect the next of kin.

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Chapter 10

Commentary: A Discussion of Ethical Issues in Skeletal Biology

Susan C. Antón

The chapters in this section provide examples of primary researchers in skeletal biology addressing issues that may result in self-imposed restrictions on their research. Yet despite their efforts, the symposium audience contained few skeletal biologists and a virtual absence of paleoanthropologists. I found this remarkable given recent claims that our subdiscipline is in dismal ethical straits (e.g., White, 2000; Lockwood, 2001).

On nearly a yearly basis claims and counterclaims over permit areas and fossil finds (Butler, 2001) get presented within the context of the scientific sessions at AAPA. I have attended multiple academic sessions in which a, usually prominent, paleoanthropologist gets up in a room of several hundred people and tells a, usually less-prominent, paleoanthropologist who has just made a claim about permit jumping or some other ethical infraction that this is an inappropriate forum in which to raise these claims. Essentially, the claimant is told to quit whining and get on with science. I am certainly sympathetic to this sentiment as a universal creed. In the best of all possible worlds there would be a forum for raising and adjudicating these claims where both sides might speak. But in our world there is not. So if that junior person does not raise the issue in the academic forum-does it not get raised at all? And is this worse than raising it in a talk that was supposed to be about the fossil finds? Would the junior person have been more in the right had they submitted an abstract that said they intended to make charges about unethical behavior? Would the abstract have been accepted?

Like most ethical issues this is a case in which neither side is wholly right—clearly the claimant feels a transgression has occurred and will continue to occur unless the wider community is informed and clearly the respondent feels that this claim is made in an inappropriate forum and perhaps unfairly broadsides the alleged transgressor. Although, I as much as anyone do not really want to hear about these kinds of things, I want to believe that if I am not hearing about them it is because they are not happening, not because there is no place but the scientific session to sort out the complicated and delicate issues. Nothing but polarization is accomplished unless the community creates an appropriate forum for these discussions. This is a step that we have not yet taken. Clearly, we as skeletal biologists face ethical dilemmas, some of which are public. Yet even these dilemmas and an editorial in the journal *Nature* calling for the creation of such a forum (Fossil-fuelled feuds, 2001) the very week of the AAPA meetings did not bring us to the symposium.

In part we might explain the low turnout of skeletal biologists based on the location of the ethics symposium in a remotely placed room. You really had to want to find this room to get there; others did. But in fact, I think that the absence is actually better seen as a reflection of how we, as biological anthropologists who study human ancestors rather than living primates, approach these dilemmas. Unlike our colleagues who study living humans and nonhuman primates we are not forced by human or animal subjects protocols to address even some ethical issues head on. In fact, the Native American Graves Protection and Repatriation Act (NAGPRA) that Larsen and Walker discuss may have been the first such formal issue to catch the attention of skeletal biologists in recent times and we were largely unprepared for it. Rather, we tend to train explicitly in the details of how to recognize a specific bony protuberance or a cross-bedded sandstone, but we expect our students to pick up other things by osmosis, including how to teach, how to treat their colleagues, graduate students, and others with competitive interests. These are things that we do not spend time formally talking about and they are areas in which bad behavior is not always punished. Even those who do talk about these issues often do so in so dogmatic and authoritarian a manner that it is hardly surprising that productive discussions do not follow. This lack of active dialogue is likely both a reflection of the difficulty of the issues, the prevailing climate, and an absence of a forum in which to discuss them. Thus I see this symposium as a good first step toward opening the discussion of what we should be doing and how we should be delivering that message to our peers and graduate students.

Larsen and Walker address the inherent dilemma that arises between the interests of bioarchaeologists and those of the living peoples potentially descended from these archaeological human remains. As they suggest, in many ways the NAGPRA laws forced the initial dialogue between bioarchaeologists and living peoples. And in some instances the dialogue has not been productive. Larsen and Walker rightly recognize that the ethical dilemma here is providing a balanced means of recognizing the competing but legitimate interests of both distant relatives and scientific investigation. And it is likely that the appropriate balance is not the same in all cases. The answer cannot

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be that one worldview "wins" and the other is silenced. This realization is a critical insight in a highly charged debate. Yet, this recognition is much more easily made than delivered upon. The anthropological community and the U.S. government have often, in fits of what might be categorized as "white guilt" or at best the "path of least resistance," offered over skeletal collections wholesale. The highly publicized case of Kennewick Man appears to be a case of the latter. Cynically, this might be seen as a cheaper solution than handing over things of economic value such as land. Alternatively, there are legitimate instances, particularly in cases of direct, immediate ancestry where possession and study of remains cannot be sanctioned. Larsen and Walker are scientific leaders in bioarchaeology and have also been two of the more successful and involved scientists in developing a dialogue with the native communities with which they work. It is noteworthy that these dialogues are difficult and must be predicated on individual trust. It is also noteworthy that these dialogues may never be wholly satisfying to either party precisely because fundamental world views are in opposition to one another. But it is likely that these may be the only means of developing a lasting understanding that protects the histories embodied by these remains.

Walsh-Haney and Lieberman offer a glimpse into the ethical dilemmas of forensic anthropology. Here we see similar issues arising regarding the balance between the interests of the victim, the next of kin, and forensic science. Because of the discipline's proximity to the judicial system, many of these are addressed in complicated laws that vary from state to state. Yet despite this relative plethora of laws, the ethical dilemmas resist simple solutions. The conflicting obligations of the forensic anthropologist to the identification and evaluation of the victim in a specific case, to the training of future scientists to identify future victims, and to the education of peers to advance the general ability to identify victims are appropriately highlighted. Again, as Walsh-Haney and Lieberman suggest, communication between opposing parties is the key to both immediate conflict resolution and to the longevity and growth of the discipline. It is noteworthy that even in this highly regulated field, self-policing is much relied upon and little training is devoted explicitly to ethical problems. It is also worth noting that this thoughtful piece was developed from the lead author's experience in forensic anthropology coupled with her coursework in general anthropological ethics. This is a good example of the kind of constructive dialogue that can begin when discussions of how to handle ethical dilemmas are given explicit room in training programs.

Monge and Mann address one's ethical responsibility toward future researchers/interests through their example of how molding and casting of skeletal and fossil remains is inherently destructive, if at a small level. They rightly note that similar, if not more dramatic, concerns can be lodged against the repeated measuring of fossil specimens and the small, but cumulative damage inflicted by calipers and other instruments. Thus access and knowledge gained from the undertaking must be balanced against harm done. The availability of casts of fossil remains allows some preliminary study to be undertaken on the cast rather than the original and allows more researchers access to at least the gross morphology of the fossil hominid. Thus molding and casting do much not only to preserve original specimens but also to frame the wider debate about hominid evolution.

Monge and Mann are right to emphasize the former benefit, yet the latter is also critical to how hominid evolution is studied and by whom. The availability of casts in research collections brings into the collective conscience the morphotype of a particular fossil in a way that slides and articles cannot. Arguably, the more widely distributed fossil casts influence more significantly the collective ideas about the morphology of our ancestors. For example, the wide distribution of Weidenreich's casts of the Zhoukoudian fossils, despite the loss of the fossils themselves, and the fewer available casts of southeast Asian H. erectus seems to have fundamentally shaped how anthropologists conceive of the morphology of H. erectus. Often the Zhoukoudian fossils end up forming the "conventional wisdom" of Asian H. erectus anatomy, despite consistent morphological differences between mainland Asian and southeast Asian fossils (Antón, 2002). Similarly, more complete specimens, such as the KNM-ER 3733 cranium, although representing only a single individual from a population, tend to be overemphasized in collective thought in comparison to more fragmentary remains, such as occipital fragment KNM-ER 2598, perhaps in part because few laboratories have casts of the latter.

In addition to this influence on the collective ideas about morphology, the availability of casts also invites discussion and evaluation of research findings and frees researchers from the control of information and specimens by a single or a few elite researchers. I am not speaking here of people that would be happy to distribute casts but do not have the requisite infrastructure to do so, or about those who choose to limit cast distribution until after the publication of new finds, but am rather referring to those who have such infrastructure but choose not to distribute casts beyond a select few. Although no doubt some of those elite believe that they are the only ones with a line on Truth (with a capital T), as historical scientists we would be foolish not to accept that the relative worth of our work (and that of others) will only be sorted out after we are all long dead. It is as much our responsibility to make specimens available for review and response as it is to work honestly and earnestly on the collection of these data. High quality molding and casting can help us to do so.

Molding and casting, although never adequately replacing the firsthand observation of original fossils, provide a number of important benefits to the community. Perhaps in the future three-dimensional imaging techniques will be detailed enough to grab the same surface detail as traditional casting

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techniques. Surely, these methods should be pursued—but at present there is no substitute for professional casts. That said, Monge and Mann are right to emphasize the need for true quality professionals in the casting and preparation process. And they should be applauded for raising the issue of balancing between the needs for molding and the damage to the specimen. There is also a reasonable expectation that training should be extended to foreign institutions so that quality casting can be achieved and curatorial issues can be addressed in the home country.

Within paleoanthropology in particular there should be a recognized responsibility toward building infrastructure and training colleagues in host countries. This includes technical training, as for example molding and casting, but ought also to extend to academic training as well. Such responsibility, however, raises its own sets of ethical issues. Ultimately, the goal ought to be for the scholars of the host countries to be independent of their western advisors for both expertise and finances. Yet host scholars often end up working exclusively with their advisors-a clear benefit to the research program of the advisor. Such collaboration is in some way understandable given the trust that must develop in any good advisor-student relationship. Yet the possible attainment of such an exclusionary collaboration may potentially color the behavior of the advisor and the advice given. Thus, what is in the best interest of the student may not be the same as that which is in the best interest of the advisor. Although we might find this to be true of some aspects of all advisorstudent relationships (i.e., it might be advantageous for an advisor to delay the graduation of a well-trained technical student running their lab longer than it is advantageous for that student), the added lens of a foreign student who potentially holds the key to field access in a host country complicates the picture dramatically. In a sense it becomes in the advisor's interest to foster distrust between the student and other professionals, whereas at least some of those professionals may be able to provide resources and expertise that the main advisor cannot. Any exclusionary relationship should be closely examined by all sides. One possible solution is to have foreign students trained only by those with no interest in working in the host country. This, however, would produce some disadvantages. Presumably those working in the host country know the specific scientific issues the best and some interests, such as building infrastructure, may be shared by advisor and student, thus ensuring a greater likelihood of success. Again, there are no easy answers and the presence of a potential conflict of interest should not dictate recusal, however, it should dictate close scrutiny and vigilance on all sides.

The ethical questions raised in this volume pose quandaries precisely because they involve opposing but legitimate interests. As such they do not yield to simple resolutions in favor of one of these interests, but require that a delicate balance be struck. Within skeletal biology (broadly defined) there are many potential ethical pitfalls a few of which have been addressed above.

Additional potential ethical dilemmas arise between the opposing interests of peers and between those of professors and graduate students. Fairness, graciousness, and good manners would address many of these issues (e.g., say please and thank you, don't take things that aren't yours, give credit where credit is due, play fair). But many are more problematic and all require one to follow not only the letter but also the spirit of the law. In reflecting upon these it seems we might do well in our graduate curricula to devote course time to ethical issues. Many of us have courses to explicitly work on other aspects of career development such as writing a grant, giving a paper, or even interviewing for a job. But how many have a structured environment in which to discuss the ethics of authorship, how to work in a different culture, how to request research access and how to follow-up? How often do we say to them "you are not the center of the universe," you need to consider another position? How often do we behave that way ourselves? And where do we train our graduate students in "how to train graduate students" except by observation? Do we address the inherent conflicts of interest involved in training graduate students from the country in which we conduct our own research or the inherent responsibility to building infrastructure and training in those countries? There are no simple solutions-but they are problems that deserve to be discussed.

The emphasis here, however, must be on discussion not dogma. Surely we each have our own strongly held beliefs about what is right and wrong. But as Larsen and Walker point out, in some instances this is not the question. It's all well and good to say "do no harm," but as we have seen defining the harm and balancing it with the good are more complex issues. Ethical dilemmas require sincere and mature reflection. They require actual communication between people not polemic. As in each of the above examples, they require mutual respect and trust. We cannot hope to have future professionals who address issues in this way unless and until we are willing to enter this type of dialogue ourselves.

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Chapter 11

Ethical Issues in Human Biology Behavioral Research and Research with Children

Sara Stinson

Human biology is a field of physical anthropology that traditionally has a strong biocultural focus. Because of the interest in the relationship between biology and culture, human biology research frequently involves collecting both biomedical measurements (such as anthropometry, lung capacity, cholesterol levels) and behavioral measures (such as questions about socioeconomic status, recording of food intake, or observations of activity levels). Human biology is also a discipline with a strong emphasis on the human lifecycle; as a result human biology research frequently involves children as research participants. This chapter discusses some of the ethical issues and questions that human biologists deal with as a result of the behavioral aspects of our research and our research with children, in particular issues arising from the principles outlined in the Belmont Report (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979).

This chapter grows, in part, out of my own fieldwork experience doing research on child growth in Ecuador and Bolivia. This includes my dissertation research in 1977 on the factors affecting physical growth and demography in rural, high-altitude Bolivia (Stinson, 1980a, 1980b, 1982a, 1983), research in 1980 on the growth of children in La Paz (Stinson, 1982b, 1985), and research from 1986–1992 on child growth and nutritional status in northwest Ecuador (Stinson, 1989; Stinson, Calvopiña, Narváez, & Guderian, 1994, Stinson, 1996). As is the case for most human biologists, particularly those who work outside their own culture, I faced a variety of ethical dilemmas in the field. Although I wish I could say that this chapter is based wholly on my understanding of these ethical dilemmas as it came about as a result of my field experiences, in fact, much of this chapter is based on my experience

during the last decade as a member of my college's Institutional Review Board (IRB), the committee that oversees research involving human subjects.

As is discussed in other chapters in this book, various levels of permission are involved in conducting physical anthropology research. U.S. scientists conducting research with human subjects are governed by Title 45, Code of Federal Regulations, Part 46 (usually referred to as 45 CFR 46), and must obtain IRB approval before beginning research involving human subjects. The current regulations were published by the Department of Health and Human Services in 1991, although they are based on earlier sets of policies (see National Bioethics Advisory Committee, 2001 for a brief history of U.S. human subjects regulations). So, for example, my 1977 research was carried out before the structure for human subjects' protection was in its current form. I remember that I had to receive human subjects' clearance from my university before beginning my research, although I do not remember exactly what form that took. The existing paperwork for my 1980 Bolivian research indicates a human subjects' approval process similar to the current one. Similarly, the extent of oversight of my research by agencies in the countries where I was working also changed over time. My research in Bolivia required formal approval from the Bolivian Institute of Anthropology, but only informal permission from the directors of the schools in which I was conducting measurements, and, for the first study, from the leaders of the rural community where I was living. When I began conducting research in Ecuador, the only formal approval required was from the government agency overseeing anthropological research, but by the early 1990s formal approvals from the Ministry of Health and the newly formed Chachi Federation were also necessary. At the time I conducted my research, representatives of the actual study participants were not as actively involved in the process as is described in other chapters in this volume.

The Belmont Principles

U.S. human subjects policies, and those of many other countries and international organizations, are based on the ethical issues discussed in the Belmont Report (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979). The Belmont Report set out three ethical principles as the foundation for research involving human subjects: beneficence, justice, and respect for persons. The commission defined beneficence to mean that the benefits of the research should be maximized and the harms minimized. The principle of justice requires that the benefits and burdens of research be fairly distributed. Respect for persons entails the ideas that individuals should participate in research voluntarily and with adequate information, and that there should be special protections for those with diminished autonomy. All of these principles have important implications for human biology research.

Beneficence

When we consider harms associated with research, we usually think about physical harms, such as pain, injury, or even death. Although these sorts of harms generally do not occur with behavioral research, behavioral research can carry the risk of emotional, psychological or social harms (Warwick, 1982). Individuals may be personally embarrassed by the questions we ask, they may feel guilty about the behavior they reported to us when they think about their responses after the fact, or they may suffer social stigmatization if others learn of their responses to our questions. Yet another potential harm is that the results of our research could affect public policy in a way that has a negative impact on our research participants. Interestingly, U.S. regulations expressly forbid IRBs from considering public policy implications in their risk-benefit assessment, although this certainly does not mean that the researcher should not consider them. The Code of Ethics of the American Anthropological Association states that "Anthropological researchers . . . must also consider carefully the social and political implications of the information they disseminate" (American Anthropological Association, 1998, p. 20).

The risks of biomedical procedures can frequently be objectively quantified; for example, a certain percentage of people will experience nausea when performing a maximal exercise test. No such quantification is generally available to inform potential participants about how likely they are to feel embarrassed or guilty taking part in behavioral research such as answering questions about what foods they ate the previous day. In part this is because behavioral research has usually been considered not be entail much risk-so there has been little attempt to quantify the risks. Another reason is that physical harms that occur as a result of research are likely to be more obvious to the researcher than are emotional harms. Yet another reason for the difference in ability to quantify harms is that in some cases the risks of behavioral research are highly individual. Questions that would be totally innocuous asked to one person could invoke strong feelings of stress and anxiety in another. And here, in fact, lies a way in which potential participants in behavioral research can determine their actual personal risk. Although we cannot usually quantify the risk of embarrassment or psychological stress as a result of behavioral research, if we provide enough information about the procedures to be followed, potential participants may be able to determine their own risk, something that usually cannot be done for biomedical procedures.

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Until you actually do the maximal exercise test, you do not know whether you are going to be one of the x% of people who will experience nausea. But it is much easier for you to know, because you have an eating disorder or because your family is too poor to have had any money to buy food that you are going to be embarrassed answering questions about your diet. One of my most vivid memories from my dissertation research is of a man who implored me not to ask him about his diet because he was ashamed of how little he had eaten.

So when doing behavioral research it is important that potential participants be fully informed about what they are going to be asked to do so that they can determine whether the procedures are risky for them. This is especially true when working outside the researcher's own culture, where it may be extremely difficult for the investigator to judge what sorts of procedures are going to result in embarrassment or guilt. This is a case where our knowledge of the cultures we are studying is useful to determine what sorts of questions are likely to cause harm; as it could also be the case that questions that would be considered sensitive in our own culture might be innocuous in another.

Social stigmatization can occur either at the individual or group level (Warwick, 1982). For individuals, there is the possibility of harms such as embarrassment, loss of social status, or even economic or legal problems should their responses to our questions become known to other members of their social group. At a group level, there is the possibility that our results could lead to negative stereotypes of the entire group. Both are potential problems in human biology research.

The possibility that individuals will be stigmatized within their own group is exacerbated because of the circumstances under which much human biology research is conducted, especially in field situations. We do not generally have the luxury of private offices in which to conduct interviews and we frequently rely on the assistance of local field assistants and/or translators. Although we can honestly assure participants that their names will not be associated with their responses in any scientific presentation of our results, confidentiality is more difficult to assure in relation to their own social group (which may be the arena that matters most to them). A situation that happened more than once during my Ecuadorian research was making arrangements to interview individuals in a village on a certain day, only to arrive to find most of the community assembled in one central location where it is impossible to assure anyone privacy in answering questions. This is hardly a situation that leads to honest responses to any question that the participants find even somewhat sensitive. But because we frequently see ourselves as guests in the community, and do not always totally understand the social rules, it can be awkward to insist upon another setting. Although one could argue that in a small village everyone knows everyone's business anyway, and that participants are not telling us anything that everyone else does not know

already, this does not necessarily make it pleasant or desirable for participants to divulge information in public. This is not to suggest that human biologists should never talk to individuals in groups. There can be many advantages of speaking to groups of informants from a research standpoint. One that I have seen in my own research (when I was interviewed a group of Ecuadorian women about how long they breastfeed) was where one individual gave the response she thought I wanted to hear, and was quickly corrected by other members of the group with statements such as "But that's not what we do, we really do x." In cases where the individuals in the group are comfortable talking in front of each other (which I hope was the case in the situation I described), this can be done with little discomfort to anyone. But we need to be aware that situations such as these have the potential of leading to social stigmatization, and we need to take steps, such as making it clear that individuals do not need to answer our questions, to make sure that this does not occur.

Human biologists tend to study the poor and marginalized rather than the rich and powerful. The groups we study, then, are especially vulnerable to negative stereotyping. For example, research results showing that child feeding practices are responsible for poor childhood growth could lead others to stigmatize the groups as "one that does not even know how to feed their children." The possibility that research results will lead to group stigmatization is more difficult for the individual researcher to control because these negative stereotypes result, in part, from how others interpret our research results. The greater oversight of the groups we are studying may impel us to more directly confront the issue of stigmatization. Foster, Bernstein, & Carter, (1998) describe an agreement made with the Apache Tribe of Oklahoma for a genetic study whereby an administrative body of the tribe would review any manuscript prior to publication, and could request that the Apache not be identified by name in the publication.

Justice

The principle of justice finds its most immediate application in the selection of research participants. For the burdens and benefits of research to be fairly distributed, research participants should be chosen from the groups most likely to benefit from the results of the research. Groups or individuals should not be targeted as research participants just because they are convenient or easy to convince to participate (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979). On the one hand, the principle of justice has been used to argue that we need to be especially careful about protecting the rights of vulnerable populations, such as the economically disadvantaged or the institutionalized, from bearing an unreasonable burden as research participants. Others have argued, however, that this protectionist position has at times denied groups considered vulnerable the benefits of research participation (especially benefits from clinical trials). A discussion of both sides of this issue is found in Kahn, Mastroianni, & Sugarman (1998).

The issue of justice is relevant to human biology research for several reasons. Human biologists frequently study populations that are potentially vulnerable because of their disadvantaged social position, and in many cases the researcher occupies a (real or perceived) position of power in relation to potential research participants. Human biologists, however, generally select populations for study because of a genuine interest in the population, rather than because individuals in a particular population will be easy to convince to participate in our research. The potential vulnerability of our study populations may be less a problem of justice than a need to be aware of power differentials in terms of obtaining truly voluntary participation. Another potential concern arises from a frequent justification for international research—that studying populations with a different way of life will increase our understanding of a health condition in our own country. We need to make sure that we are not asking individuals to participate in research that will only benefit some other population, rather than their own.

Research with Children

The Belmont Report principles state that there should be special protections for research participants with diminished autonomy (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979). Children are included in this group because of their limited ability to understand what is being asked of them. U.S. regulations thus provide extra safeguards for research involving children. These include the requirement of parental permission and child assent, and the prohibition of research with children that involves more than minimal risk, except under special circumstances.

According to U.S. regulations, assent means "A child's affirmative agreement to participate in research. Mere failure to object should not be construed as assent." (45 CFR 46.402). The decision about whether child participants in a particular research project are capable of giving assent is left up to the individual IRB; there are no specific guidelines as to the age at which assent must be sought. Assent can be a difficult issue in cultures in which ideas about the rights of children are different from our own. It is easy to imagine situations in which the parent wishes the child to participate in a research project, the child does not want to, but the parent insists. In the United States it might be possible to explain to the parents that federal regulations require that the child give assent, but this explanation is unlikely to carry much weight outside the United States. In Ecuador I frequently faced the situation of having a parent want me to measure a crying child and trying to explain to the parent that I really did not want to measure a child who so obviously did not want to be measured. This places the researcher in the difficult situation of trying to translate U.S. regulations into terms that are meaningful in another culture, while at the same time trying not to offend her/his hosts.

Research with children cannot involve more than minimal risk except under specific circumstance. This is not generally a problem in human biology research because the research we do with children rarely involves much risk of physical or emotional harm. Minimal risk is defined as "the probability and magnitude of harm or discomfort anticipated in the research are not greater in and of themselves than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests." (45 CFR 46.102). This is a definition that certainly leaves room for interpretation, especially as to what the standard should be for harms or discomforts ordinarily encountered in daily life. There has, for example, been debate about whether this definition indicates a different standard of minimal risk for ill individuals (Nelson, 1998). Procedures such as a spinal tap would certainly be more than minimal risk for a healthy individual since they present greater discomfort than the individuals would ordinarily encounter in daily life. But what about an individual who is hospitalized and has received multiple spinal taps for diagnostic purposes? The National Bioethics Advisory Committee (2001) has recently recommended that the minimal risk standard should be interpreted in terms of the harms and discomforts ordinarily experienced by the general public-so that the standard for minimal risk would be the same for all individual in the population. How the concept of minimal risk should be extended to the populations frequently studied by human biologists, where the lives of children are inherently more risky than those of children in the United States, is less clear.

IRB Flexibility

The definition of minimal risk deserves some attention because minimal risk is important in several contexts in the U.S. regulations. For research that involves no more than minimal risk, IRBs have substantial latitude as to how they apply the requirements of informed consent, parental permission, and child assent. The IRB can waive the requirement of written documentation (i.e., a consent, permission, or assent form), providing that the research does not involve any procedures for which written consent would be required outside the research setting. Much of the behavioral research that human biologists do would certainly fit the latter part of this requirement—although you would normally need written consent to remove a gall bladder, you would not need written consent to ask someone questions. Under a somewhat more stringent set of circumstances, IRBs may waive or alter some or all of the requirements for informed consent completely.

I mention IRB flexibility because many of the complaints we hear about the federal human subjects regulations hindering research are not a result of problems with the regulations, but of problems with how IRBs are applying the regulations (see, for example, American Association of University Professors, 2001). IRBs, in fact, have considerable leeway, and many of the variations from the standard written consent form may be particularly applicable for human biology research. Because most of my field research was with populations in which the majority of individuals could not read or write, my IRB regularly waived the requirement of a signed consent form.

As human biologists we need to educate ourselves about potential ethical issues in our research and think about these as we design our research. I know that prior to joining my institution's IRB, I did not think much about ethics until it came time to fill out the forms for IRB approval, and even then I am fairly certain that I was mainly thinking something like "What do I have to do to get this project approved as quickly as possible, and why do I have to deal with all this bureaucracy in the first place since I'm not going to be doing anything that could harm anyone anyway?" This is not an approach that I would recommend today. The more we understand the ethical aspects of our research, the better position we will be in to design good research and to work with IRBs to educate them about the types of research we do and about how deviations from the standard model might be applicable to us.

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Chapter 12

Institutional Review Boards: The Structural and Cultural Obstacles Encountered in Human Biological Research

Stacy Zamudio

In contrast to most of the papers in this volume, this paper provides an overview of how the changing culture of Institutional Review Boards (IRBs, Human Subjects Protection Committees) has come to present obstacles to the ethical, cost-effective, and efficient conduct of human biological research. No one would argue that human subjects protection is unnecessary or should not be vigorously pursued and protected. The arguments pursued in this chapter are in no way intended to convey the message that ethical treatment of human subjects is not important. However, I and many others of my generation of human biologists are concerned with the way in which the procedures designed to protect human volunteers in research have evolved: they are extremely complex and do not match the intensity of review with the potential harm or benefit associated with the questions being asked

This chapter is divided into two sections. The first considers what I refer to as "structural problems" with the IRB process. In this category of our discussion, three structural problems will be considered and examples of their negative impact on the conduct of research, teaching and training will be given. The first and most important structural problem is that of multiple IRBs, each with differing interpretations of how the federal guidelines concerning protection of human subjects should be applied. It is this issue which receives the bulk of attention in this chapter. The second structural problem concerns the shift in medical economics and hence the culture in which medically oriented human biological research must take place. The third structural problem is imposed in part by increased regulatory vigilance, for example, the expansion of requirements for IRB approval into classroom and other educational exercises designed to teach students how to acquire research skills.

A second issue to be considered in this paper is that of the United States, and in particular Department of Health and Human Services-National Institutes of Health rigidity with respect to the process of informed consent. Our assumptions about what constitutes free and unfettered consent to participate in biological research may be in violation of the cultural norms of other countries and peoples. The assumptions of our governing institutions about what exactly constitutes an adequate IRB and human subjects protection may present obstacles when working abroad. U.S. federal regulations concerning informed consent are not always congruent with cultural values and expectations of our colleagues and subjects in foreign countries. Several examples of this problem will be presented and discussed.

The viewpoints and issues I present in this chapter are more relevant to situations engendered by National Institutes of Health (NIH) funding than National Science Foundation (NSF) funding. However, as the NIH is far more powerful than the NSF in setting standards for the conduct of human research, and because I have personally observed NIH-style guidelines for the conduct of research being imposed on anthropologically oriented human biological research, I think that the issues discussed in this chapter will become increasingly relevant. What I present here is based on my experience and reflects my opinion, and it will be apparent that I work within the biomedical system to a greater degree than many other human biologists. But, because human biologists often use the medical system to find subjects for study, I believe the problems identified here will be increasingly encountered by our colleagues and trainees in the future.

I. Structural problems with IRBs: Multiple IRBs are involved in multisite collaborations. Each institution is free to interpret many of the guidelines offered by the federal government to suit their own circumstances. Some interpret these guidelines more broadly or narrowly than others. Where such differences occur, the lack of agreement between IRBs can make multisite collaborations difficult.

Case Study 1:

From 1996–1999 I was privileged to work on a collaborative research project involving four different Institutions. The protocols involved were complex, and carried more than the "minimal risk" most of our human biological research entails. (A study with minimal risk would involve no more than

nonpersonally disturbing questionnaires, perhaps a venous blood draw, noninvasive anthropometric measurements, or other noninvasive procedures such as wearing a heart rate or blood pressure monitor in a nonprotected subject group. A protected or special subject group would be pregnant women, fetuses, prisoners, the mentally deficient, or children). Each of the four institutions required that approval be obtained from their own IRB, even though the funding award was made to only one institution. Fully 20% of my total work effort for an entire year was spent on obtaining the IRB approvals from these four institutions; this was in addition to considerable time invested from other investigators located within each institution.

Each institution's IRB had its own particular format for the protocol and human subjects consent form. For example, institution A, which was the performance site for half the studies, required that each human subjects consent form open with statements derived from the Helsinki convention-essentially a list of subject rights. This was then followed by a brief, numbered list of all the tests to be performed. Then the tests themselves were described in full detail, along with the risks inherent to each. Because this was a complex study, the consent forms that resulted from the multiple IRB review processes were nearly 20 pages in length. It was this length that convinced the IRB at institution B (the organization that had actually received the grant money for the project) to accept the organizational structure favored by the IRB at institution A. But getting agreement between the two IRBs required presenting to the IRBs the proposal that multiple consent forms-one for each institution-would have to be signed by each volunteer. It was this prospect that convinced institution B, reluctantly, to agree to the format used by institution A. But the real sticking point between all four Institutions had to do with what are referred to as the "liability clauses."

What follows below are the liability clauses that each institution ultimately REQUIRED, and all of these clauses were located one section of the single consent form agreed to by three of the four institutions. The fourth institution would not permit any of these clauses to be present, as their rules specified that subjects not only would receive whatever medical care they needed, but could also ask for compensatory redress for any injuries resulting from the research. Ultimately, we used two different consent forms, one agreed to by three of four institutions, and a second form, agreeable to the fourth institution. Each form was approximately 20 pages long.

INSTITUTION A: All forms of medical diagnosis and treatment whether routine or experimental—involve some risk of further injury. In spite of all precautions, you might develop medical complications from participating in this study.... You are authorized all necessary medical care for injury or disease which is the proximate result of your participation in this research.... Other than medical care that may be provided (and any other remuneration specifically stated in this consent form), there is no other compensation available for your participation in this research study; however, you understand this is not a waiver or release of your legal rights....You do not waive any liability rights for personal injury by signing this form. For further information, please call....

INSTITUTION B: In the event your participation in this research, supported by _____, results in injury to you, medical treatment will be available, but you will have to pay for this care. You will not be paid for any other loss as a result of the injury, such as lost wages, pain and suffering. Further information can be obtained....

INSTITUTION C: In the unlikely event you are injured as a result of participation in this study, _____ will furnish humanitarian emergency medical care (for non-veteran participants) or medical care (for veteran participants) as provided by Federal statute. Compensation for such injury may be available to you under the provision of the Federal Tort Claim Act (for non-veteran and veteran participants) and/or 38 U.S.C. section 1151 (formerly section 351)(for veteran participants only). For further information, contact....

Clearly, the liability clauses listed above are in conflict with one another. One indicates that signing the consent form does not waive a subject's right to seek redress for personal injury, whereas another specifically states that such redress will not be permitted. The investigators debated at length on how to overcome this problem, and although we eventually decided to pursue getting private insurance for all participants to cover injuries, should any arise, it ultimately proved impossible to obtain such insurance.

We were fortunate that all went well in these studies, and that no one was injured or harmed in any way by the research. As is well known in hospital risk management circles, the relationship formed between caregiver and patient is the strongest correlate of whether or not lawsuits will be filed. Caregivers with excellent relationships with their patients, who explain all procedures and their risks clearly and well, are not often accused of malpractice. The same principle holds true in human research. It is critical that investigators develop comfortable and humane relationships with their subjects. In the project discussed above, in which a dozen or so investigators and a dozen or more research volunteers were in close proximity to one another for weeks at a time, the relationships that developed between subjects and between subjects and investigators in large part precluded frivolous complaints about possible long-term injuries due to the tests being performed.

Case Study 2:

The interpretation and conveyance of the principle of beneficence varies from IRB to IRB. As has been reviewed elsewhere in this volume, one of the four considerations that must be present when dealing with human subjects consent for participation in research is beneficence. Beneficence requires not only that one do no harm, but that one should be trying to do good. Some of us may well argue that this is the most important ethical concern in the conduct of human research. This case example derives from one of my doctoral students who had been employed within a biomedical research institution for many years. He had extensive experience both in clinical trials of psychotherapeutic drugs, as well as questionnaire-based research. Because he was enrolled in a doctoral program on a different campus, he sought approval for his dissertation work, concerning perceived suffering in hospice patients from the campus at which he was a student. However, because of his extensive work experience, he based his protocol description and consent form on the rules established by the biomedical research institution. There were two conflicts that resulted from his using the biomedical research institution's model for an IRB application on another campus, both stemming from the more conservative and medico-legally oriented interpretation of federal guidelines by a biomedical research institution relative to a traditional undergraduate/graduate university. However, as this example demonstrates, the traditional university appeared to come closer to the goal of satisfying the principle of beneficence than did the biomedical research institution.

The biomedical research institution permitted the human subjects consent forms to state in the opening paragraph why the work is important, for example, "this study might increase our knowledge about what causes pregnancy complications." However, it specifically forbids any discussion of benefit, unless the study involves an experimental drug or other disease treatment regimen that might result in some tangible benefit in terms of cure or inhibition of progression, and even this is handled in a somewhat equivocal fashion. For nontherapeutic studies the biomedical research institution required the following statement to be included on the consent form: "You will receive no benefit from participating in this research study and there are risks as mentioned in the Risk section." The instructions to applicants further specified: "Do not use additional phrases that suggests that the study will benefit society and/or patients in the future."

Further, the following statement had to be included in the consent form if the protocol was deemed of any more than minimal risk, regardless of whether or not the studies performed are invasive or noninvasive: "If you are hurt by this research, we will provide medical care if you want it, but you will have to pay for the care that is needed. You will not be paid for any other loss as result of the injury, such as loss of wages, pain and suffering. Further information can be obtained by calling (Investigator name at (XXX) XXX-XXX [Phone Number])."

Because my student had done previous research with hospice patients, approved by the biomedical research institution and he knew they required inclusion of the above phrases, these statements were included in his application to the IRB at the traditional university. This IRB was concerned about the above phrases. The IRB at the traditional university believed that without addressing the principle of beneficence, in other words, what good could come of this research, then the research should not proceed. Because they were unaware of the biomedical research institution model, they were surprised by the statement about causing injury and not paying for it. They felt that statements about injury were unnecessary for a protocol that essentially involved an interview consisting of one or two questions. However, the resolution of these issues delayed the start date of my student's research by a month or more. Ultimately, the student's consent form contained the following statement about benefits:

Although no benefits *can be guaranteed* to you, it is possible that study participation will reveal areas of suffering that the hospice staff was previously unaware of. With your permission, the results of this interview can be shared with the hospice staff. This might allow them address your areas of concern of which they were previously unaware. It is also possible that results from this study might permit hospices and the persons who work in hospice to develop better ways to relieve suffering in their patients.

The statement about possible injury was omitted. One result of this student's experience was that the traditional university IRB agreed that it would accept approvals granted by their sister campus, the biomedical research institution, in other words, students involved in projects on both campuses need not get approval from both campus IRBs. However, the reverse courtesy was most certainly not extended to the traditional university campus—the biomedical research institution would not accept any other Institution's approval as a substitute for their own. Ignoring the principle of beneficence, rendering it so minor as to be mentioned only in passing in an opening paragraph about why the study is important, and then explicitly denying any benefit in a formally required set of words, seems to be counter to one of the four ethical principles informed consent. One could ask, why should anyone participate in any research at all, if one cannot anticipate that "the study [might] benefit society and/or patients in the future"?

Case Study 3:

The process of applying for permission to recruit subjects where multiple IRB approvals are required can be discouraging to trainees and will turn otherwise talented students away from research careers. This final example of the difficulties posed by multiple IRBs also stems from a doctoral student's experience. This student was interested in domestic violence during pregnancy. She had developed an anonymous questionnaire to be used to ascertain the incidence of domestic violence during pregnancy in a variety of primary care settings and to address some specific hypotheses about factors that predict an increase or decrease in the amount of violence an abused woman suffers prior to versus during pregnancy. This is an important topic, and clearly a sensitive one involving several sticky issues for IRBs. Pregnant women comprise a special population, and there is a legal obligation to report suspected abuse where it is detected. The only way in which this student could conduct her research was using an anonymous questionnaire. This would have been fine, could she have conducted all of her research in one place. She received NIH funding for the conduct of this study within a primary care network. The primary care network was headed by a group within a biomedical research institution, and hence a approval was obtained from the IRB at the biomedical research institution. However, when the student went to actually conduct her research, she found that many of the participating primary care facilities were themselves part of other organizations that also had their own IRBs and they required additional approvals. In each case, these additional approvals required following complicated and time-consuming pathways, with multiple follow-up meetings to ensure that all concerns were addressed. At one site within the primary care network (theoretically they all should have considered the parent organization's IRB approval sufficient), she was denied the opportunity to survey subjects because the site did not have an internal IRB to review her protocol and give approval. After six to eight months of hard work, the student found that her access within the original primary care network was not going to yield the sample size needed, so she turned to other primary care sites, some quite distant from her original sites, and each of which also required a separate IRB approval. In all, by the time she finished her study, she had sought approval from a total of seven IRBs within a time period of eight months at an estimated time investment of 30 hours per approval. The biomedical research institution approval alone required two solid weeks or work, an estimated 80 hours. This student said: "I will never do a multiple site study where I need to go through multiple IRBs again. It's not worth it, especially for special populations."

II. Structural problems with IRBs: The negative impact of "for-profit" and/or "managed care" medical models on human biological research.

In the previous section we considered situations in which IRBs, with the best of intentions in protecting human subjects, actually present obstacles to the conduct of research. We specifically considered that the lack of agreement from IRB to IRB in how the guidelines for ethical consent procedures are interpreted causes misunderstandings, delays, frustration and confusion for both established investigators and trainees. In this section we consider first how IRBs are now sometimes being used to prevent or at least to discourage research, and second, how the medical culture promoted by managed care or for-profit economic models results in the inhibition of and increased costs for doing human biological research.

We (persons living in the United States) are all aware that the transition to primarily HMO-based medical care has impacted upon our personal access to the health care system. There has been little written about the impact of changes in medical economics on the conduct of human biological research. It has been chilling. Research, unless one charges the investigator, does not pay within systems where profit is measured at the end of the fiscal year. Where the bottom line is money, especially money that goes out to shareholders on a quarterly or annual basis, if a clinician or other caregiver's time is spent in efforts that do not generate revenue, those efforts will be discouraged within the culture of managed care or for-profit institutions.

Let me give several examples of this phenomenon, which is difficult to "measure" with anything more than anecdotal descriptions. When I first began conducting research, in the late 1980s, the regional medical school and affiliated hospital approval process and consent form was accepted as valid by virtually all other area hospitals and private practices. If one had approval from the medical school IRB, and provided copies of the approved protocols and consents to other institutions and private practices, they would allow subjects to be recruited via flyers, or by encouragement from personal physicians or other caregiver contacts. In general both the university-based and external physicians and private practitioners were supportive of research efforts.

By the mid- to late 1990s, most area hospitals except the university hospital and the regional safety net hospital had been purchased by for-profit corporations. Within the same time period, each hospital established its own in-house IRB to approve of research, whether such research was internally or externally generated. By the late 1990s, virtually all of these IRBs had imposed an annual fee ranging from \$400–1200 to simply review an investigator's protocol—no guarantee as to whether or not it would be approved. Clearly,

such fees are beyond the means of persons who do not have significant funding, which limits research efforts in the for-profit medical care setting. These charges discourage small research projects such as those generated by masters of doctoral students, or pilot studies intended to explore the feasibility of larger studies. For-profits suggest that they must charge for protocol reviews because physicians and other caregivers must be paid for the time they give up to serve on an IRB, because that is time taken away from their ability to engage in revenue generation. In reality, charging for review simply discourages applications for approval of research.

The negative impact of economic models in which medical practice must result in profit has not only affected the for-profit and managed care sectors of biomedical service organizations. Even large teaching hospitals are now primarily run under managed care economic principles, and the use of any facility or resource without generating revenue is increasingly subject to censure (and then to formalized systems of charges).

Some clarification of the system of funding of research support services is needed here. At virtually all U.S. institutions of higher education, in other words, any that are eligible to receive external grant funding, there is a charge added on to investigators' grants. It is usually a percentage over and above the "direct costs" that is the actual amount of money required by the investigator to do the work proposed. This "overhead," also known as "indirect cost recovery" is well in excess of 50% at most major research institutions, and even exceeds 100% in some places. This means that if you write a grant proposal to study human growth, and your institution's indirect cost rate is 50% and your direct costs for doing the research are \$100,000 per year, the institution will charge the granting institution \$50,000 per year to support you and your research. For this "overhead" investigators are supposed to receive their facilities, some administrative support (e.g., secretarial and grant management services), electricity, telephone, and research support in terms of infrastructure and access to potential subjects. However, in the past several years, services that investigators routinely had expected to be provided as part of their indirect-cost monies are now increasingly being subject to additional charges. For example, as recently as the mid-1990s, biomedical research institutions rarely, if ever charged a fee for IRB review. This has changed, with my former institution, for example, initiating in 1999 a charge of \$1,200 for review of a protocol. They will waive this fee readily for internal, investigator-initiated projects that do not have external funding, but if an investigator has or is seeking funds, it is expected that this charge will be built into the grant budget. Because this is clearly a required Institutional research support service, it would seem that additional charges for reviewing research protocols are superfluous given the >50% "tax" (indirect cost recovery) added to investigators' grants. The trend toward charging a fee for IRB review cannot be directly attributed to the introduction of managed care into academic health sciences centers nor to the increased regulatory authority and investigative capacity of federal agencies responsible for ensuring compliance, but both are likely to be driving up the costs of maintaining an IRB.

The erosion of what indirect costs paid to institutions support extends into other domains as well, and again appears to correlate with the adoption of managed care and for-profit models of medical service. Whereas 10-15 years ago one could collaborate with physicians on the hospital side of the academic health sciences center, and could use facilities within the hospital for one's research, these days one must pay fees to the hospital in order to use hospital facilities for research purposes. For example, in ultrasound studies conducted in collaboration with a radiologist and a certified ultrasound technician, and with the Radiology department chair's blessing in 1987–1991, my colleagues and I used the ultrasound facilities at the regional university hospital in (mostly) off hours for the conduct of research. As of 2001, there is complicated and time-consuming application process that must be pursued prior to being permitted to use the hospital's facilities. The net result of the application process (other than significant delay in getting one's research underway) is that a per-study fee is imposed by the hospital to use rooms, equipment or any other service associated with the hospital. Although these fees can be budgeted into NIH grant proposals, they are in excess of what the grants available to most anthropologists can fund. Further, the level of paperwork involved has increased the costs of doing research both in terms of dollars and energy. These days, academic health sciences center-based investigators committed to human research must have one administrative person completely dedicated to IRB, hospital permits, and other types of human subjects regulatory paper management, or he or she has no time left for research. The support person generally must be paid for from their grant funds as opposed to funds derived from the institution's indirect cost recovery monies.

III. Structural problems with IRBs: Increased regulatory vigilance (or fear of vigilance) can inhibit our ability to train students.

This last structural problem will be addressed only briefly. There is a movement towards requiring IRB approval for students to practice techniques such as interviewing or other face to face research techniques involving humans. Several years ago, students in our methods classes could identify a problem of interest to them, and could go out into the "field" and conduct (or attempt to conduct) an in-depth interview, a focus group, or some other research method of utility within the context of the question asked. We now need IRB approval for students to engage in such learning experiences. Although it is obvious how useful it might be for the student to learn how to obtain an IRB approval, it is actually the instructors of these courses that must seek approval, because there is never sufficient time within a quarter or semester system for students to obtain individual approval and conduct the exercise. Although there are arguments to be made on both sides of this issue—one would not like to have one's undergraduate students causing offense by interviewing people randomly about personal or sensitive topics—there is still a reasonable expectation that the anthropologists/human biologists teaching courses in methods will exercise caution in reviewing the projects that their students choose. Echoing the themes above of excessive paper work, this trend seems one more way in which to preemptively avoid legal or regulatory review problems that may or may not ever occur.

The second part of this paper will be more brief and will explore some of the interesting obstacles that U.S. cultural hegemony (or the assumption thereof) can create when working with persons from other cultures and governmental structures. I am going to present just a few examples, some real, some hypothetical, in an effort to stimulate more discussion of how we might, as a profession, contribute to a unified position on the handling of human biological research within non-U.S. cultural situations. As some of these examples will make clear, the imposition of, for example, NIH guidelines concerning the composition of an IRB for approval of procedures relating to informed consent, can be deemed offensive by other cultures.

Case Study 1:

The NIH guidelines require that when conducting research in a foreign country, U.S. investigators must receive IRB approval from their home institution, and they must receive approval from a local IRB (in other words, as close as possible to whatever city/place in whatever country they are working in). This would be fine, except the NIH guidelines further require that this foreign IRB will not be recognized as valid by the NIH unless it includes a minimum of five members, one of which must be female and one of which must represent the lay public. This is not the case with the NSF, which accepts that the local IRB is best able to know local conditions and values and will act accordingly. A colleague of mine, working in a foreign country with NIH funding, found that the local IRB (as was entirely predictable in this country) was comprised of three male physicians, and that the suggestion that members of the lay public and women must be included for the IRB to be deemed valid was initially a source of consternation and resentment. My impression was that the resentment was not because women and lay members of the public would be disrespected, but because the requirement is considered arrogant-an implicit accusation that persons who should be in the best position to evaluate protocols would not do so with integrity. Although this situation was resolved in an amicable if not rapid fashion, it could easily be extended into a number of other, less easily resolved scenarios. What about countries in which women have no rights? We can say that we simply will not work in countries in which women do not have fundamental rights. We could extend that ban to countries which do not embrace our viewpoint on general human rights. But this would be counterproductive, and if the project involved was one in which, say, the health status of women in countries where women are oppressed was being evaluated, it could be considered unethical to not do the project.

Case Study 2:

Individual autonomy is an assumption of the Helsinki convention and one of the foundations for informed consent and the ethical conduct of human research. However, not all cultures value individual autonomy to the same extent as Western cultures, and in some situations the idea of individual autonomy may be culturally noxious. Two situations, one real, and one hypothetical come to mind as examples. In some cultures, dwelling in groups of 20-100 persons primarily comprised of kin is a fairly common social living arrangement. There is often a single family member, usually male, who is considered, for all intents and purposes, the leader of the group, and from whom permission for various activities must be obtained. I once worked in such a situation. Although individual consent forms were given to people, and a mark was made by the individual subject to acknowledge that the piece of paper was read to them (because the persons involved in this situation could not personally read or write), it was apparent that permission for participation in the research derived from the head of the group. Although individuals were certainly free to decline or accept participation, none would have participated at all had not the head of the household/compound/village been approached first and given their blessing. This sort of social arrangement is completely ignored by Western conceptualizations of informed consent.

The situation becomes even more interesting (and dangerous) when considering research involving children. The Western model of informed consent requires that parents give informed consent and the that the child give assent, in other words, that beyond a certain age, the study must be explained to children and they must give their assent to the procedures involved. The very idea that children might have some say in what happens to them could provoke violence in some cultures. What would happen to a Western researcher working in such a culture if s/he tried to obtain assent? What would happen to him or her if s/he honored the local system and did not seek assent? I sometimes wonder if 20 years down the road those of us who have worked within cultures in which a "headman" system pertains, or in which women or children have no rights, are going to be accused of coercion, of failing to comply with IRB regulations, or of taking advantage of our anthropological knowledge of cultural systems in a fashion that is contradictory to the rigorously upheld principle of individual autonomy favored by Western cultures. Although we may pay lip service to the idea that one cannot be held to standards that will come into effect in the future, the recent controversy concerning the work of James Neel and Napoleon Chagnon should give some of us pause.

Summary

The examples of culture conflict offered above with respect to the DHHS-NIH mandated composition of IRBs and the Western principle of individual autonomy are directly relevant to the issue of ethics in the conduct of human biological research. But you may ask what the first large section of this chapter about the IRB approval process and the evolving culture of the biomedical system has to do with ethics in human biology. I look at it as the wave of the future-and the future holds the promise that small projects will become increasingly difficult and only large players (major research institutions, individuals with large grants) will be able to conduct human biological research. The potential for inhibition of small projects is real. IRB approvals may be needed to teach or practice techniques. When our students begin to learn how to do research on human subjects, where do they start? They used to start by practicing techniques on their fellow students, and perhaps by approaching a few strangers (or near-strangers) to practice their interview or recruitment techniques. The more difficult it is for teachers to teach these techniques, for students to practice them, and for pre- and postdoctoral trainees to engage in human biological research, the less often this sort of work will take place. In effect, we are discouraging our students from engaging in research on human subjects because the process of obtaining approval is too complicated. The cases discussed above when considered from an institutional point of view share in common less concern for the protection of human beings and the ensuring of informed consent, than they do with ensuring that paper trails will be infallible and that institutions and the persons representing those institutions will not run afoul of the regulatory process. In some cases the IRB system has been deliberately manipulated to make research more difficult because it is not immediately profitable. The systems in place to protect human subjects have become so focused on process and procedural rigor that both investigators and IRB committee members sometimes lose sight of the principles of ethical conduct that should shape the sort

of research we do. Excessive attention to process leads to time and energy being wasted, instead of doing the work and contributing to improvement in the human condition.

One might ask what are the possible solutions? A system as complicated as that designed to protect human subjects cannot be regulated fully—there's still a huge amount of trust and responsibility put in the investigators. Investigator responsibility is critical and there must still be reasonable regulatory oversight, but the approach should be to balance and streamline the process so that it is not too burdensome. The objective should be to encourage investigators to adapt and modify procedures if necessary, to fit in with the basic ethical principles.

I do not see an end to the increasing complexity of IRB approvals where biomedical research is concerned. And it seems to me that it is therapeutic and/or invasive clinical research that is wagging the dog, so to speak, in terms of increasing the complexity of the IRB process. A simplified IRB system would be an important step forward. Although this is probably impossible, the current trend towards every single institution that might have an interest in research (or be a site for research) to have it's own IRB wastes time, energy, and resources. As a first step, it would be useful to designate only a limited number of sites within a given region (based on population size?) as having IRB authority for their region. Presumably this authority would derive from the federal government, and there would be some agreement from region to region on how to interpret the guidelines for ethical conduct of human research that have been put forward by the Federal Government. Within this limited IRB system (i.e., not every single clinic, school, campus of a university, HMO, or for-profit corporation could have an IRB), a strategy for complete separation of IRB reviews for therapeutic and/or invasive clinical research from nontherapeutic human research should be pursued. If the therapeutic/ clinically oriented research could be separated from the non-therapeutic research, I can think of a couple of ways to divide nontherapeutic protocols for review. One would be to divide reviews by methodological intensity (basically equivalent to physical risk). In this schema, protocols that are completely noninvasive, in other words, they involve questionnaires, surveys, interviews, no laying on of hands whatsoever, would be considered separately from those wherein the methods involve physical, but noninvasive contact, for example, anthropometry or the placement and wearing of noninvasive monitors. Theoretically, these categories of methodological risk should be relatively easy to review and evaluate as to whether or not the subject is adequately protected-reviewing them separately from protocols that generate more concern would hasten the review process for these minimally risky protocols. Those with minor invasive procedures, for example, venous blood draws, swabs of mucous, breathing tests, urine or fecal collections, would be considered as a separate group. Those involving more invasive procedures, for example, muscle or other biopsies or arterial blood draws, would be considered as a fourth group. If each category of risk in nontherapeutic research went to an IRB thoroughly versed in dealing with that type of research, the process could be streamlined relative to what it is now. Another organizational schema could be disciplinary. Within institutions or even within states with multiple university systems and campuses, why not divide up one single, multicampus (or regional) IRB to reflect the types of projects that are subject to IRB review? Why not let the social science IRB section review socialscience-oriented proposals, the anthropology IRB section review the anthropologically oriented proposals, the education specialists review educational interventions? This would not obviate the requirement that other disciplines, minorities, and the lay public be represented in each area of research, but it could also streamline the process.

For human biological work in other cultures, I would suggest NSF-NIH aid in designing consent procedures and lobbying for acceptance of culturally appropriate consent procedures to protect human biologists working with non-Western populations from inadvertent violation of current and future federal law and guidelines. Perhaps we could have an IRB under the supervision of the anthropology division of the National Science Foundation with oversight of projects funded by the NSF, and even those funded by the NIH should the work involve field sites in other countries/cultures. Although this should not obviate the requirement of local IRB approval (i.e., the country/ culture in which the work is being done), it could circumvent some of the problems inherent in imposing a U.S. model of informed consent on populations with other value systems. If such an IRB (NSF-based, national) could supercede the authority of the individual institutional IRB, some conservation of effort might be achieved. Theoretically, an IRB with authority under NSF can ask a person from the country/culture involved to comment on the appropriate manner in which to obtain informed consent. Although some of these suggestions may seem to be wishful thinking, they are offered in the spirit of opening up discussion on how to accomplish the ethical conduct of human research without burdening investigators and institutions to the point where they simply give up on the endeavor.

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Chapter 13

Darkness in El Dorado: Claims, Counter-Claims, and the Obligations of Researchers

Trudy R. Turner and Jeffrey D. Nelson

In an email message sent in late August 2000, Terence Turner and Leslie Sponsel, two cultural anthropologists, warned the president of the American Anthropological Association and the chair of the ethics committee that a major crisis was about to erupt in the anthropological community. They claimed that they had just received and read a manuscript by Patrick Tierney entitled Darkness in El Dorado (2000). They stated that in the book Tierney accused the noted geneticist, James V. Neel, of deliberately starting a measles epidemic among the Yanomami in order to test his hypotheses about the genetics of chiefdom. Neel, according to Tierney, had done this by injecting the Yanomami with a virulent measles vaccine, Edmonston B. In inflammatory language they warned that these revelations would shake anthropology. The email rapidly spread through the anthropological community around the world. As quickly as the major allegations were made, they were dismissed. Numerous scholars and experts on measles reviewed the allegations and the choices that Neel made (e.g., Katz, 2000; IGES, 2001, ASHG, 2001). None found merit in the accusations of experimentation to determine the effects of headmanship. Nor did they accept the contention that injection with the vaccine Edmonston B could start an epidemic. The overwhelming response led to the allegations never appearing in the book. There were, however, other allegations of improprieties in the book that concerned anthropological practice among the Yanomami. These allegations focused primarily on cultural anthropology practitioners.

In response to the furor raised by the book the executive board of the American Anthropological Association established the El Dorado Task Force to conduct an inquiry into the allegations contained in *Darkness in El Dorado*.

The task force included cultural anthropologists, representatives of the AAA committee on human rights and the ethics committee, and a biological anthropologist (TRT). The task force determined that the inquiry was not only an investigation into the truth or falsity of the allegations concerning the behavior of the medical team dealing with the measles epidemic and the behavior of cultural anthropologists during the more than 30 years of interaction with the Yanomami but also a reflection of a moral and scholarly kind. After a year of intensive effort, five face-to-face meetings and comments from the anthropological community the task force completed its final report. In this paper we review the major issues of concern to biological anthropologists. We too are concerned not solely with the veracity of the book, but with the ethical implications of the ensuing debate. Our discussion here will focus on the four issues—the measles epidemic, informed consent, the relationship between science and humanitarian concerns, and civility of discourse.

We have reviewed material related to the 1968 expedition including the Neel correspondence, documents, and field journals housed at the American Philosophical Society in Philadelphia. This is much of the same material reviewed by Terence Turner. In addition, we have spoken to and corresponded with members of the New Tribe Missions, some of whom who were present in Venezuela during the 1968 epidemic. We have obtained the Atomic Energy Commission (AEC) grant proposals for the years 1960–1973 and reviewed Neel's published works relevant to the 1968 expedition. Our conclusions about James Neel differ substantially from those of Tierney and Terence Turner. We believe that Neel worked hard under difficult circumstances to prevent and minimize the effects of the measles on the Yanomami. And in fact, he saved many lives. In addition, Neel's work reveals a history of concern for the populations he studied.¹

The Measles Epidemic

The Story²

In September 1967 James Neel was in the final planning stages for the 1968 field expedition to the Makiratare and Yanomami of Venezuela. He knew from previous field work and blood sampling that some of these groups were "virgin soil" populations for various infectious diseases.³ Neel was aware of the potentially devastating effects that these diseases could have on populations that had never been exposed to viral agents such as measles and smallpox. He therefore wanted to vaccinate for specific diseases in these areas.⁴ Although he had been laying the groundwork for vaccination since early 1967⁵ it was in September that he asked the missionaries for aid in launching

a vaccination program.⁶ In November, Neel visited the CDC and met with virologists about the upcoming expedition.⁷ In December, his desire for a vaccination program took on an immediacy due to the presence of a reported measles epidemic in Brazil.⁸ In the few weeks following notification of the epidemic, Neel secured donations of 2,000 doses of vaccine and accompanying doses of gamma globulin.⁹ One thousand doses of Edmonston B vaccine were sent to missionaries in Brazil, while Neel carried 1,000 doses of vaccine into Venezuela.¹⁰

Days before Neel left the United States he realized that he had received children's doses of gamma globulin.¹¹ In a letter to Black (an epidemiologist), Centerwall (a physican accompanying Neel on the expedition) acknowledged that the expedition did not have enough gamma globulin to obviate the effects of the measles vaccine in adults.¹² Centerwall devised a protocol to vaccinate half of a village at a time, thus leaving the other half of the village able to care for the vaccinated.¹³ The expedition also brought aspirin and antibiotics to care for individuals having reactions to the vaccine or other complications.¹⁴ When Centerwall wrote "the half village protocol" there was no confirmation of a measles epidemic in Venezuela.

Neel and the field team spent two weeks in Caracas awaiting transport and continuing to outfit for the field season.¹⁵ On their final night in Caracas they attended a party where they were informed for the first time that measles was present along the Ventuari River.¹⁶ The next day two teams went into the field. Neel and most of his team went north to the area around the Ventuari and Cuara Rivers.¹⁷ Chagnon, Asch, and Roche (a Venezuelan physician and scientist) went southward to the Ocamo mission near Mavaca. Roche began to vaccinate at Ocama; there is no evidence from the Neel documents that he extended the vaccinations beyond the mission.¹⁸ Neel, in the north, vaccinated nearly 60 people in a two-week period.¹⁹ Because measles had been through that area in 1962²⁰ Neel vaccinated only children under the age of 5 and those adults who claimed never to have had the disease. Additionally, 101 doses of vaccine were given to the Seeley and Eddings Missions.²¹

On February 6, 1968 Neel arrived at Ocama and began to care for the sick at the mission.²² Between February 6 and February 16 Neel, his team and the missionaries vaccinated over 500 people. On February 16, after news that measles had struck a village, Neel devised the "all-Orinoco" plan.²³ Between February 16 and the end of the 1968 field season the Neel team vaccinated over 200 people.²⁴ In total Neel, his team and the missionaries vaccinated 1,033 people.²⁵ This not only exhausted Neel's supply of Edmonston B but also utilized some Schwarz vaccine that was available at Ocama, Mavaca, Tama Tama, and Patanowa-teri.²⁶

On his return from the field Neel continued to solicit vaccine from manufacturers in the United States.²⁷ He was successful in securing a donation of an

additional 1,000 doses of vaccine in April 1968.²⁸ During the same time the Venezuelan government also continued to receive vaccine. Two years later in 1970 Neel attempted to get a trivalent vaccine (measles, mumps, rubella) from the Dow company.²⁹ This was an experimental vaccine that required taking blood samples at specified times after the vaccine was given.³⁰ Neel realized he could not follow the protocol, withdrew, and cancelled the trials.³¹ However, because of the relationship Neel had established, Dow subsequently donated measles vaccine to be used for the Yanomami.³²

Issues of Contention about the Measles Epidemic

The allegations concerning the response of the 1968 expedition to the measles epidemic have changed over time. The initial allegation was that Neel caused the measles epidemic in an experiment to test the response of individuals to a disease pressure.³³ Neel was supposedly testing to see whether headmen were genetically superior to others. Tierney's book, however, has notes about Neel doing an experiment. The direct accusation was removed prior to publication. This allegation has been completely refuted. The vaccine did not cause measles and, as the team later realized, measles was in the area (Ocamo) at about the time they arrived.³⁴ The half-village protocol designed by Centerwall has been cited as evidence that an experiment was in process.³⁵ However, we note that the protocol was designed to accommodate the shortage of gamma globulin. In addition, because of the urgency of vaccination, it was never followed. The Dow correspondence of 1970³⁶ is also cited as evidence that Neel was willing to experiment on these populations.³⁷ However, it was Neel who realized that he could not fulfill his obligations and called a halt to the protocol before it even began.³⁸ During the course of the inquiry it was suggested that Neel, because of his training, must have been conducting some sort of experiment or collecting some sort of data for analysis even while he was vaccinating and thus did not give his full attention or time to the vaccination program. The proof for this is that when Neel returned to the field a year later he took follow-up blood samples from one of the 28 villages he vaccinated to determine immunity. Therefore, he must have been conducting an experiment. The Final Report of the Task Force discusses the difference between an experiment with hypothesis testing and a formal protocol and the observation of conditions that occur as sort of a natural experiment. Critics of Neel make no distinction between these two.

The second allegation is closely related to the first. Rather than beginning an epidemic, Neel chose an inappropriate vaccine.³⁹ Edmonston B produced a more severe reaction than the Schwarz vaccine. Turner has suggested that Neel chose this vaccine without regard for side effects and because it was free.⁴⁰ We note that Neel had little time to procure the vaccine. In addition, he engaged in discussions with the CDC and other virologists about the appropriate vaccine.⁴¹ In a report of the ASHG, Black has stated that Edmonston B was the appropriate vaccine for a virgin soil population because it confers a longer-term immunity.⁴² Ryk Ward, a biological anthropologist and member of the expedition, remembers that this longer term immunity was discussed before the team went into the field. In any case, Edmonston B was in use around the world in 1968.⁴³

A third allegation was that Neel did not have permission to vaccinate.⁴⁴ On December 11, 1967, Neel wrote to Layrisse (IVIC, Venezuela) requesting permission to vaccinate: "I believe I can obtain about 2,000 immunizing doses of measles vaccine free. CAN YOU OBTAIN PERMISSION FROM THE VENEZUELAN GOVERNMENT FOR US TO VACCINATE ALL THE INDIANS WE COME IN CONTACT WITH?"⁴⁵ A note in Neel's handwriting mimics the wording in his urgent letter to and states "Agree bring 2000 doses immunizing vaccine. Miguel Layrisse."⁴⁶ Although this is an undated note, the syntax is identical to the initial request. In addition, an examination of the Neel papers indicates that he frequently hand wrote confirmations of cables and drafts for cables.

A fourth allegation was that Neel did not take time to care for the ill in the villages.⁴⁷ Several times in his field notes, Neel details his care for the sick (see for example: 2/6/68 "Make Ocamo about 8pm and immediately put to work on sick call," 2/17/68 "Meet with French group and organize a bleeding, g-g [gamma globulin], penicillin team," 2/18/68 "exhausted, my last act to see a preme born today," 2/26/68 "A touch of sick call").⁴⁸ In his 1970 article, Neel gave further details concerning his ministrations to Yanomami who had bronchopneumonia.⁴⁹ Neel was prepared for some illnesses and reactions to the vaccine. He brought aspirin and antibiotics with him to the field.⁵⁰

Another allegation was that Neel did not alter his research schedule to accommodate the ensuing measles epidemic.⁵¹ Turner claims that even after hearing reports of measles among the Yanomami (at the party in Caracas), Neel made only the slightest changes to his research plans and objectives.⁵² Turner claims that Neel did not alter his plans because his scientific concerns were paramount and his humanitarian efforts were secondary.⁵³ Turner's support for this statement derives from letters discussing the plans for the expedition written before Neel entered the field and from entries in the Neel journal.⁵⁴

Neel's correspondence and written papers indicate a long-term concern with the devastating effects of infectious disease on "virgin-soil" populations.⁵⁵ He had been in contact with the New Tribes Mission missionaries for several months about the possibility of vaccination.⁵⁶ The measles epidemic in Brazil brought an immediacy to these concerns.

Neel's field journal⁵⁷ is a detailed accounting of his scientific, medical and personal experiences. Turner uses the field journal as evidence of his

belief that scientific concerns were paramount for Neel.⁵⁸ The first entry Turner uses to support this belief concerns the party Neel attended before he left for the field.⁵⁹ The other entries concern Neel's frustration with the vaccination process.⁶⁰

Neel learned about measles from Eddie Romero ("Commissioner" for Indian Affairs) in the Upper Ventuari at a party in Caracas the night before he left for the field.⁶¹ Contrary to Turner's assertion, Neel seems to have been in favor of accepting aid in vaccinating from the Indian Affairs commissioner.⁶² Although in a correspondence dated 11/28/67 Neel received an unconfirmed report of measles on the Upper Orinoco (Brazil),⁶³ the only clear message that measles was in any specific area in Venezuela came from Eddie Romero during this conversation. The area the Indian Commissioner discussed was the area where Neel was planning to go. Consequently, there was no need to alter his itinerary.⁶⁴

Turner states that Neel did not begin in earnest to vaccinate until February 16, 1968 when he formulated the all-Orinoco plan.⁶⁵ We have reviewed the Neel notes and find that he did most of the vaccination before the plan was formulated.⁶⁶

Total number of vaccinations	Erbato, Caura and Upper Ventuari	Orinoco	Upper Orinoco before 2/16	Upper Orinoco after 2/16	Upper Orinoco date unspecified
1033	157	40	536	227	73

Turner also claims that Neel's frustrations with the vaccination process led him to consider abandoning giving vaccinations.⁶⁷ Turner's accusation is based, in part, on three words, "if at all" written in the field journal: "At Patanowa-tedi we will also make our principle collections of biologicals, and I will concentrate on this while Bill does PEs. Thus, I will get stools and soils while Bill does PEs for 3–4 days—then we get blood, saliva, and urine (? And dermats), *then* inoculate if at all."⁶⁸

In several entries in his journal Neel addresses the vaccinations specifically as a "a gesture of altruism and conscience."⁶⁹ Likewise, he notes how frustrating this vaccination process is: "more of a headache than bargained for."⁷⁰ However, he *never* suggests that he "seriously considered jettisoning the 'altruism and conscience' of the vaccination campaign and [abandon] the vaccinations altogether";⁷¹ he does, however, clearly state in frustration that he would like to put the vaccinating into the "hands of the missionaries."⁷² Moreover, the context of "if at all" must account for the fact that the Indians had a history of fleeing those administering the vaccinations: "they took off in fright when they heard we were giving inoculations."⁷³ Vaccinating "if at

all," administering the vaccinations "at the very last,"⁷⁴ or placing the vaccinations into the hands of the missionaries may be indicative of this "flight" problem.⁷⁵ Additionally, Ryk Ward remembers that by the time the expedition reached the Patanowa-teri they were running short of vaccine and were not sure that they would have enough material left to vaccinate the village.

All this was written before Neel was aware of the magnitude of the epidemic and before the all-Orinoco plan was devised.⁷⁶ Once he was aware of the magnitude of the epidemic he immediately took steps to prevent further spread of measles.⁷⁷ At this point, he gave preventative doses of MIG to those exposed, but who were not yet sick and not vaccinated.⁷⁸ He also administered penicillin to those who were the most ill.⁷⁹ The sound tapes of the Neel expedition also indicate that at one point he pleaded with the Venezuelan authorities to send more material and aid. It must be remembered that no matter how Neel may have felt, he never stopped vaccinating.

Informed Consent

Another allegation against Neel and the field team is that they obtained samples without using proper procedures for informed consent. Our discussion concerns two points—what can we determine about the procedures Neel followed and were they in compliance with the norms of the time. In discussions of informed consent during the 1968 expedition, it is important to recognize both the codes that were in force governing consent during that time and also to understand the way in which consent was actually obtained by researchers working with similar populations during the time period.

Important Codes Regarding Informed Consent in 1968

There are several excellent reviews of the history of informed consent by ethicists, philosophers, attorneys and historians of science (Beecher, 1970; Tranoy, 1983; Engelhardt, 1986; Faden & Beauchamp, 1986; Beauchamp & Childress, 1989; Gert, Culver, & Clouser, 1997; Doyle & Tobias, 2001). In discussions on the history of informed consent a distinction is often made between the consent practices of practitioners of clinical medicine and the consent practices of researchers using human subjects. The earliest authors of treatises on clinical medical ethics were guided by the principle of beneficence and dealt little with the principle of autonomy. Standards for research using human subjects began as a reaction to the medical experimentation of Nazi Germany. The ethical principle of respect for persons or autonomy was of primary importance in the resulting Nuremberg Code. This principle of autonomy was then, and continues to be articulated, as voluntary or informed consent. The Nuremberg Code became the model for many of the governmental and professional codes formulated in the 1950s and the 1960s even though it presented an ideal without detailing the particulars of application. Among the most important codes and laws enacted during this time period were the 1953 NIH Clinical Center code, the 1962 Drug Amendment Act and the 1964 Helsinki Declaration. All of these codes deal with the issue of informed consent. The Helsinki Declaration was formulated by the World Medical Association and was used by many other agencies to develop their own guidelines. Unlike the Nuremberg Code, the Helsinki Declaration distinguished between therapeutic and nontherapeutic research. In 1966 the Public Health Service instituted a requirement of peer review of research. However, this was entrusted to the local institution and there was little oversight.

These codes were often difficult to apply. It was not until the 1970s that additional clarifications and standards were set. In 1971 the Department of Health, Education and Welfare issued guidelines for human subjects research. In 1974 Congress created the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. The commission was charged with developing a new set of guidelines for human subjects research. These guidelines became known as the Belmont Report. The report and the principles it represents—autonomy, beneficence, and justice—have been codified into federal regulations and are routinely used by IRBs in their analysis of research protocols. The National Research Council continues an on-going examination of ethics issues and prepares updated guidelines. More recently, the National Bioethics Advisory Commission, established by Executive Order in 1995, was charged with making recommendations to the National Science and Technology council regarding both clinical and human biology and behavior research.

The 1968 Yanomami expedition took place several years before the articulation of the bioethics principles in the Belmont Report. Although there were guidelines at that time, the methods by which one obtained consent and explained risks and benefits had not been firmly established.

One of the first documents to discuss the relationship of an investigator to a non-Westernized study population was a 1964 WHO report. In 1962, the WHO convened a study group of scientists to discuss the organization of studies of "long-standing, but now rapidly changing, human indigenous populations." The resulting report, "Research in Population Genetics of Primitive Groups" (Neel, 1964), was authored by James Neel. In the report Neel discussed the relations of the research team with the population studied. The group met again in 1968 and produced a second report, Research on Human Population Genetics (Neel, 1968), again authored by Neel, reiterating, with slight modification, the principles of the first report. The report stated: Any research team has certain ethical obligations to the population under study. The investigator should always be bound by the legal and ethical considerations governing the conduct of medical and biological research workers. It is essential that harmonious relations be maintained both during and after each research visit. From previous field experience, the following factors have been found to be especially important.

- (a) The privacy and dignity of the individual must be respected at all times and the anonymity of subjects must be maintained in publications. The comfort and individuality of subjects must be safeguarded, e.g., some people are unwilling to queue, or to have others present during examination or questioning. Care should be taken that individuals do not undergo an excessive number of examinations at any one time.
- (b)Satisfactory reward should be provided for the subject's participation in the research and for any services provided. The nature of the recompense should receive careful consideration. The advice of local authorities may be invaluable, both on this question and in general, so as to avoid giving offence through ignorance of local customs.
- (c) The local population should benefit from such studies by the provision of medical, dental and related services.
- (d)The maintenance of congenial social relationships will be enhanced by methods suitable to particular areas, e.g. eating with families on occasion, exchange of information.
- (e) All groups have learned individuals, e.g., experts on oral traditions and those with systematized knowledge and interpretations of natural phenomena. Consultation and exchange of information with such persons will often be of immediate value to ensure good relations and lead to the appreciation of the achievements of such peoples. Such information is pertinent to their cultural and therefore biological history.
- (f) There should be the utmost regard for the cultural integrity of every group. All possible measures should be taken to prevent the activities and presence of the research team from adversely influencing the cultural continuity of the population being studied.

Issues of research involving indigenous populations were not examined in depth again until the United Nations Working Group on Indigenous Populations began meeting in the 1980s. Discussions in the United States in the 1990s on research among indigenous peoples were triggered by NAGPRA and the planning of the Human Genome diversity project. The NRC and the National Bioethics Advisory Commission both issued reports on research initiatives in the late 1990s.

Practices Relating to Informed Consent

In order to determine the practices of researchers in the late 1960s regarding informed consent, TRT surveyed a number of individuals who were active in the field at that time. TRT selected individuals to consult, in part, after reviewing various journals (*American Journal of Physical Anthropology, American Journal of Human Genetics*, etc.) to determine who had published on genetics of indigenous populations in the late 1960s and early 1970s. Among the individuals responding were: Alan Fix, Jonathan Friedlaender, Eugene Giles, Henry Harpending, Geoffrey Harrison, Newton Morton, William Pollitzer, Francisco Salzano, Jack Schull, Emoke Szathmary, and Kenneth Weiss. These individuals did research in the following areas of the world and with the following populations and nations: Ayamara, !Kung Bushmen, Japan, Brazil, Micronesia, Venezuela, Paraguay, Solomon Islands, Canada, the United States, Haiti, Malaysia, Ethipia, and New Guinea. Each individual was asked the following three questions:

- 1. How did you attempt to get informed consent from individuals?
- 2. Did you have discussions about informed consent while you were in the planning stages of your research?
- 3. Did you exchange/reciprocate anything for samples?

HOW DID YOU ATTEMPT TO GET INFORMED CONSENT?

Although there were some differences in responses about how information was conveyed to individuals, all of those surveyed stressed that voluntary consent was assumed because some individuals in the population elected not to participate. Some of the respondents indicated initially that they had government approval to conduct the research, whereas others dealt with the local population or individuals. The leaders of the study group were often consulted first and their approval was sought. If the researchers worked with medical personnel, the medical personnel were often responsible for obtaining consent. If they were not accompanied by medical personnel, researchers told the individuals/groups that they could not provide medical assistance. In every case some explanation of what the individuals were looking at in the blood samples was provided. WAS THERE ANY DISCUSSION OF CONSENT IN PLANNING STAGES OF PROJECT? Everyone said there was no discussion in the planning stages of the project.

WHAT WAS GIVEN IN EXCHANGE/RECIPROCITY FOR SAMPLES?

If medical personnel were present, medical and dental exams were given. If a doctor was present, medical help or immunizations were provided. The following items were given: tobacco, candy, small sums of money, photographs, toothbrushes, bubble gum, powdered milk, rice, machetes, or a community purchase, such as a film projector. It should be noted that Neel did consult with local authorities concerning remuneration. In a September 20, 1966 letter to Reverend Macon C. Hare he states:

With respect to the matter of trade goods, I would say that it has been our custom after we have completed the work-up of each family to make its members a suitable present. Here I would repeat, as mentioned above, that we would rely on the advice of those in the field concerning what is appropriate to the present situation. We know by experience that we must do something to enlist the cooperation of the Indian, but, on the other hand, do not wish to upset whatever "economy" you have been attempting to establish

Although the type of goods Neel provided were at one end of the types of materials provided by other researchers, they were not unusual for researchers working with the Yanomami (AAA El Dorado Task Force Papers, 2002).

Partly in response to issues raised by *Darkness in El Dorado* the Committee on Ethics of the American Anthropological Association issued a working paper on remuneration. The working paper follows guidelines set forth by the 1993 United Nations Draft Declaration of the Rights of Indigenous Peoples, stipulates that types and kinds of remuneration should be in the hands of the population studied.

The Impact of Neel's Work with the WHO

The participants in the WHO meetings on research with indigenous populations conducted research around the world. Many were involved in the Human Adaptability section of the International Biological Program (Collins & Weiner, 1977). The participants and their students worked in the Kalahari, the Andes, New Guinea, the Solomon Islands, and other locations. Many of the respondents to the survey were under the IBP umbrella. The WHO document Neel authored reflects the standard of conduct for work with indigenous populations as well as the protocols for obtaining samples from populations. Thirty years later, however, the Yanomami feel as if they were not provided with adequate information for informed consent. Scientists who were part of the expedition have stated that the Yanomami were told that they were going to look for diseases in the blood. This was certainly true; there are many publications about Yanomami health. However, the Yanomami expected that they might receive greater medical benefits from the work. Although Neel and his team did help during the measles epidemic and after they could not continue to meet the medical needs of the Yanomami. And as a result, those Yanomami who have spoken to outsiders since the publication of Tierney's book contend that there remains a feeling of betrayal.

Scientific Research and Humanitarian Concerns

Turner (2001a) saw the tension between Neel's scientific program and his humanitarian concerns as leading to his drive to complete his research program at the expense of giving additional vaccinations and aid to the Yanomami. Turner claimed that because Neel was funded by the AEC and because he had ties to the CDC, IVIC, IBP, and the WHO he represented "Big Science." Turner claimed that because of this "institutional imperative" Neel's motivations were neither simple nor direct. We recognize that Neel had numerous responsibilities and that these tensions played themselves out in a complex synchrony. However, we believe that his humanitarian efforts we not overridden by his scientific goals. Ultimately, whatever internal tensions Neel may have felt did not stop him from working hard for the welfare of the Yanomami.

Whatever happened 30 years ago on the Orinoco, the real questions remain: What is the relationship between the researcher and the population and the individuals studied? What does a researcher owe the population and how has this changed in the past 30 years?

The current ethic is that an individual is owed the truth concerning what is being done and risks and benefits of participating in a research program. As it was in James Neel's time, this continues to be problematic when dealing with indigenous populations. The issues of medical aid to a population are equally complex. Anthropologists without sufficient medical training who provide medication or medical aid are practicing medicine without a license. The Ethics Committee of the American Anthropological Association has recently issued a briefing paper on the responsibilities of the researcher during medical emergencies (www.aaanet.org/committee.ethic.member.htm website). The protocol written in 2001 appears to be similar to the protocol Neel followed in 1968 33 years earlier in 1968. Some anthopologists (Hurtado and Salzano, 2003) take a more activist stance in suggesting that anthropologists actively work to improve the health of the individuals they study by ensuring that information they collect reaches government agencies and others who can provide aid. There can also be psychological damage to individuals and populations that can have lasting effects. The Yanomami example—where the individuals and the population feel a sense of betrayal—is instructive to current researchers.

Disposition of Biological Material

Tierney's book and the ensuing controversy prompted the Yanomami to review the disposition of samples taken from them 30 years ago. Some of these samples remain stored in laboratories in the United States. Yanomami cultural beliefs require that everything of a person be destroyed when a person dies. The maintainence of these samples is seen by the Yanomami as an affront to their beliefs. They assert that they were not told that these samples would be kept for this length of time and indeed it is doubtful that anyone taking the samples would have thought they would have been kept this long. Currently negotiations are under way to bring together the scientists and the Yanomami to work together to negotiate a way of handling these samples.

Conclusion

The intensity of the discourse concerning *Darkness in El Dorado* and James Neel was signaled by the initial Turner-Sponsel e-mail. Turner and Sponsel state that the e-mail was confidential, however, the use of inflammatory language had a shock value that led to an immediate and marked response by supporters and critics alike. This beginning shaped the discourse. The response to the most serious accusations that Neel had started a measles epidemic was overwhelming. When confronted with all the evidence the most vocal critics of Neel backed down, but continued to look for ways to undermine a professional reputation in a more muted way by shifting the discourse to the broader discussion of the tension between science and humanitarian concerns. Although we recognize that these tensions exist, James Neel was well aware of these tensions while in the field. We understand this not to be problematic but paradigmatic of scientific research with human populations in general. It is not an either or choice and was not for James Neel.

Legitimate concerns were raised about the relationship between the research community and the Yanomami. The rights of individuals and populations and the obligations of researchers—scientific, legal, and humanitarian have engaged scientists to a greater and greater extent over the past decade. The current consensus is that if a population is to be studied, the population should be an active partner in the overall process and receive some type of appropriate compensation. Many of the other contributions in this volume detail the on-going process of partnership with local communities. But we note that the responsibilities that researchers have to the communities they study—responsibilities of honesty and integrity—apply to relationships among members of the scientific community as well. Intellectual discourse relies on this sense of decorum and responsibility.

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Notes

1. See J. V. Neel, *Physician to the gene pool* and F. M. Salzano S. M. Callegari-Jacques, *South American Indians*.

2. This is the authors' reconstruction of the 1968 expedition, based on a careful reading of all the available correspondence, documents, and Neel's field journal. These are housed at the American Philosophical Society in Philadelphia. Turner and Stevens compiled an annotated index of papers in the collection that relate to the 1968 expedition http://www.umich.edu/~idpah/SEP/sep_tn.html. To facilitate comparison, we have used Turner and Stevens reference numbers for document and correspondence. DOC refers to document, COR refers to correspondence.

3. COR 29: Letter from Neel to Dr. Rrobert A. Hingson, 15 September 1967; COR 54: Letter from Neel to Dan Shaylor, 19 September 1967; COR 57: Letter from Neel to Neill Hawkins, 10 March 1967; COR 77: Letter from Neel to Layrisse, 30 August 1967.

4. COR 29: Letter from Neel to Dr. Robert A. Hingson, 15 September 1967; COR 54: Letter from Neel to Dan Shaylor, 19 September 1967; COR 57: Letter from Neel to Neill Hawkins, 10 March 1967; COR 67: Letter from Neel to Neill Hawkins, 10 March 1967.

5. COR 57: Letter from Neel to Neill Hawkins, 10 March 1967.

6. COR 37: Letter from Neel to Robert Shaylor, 21 November 1967; COR 54: Letter from Neel to Dan Shaylor, 19 September 1967; COR 67: Letter from Neel to Neill Hawkins, 10 March 1967.

7. COR 26: Letter from Neel to Casey, 30 August 1967; COR 28: Letter from Neel to Dr. Joseph H. Schubert, 30 August 1967; COR 124: Letter from Casey to Neel, 19 November 1967; COR 126: Letter from Casey to Neel, 17 August 1967; COR 131: Letter from Leo Kaufman, 19 October 1967; and an uncataloged correspondence from Max D. Moody, M.D. to Neel, 22 August 1967, regarding Neel's forthcoming trip to the NCDC.

8. COR 5: Letter from Neel to Layrisse, 11 December 1967; COR 38: Letter from Dan Shaylor to Neel, 11 December 1967; COR 39: Letter from Robert Shaylor to Neel, 28 November 1967.

9. COR 5: Letter from Neel to Layrisse, 11 December 1967; COR 22: Letter from Neel to Layrisse, 21 December 1967; COR 47: Letter from Dr. R. R. Widmann to Neel, 19 December 1967; COR 52: Letter from Neel to Dr. da Silva, 27 December 1967.

10. COR 52: Letter from Neel to Dr. da Silva, 27 December 1967.

11. COR 47: Letter from Dr. R. R. Widmann to Neel, 19 December 1967

12. COR 15: Letter from Centerwall to Dr. Francis L. Black, 10 January 1968.

13. COR 179: Letter from Centerwall to missionaries in Brazil.

14. COR 37: Letter from Neel to Robert Shaylor, 21 November 1967; 54; DOC 71.

15. DOC-1: Neel field journal.

16. Ibid., p. 60

17. COR 54: Letter from Neel to Dan Shaylor, 19 September 1967; COR 56: Letter from Chagnon to Robert Shaylor, 19 September 1967; DOC-1: Neel Field Journal, p. 50, 61.

18. DOC-1: Neel field journal.

- 19. Ibid., p. 63, 69, 72, 73, 110, 111.
- 20. Ibid., p. 61, 63.
- 21. Ibid., p. 110, 111.
- 22. Ibid., p. 81.
- 23. Ibid., p. 98-99, (see also p. 97).
- 24. Ibid., p. 110-111; appendix A.
- 25. Ibid.

26. Ibid., p. 110-111.

27. COR 11: Letter from Neel to Dr. Kenneth J. Wilcox, Jr., 26 April 1968; COR 12: Letter from Dr. S. J. Musser to Neel, 19 April 1968; COR 41: Letter from Neel to Robert Shaylor, 22 April 1968; COR 49: Letter from Dr. Kenneth J. Wilcox, Jr. to Neel, 19 April 1968: COR 50: Letter from Neel to Roche, 22 April 1968; DOC-4: receipt from Phillips Roxane, Inc., 18 April 1968.

28. COR 13: Letter from Neel to Dr. S. J. Musser, 26 April 1968.

29. COR 2: Letter from Dr. Joseph E. Jackson, 23 December 1970; COR 3: Letter from Neel to Jackson; COR 59: Letter from Neel to Dr. Joseph E. Jackson, 30 December 1970; DOC-2: "Statement of Investigator" Draft protocol Submission for a study, 22 December 1970.

30. COR 3: Letter from Neel to Jackson, 30 December 1970.

31. Ibid.

32. Uncataloged correspondence, 14 January 1971: William J. Oliver, M.D. to Dr. Frank DiMoria, regarding the "Attenuvax" donation.

33. Turner, 2001a, p. 13, 45.

34. Lobo, et al. 2001.

35. Turner, 2001a, p. 25-30.

36. COR 1: Letter from Dr. Joseph E. Jackson to Neel, 4 November 1970.

37. Turner, 2001a, p. 52.

38. COR 3: Letter from Neel to Jackson, 30 December 1970; or COR 59:one correspondence cataloged under two different numerical designations—see COR 3.

39. Turner, 2001a, p. 13, 16-17.

40. Ibid., p. 16-17, 23, 29.

41. COR 26: Letter from Neel to Casey, 30 August 1967; DOC 28, 124, 126, 131.

42. http://www.journals.uchicago.edu/cgi-bin/resolve?AJHG013452

43. http://www.anth.uconn.edu/gradstudents/dhume/

44. Turner, 2001a, p. 22.

45. COR 5: Letter from Neel to Layrisse, 11 December 1967.

46. Uncataloged document.

47. Turner 2001A, p. 31.

48. DOC-1: Neel field journal, p. 81, 100, 103, 114.

49. Neel, et al., 1970

50. DOC-71: Equipment list for the 1968 expedition, U.S. Customs stamp, 11 January 1968.

51. Turner, 2001a, p. 19, 48-49, 53-54.

52. Ibid., p. 17, 47, 51, 53-54.

53. Ibid., p. 55, 56-57, 59.

54. See Turner & Stevens, 2001b, Part IV, No. 6: Research Plans, Itinerary for Expedition.

55. COR 29: Letter from Neel to Dr. Robert A. Hingson, 15 September; COR 54: Letter from Neel to Dan Shaylor, 19 September 1967; COR 57: Letter from Neel to Neill Hawkins, 10 March 1967; COR 77: Letter from Neel to Layrisse, 30 August 1967; See J. V. Neel, *Physician to the gene pool* and F. M. Salzano & S. M. Callegari-Jacques *South American Indians*.

56. COR 37: Letter from Neel to Robert Shaylor, 21 November 1967; COR 54: Letter from Neel to Dan Shaylor, 19 September 1967.

57. DOC-1: Neel field journal.

- 58. Turner, 2001a, p. 55, 56-57, 59.
- 59. DOC-1: Neel field journal, p. 60.
- 60. Turner, 2001a, p. 32.
- 61. DOC-1: Neel field journal, p. 60.
- 62. Ibid., p. 60. Our reading is, "Decision: invite them in also."
- 63. COR 39: Letter from Robert Shaylor to Neel, 28 November 1967.
- 64. DOC-1: Neel field journal, p. 60.
- 65. Turner, 2001a, p. 19.
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- 72. DOC-1: Neel field journal, p. 79.
- 73. Ibid., p. 76.

- 74. Ibid., p. 79.
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Chapter 14

A Case Study of Ethical Issues in Genetic Research: The Sally Hemings-Thomas Jefferson Story Sloan R. Williams

Introduction

The field of research ethics is a dynamic one, particularly in recent years. The standards and guidelines issued by the federal government and university institutional review boards (IRBs) undergo constant review and revision as new issues arise. Foster and colleagues' study provides an excellent opportunity to examine some of the ethical issues that frequently arise in nonmedical genetic research, the guidelines that have been developed to address them and some additional concerns that may need more careful attention in the future.

Foster and colleagues used Y chromosome haplotyping of the descendants of Sally Hemings, Field Jefferson (Thomas Jefferson's paternal uncle), and John Carr (the paternal grandfather of Thomas Jefferson's nephews) to determine whether Thomas Jefferson could have fathered any of Sally Hemings's children. Although more of a historical genetic study than an anthropological one, the work raises concerns also encountered in modern anthropological genetic research when participants agree to become involved to learn more about their own or their culture's history. They are more likely to experience psychological or social harms by agreeing to participate in these studies than to risk the physical harms that are often the dominant concern in medical research.

Shortly after Foster and colleagues' research was published in 1998, I was approached by members of the Woodson family, descendants of one of Sally Hemings's sons, for help in interpreting the results of the study. Although originally approached for my genetic expertise, as an anthropologist, I soon became interested in the effect the study had on the family and the ethical issues raised by the research. Eventually, I decided to study the subject

more formally and interviewed many of the individuals involved in or affected by the research, including Dr. Foster, the study participants and some members of the Woodson family. Through these interviews, I was able learn more about the means by which the study was constructed and to more fully assess the effects of the study's outcome on those who were affected by the study, particularly the Woodsons.

In this chapter, I will begin by providing an overview of the historical debate that motivated the genetic study. Then, a brief summary of Foster and colleagues' methods, results, and conclusions will be presented. The remainder of the chapter will be devoted to a description of some of the ethical issues raised by the research which include: the difficulties that may be experienced when attempting to translate the principles of respect for persons and beneficence into actual practice; the importance of community consultation or group consent in research; and the potential pitfalls of long-term sample archiving and usage. Finally, the chapter ends with a discussion of the lessons that can be learned from the research to facilitate future researchers in anticipating and planning for similar concerns in their own research.

Background

The Historical Debate

Madison Hemings's account of his life was published in the Pike County Republican in 1873 as part of a series on African Americans living in the Ohio area (reprinted in Gordon-Reed, 1997, p. 45–58). Hemings outlined his family history, describing his childhood at Monticello, Thomas Jefferson's plantation, and the later lives of his siblings, Beverly, Rachel and Eston. According to Madison Hemings, Sally Hemings, born in 1773, was the youngest of six children born to Betty Hemings, a slave, and John Wayles, her owner and Thomas Jefferson's father-in-law. The Hemings family moved to Monticello when Martha Jefferson inherited them after her father's death. As a teenager, Sally Hemings accompanied Thomas Jefferson's younger daughter, Maria, to Paris and served as her companion there for slightly more than two years, while Jefferson served as the United States' ambassador to France. Sally became Jefferson's mistress while there.

Shortly after returning to Monticello, Sally bore the first of her six or seven children (public records were not kept of slave births and deaths, so the exact number and identity of Sally Hemings's children is unknown) (Figure 14.1). Madison Hemings, who was the second youngest child, states that there were five children, four of whom, Beverly, Rachel, himself and Eston, lived to adulthood. He was unaware that a third daughter had died in infancy,

however, and possibly that an older brother had left the plantation to avoid further scandal a few years before his birth. James Callender published two reports in the Richmond Recorder in 1802 (reprinted in Lewis & Onuf, 1999, p. 259–261) reporting that Jefferson had fathered children by a slave whom Callender identified as "SALLY" and noting the presence of a slave boy at Monticello named Tom who bore an amazing resemblance to Jefferson. According to Woodson oral history, Sally's eldest child, Thomas, left Monticello at the age of 12 years as a result of the scandal caused by Callender's news stories. Thomas moved to the plantation of a relative of Thomas Jefferson's, John Woodson, located some distance away and adopted the name of Woodson (B. Woodson, 2001).

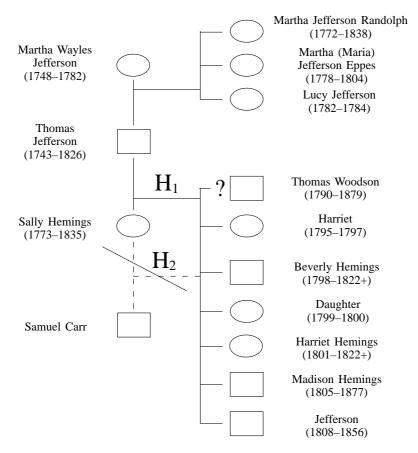


FIGURE 14.1 Diagram of Foster and Colleagues' two hypotheses: H_1) Thomas Jefferson fathered Hemings' children H_2) Samuel Carr fathered Hemings' children.

Jordan was the first biographer seriously to consider the possibility that Thomas Jefferson fathered Hemings's children, almost 100 years later. Soon after, Brodie rediscovered Madison Hemings's memoir and argued that the relationship had definitely existed. More recently, Gordon-Reed revisited the issue and argued for a more balanced treatment of the evidence, concluding that Jefferson had fathered Hemings's children as well. Both Brodie and Gordon-Reed used secondary sources such as reports from other newspapers written at the time of the scandal caused by Callender's articles and the testimony and corroborative statements that appeared in other stories in the Pike County Republican to provide support for Callender's and Madison Hemings's statements. They also argued that there was abundant evidence that Sally Hemings's children had received special treatment above and beyond that received by other members of the Hemings family. Specifically, Jefferson freed Sally Hemings's four children who reached adulthood. Jefferson freed only four other slaves out of the several hundred he owned during his life (Wood, 1999), so this was unusual treatment.

Jefferson biographers (Burstein, 1995; Dabney, 1981; Ellis, 1997; Malone, 1948–1981; Miller, 1977; Parton, 1874; Peterson, 1960; Randall, 1858 [1972]) generally dismissed the claims that Jefferson fathered children with Sally Hemings. They argued that a relationship of that type would not be in keeping with Jefferson's character. They dismissed Callender's reports as the rantings of a disgruntled and vindictive journalist, and considered Madison Hemings's account to be an example of wishful thinking at best. Most believed the claim of Thomas Jefferson Randolph, Jefferson's grandson (first published in Parton, 1874), that Sally Hemings's children were fathered by Thomas Jefferson's nephew, Peter Carr.

As neither side's case was sufficiently compelling to end the argument, the debate reached an impasse. One group argued for the legitimacy of Callender's reports, Madison Hemings's memoir and the other oral histories. The other group argued that Thomas Jefferson had never formally acknowledged the children or his relationship with Hemings, so there was insufficient evidence to establish such a relationship. Gordon-Reed (1997, p. 243) noted that historians occasionally would state that the controversy would never be settled unless Jefferson's remains were exhumed. She considered their comments to be intentionally obstructionist because the likelihood that Jefferson's remains would be disturbed was remote, but she also realized that modern genetics methods would not require it and had heard rumors that such a study was in progress.

The DNA Study

A dinner party conversation in 1997 first sparked Dr. Eugene Foster's interest in whether genetic techniques could be used to determine the likelihood that Thomas Jefferson had fathered Sally Hemings' children. At first, Dr. Foster, a retired pathologist, thought the techniques then available were inadequate for the task. When a colleague convinced him otherwise, he contacted Dr. Chris Tyler-Smith at Oxford University. Tyler-Smith agreed to perform Y chromosome analyses in his laboratory with additional analyses to be performed by scientists at Leiden University in the Netherlands.

Foster designed the study to test what he considered to be the two dominant hypotheses, that the father of Hemings's children was either Thomas Jefferson or one of the Carr brothers (Figure 14.1). Male descendants of Field Jefferson, Thomas Jefferson's paternal uncle, were used (Figure 14.2) because Thomas and Martha Jefferson's children were all daughters. Three descendants of John Carr, the grandfather of Samuel and Peter Carr agreed to be tested. Foster could find descendants of only two

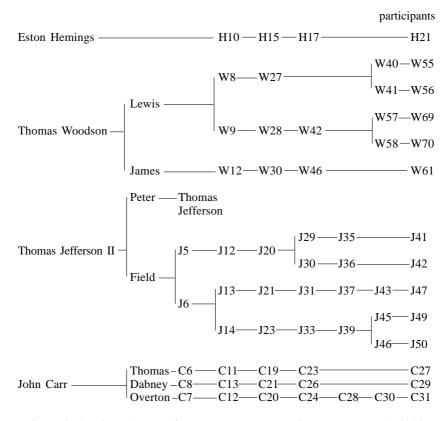


FIGURE 14.2 Genealogies of Participants (adapted from Foster et al., 1998)

of Sally Hemings' four sons. He found direct male descendants of Thomas Woodson and Eston Hemings Jefferson, but could not locate male descendants of Beverly or Madison Hemings. Thomas Woodson and his descendants retained their African American identity and all of the branches of their large family shared a detailed oral history describing their family's relationship to Sally Hemings and Thomas Jefferson. When Eston Hemings and his family moved to Madison, Wisconsin and passed into white society, Eston took the name of Jefferson. His descendants continued to believe that they were somehow related to Thomas Jefferson, but they lost the knowledge of their relationship to Sally Hemings. Their link to Sally Hemings was reestablished when one of Eston Hemings's descendants contacted Brodie after her book was published. Beverly Hemings passed into white society after leaving Monticello in 1822 and married, but produced no sons (Gordon-Reed 1997, 245-58). Madison Hemings continued to identify himself as African American after he moved to Ohio, but many of his male descendants passed into white society and discontinued family contact, so a direct-line male relative could not be found (Stanton & Swann-Wright, 1999, p. 178).

Foster included 14 participants in the study, all direct line male descendants of Thomas Woodson, Eston Hemings, John Carr, or Field Jefferson (Figure 14.2). Foster personally collected blood samples from each participant and used the meeting to explain the study to each participant and obtain written consent to include him in the research (see Appendix; Foster's consent form). The consent form that Foster had written after consulting with a lawyer familiar with medical ethics, dealt mainly with the physical risks and procedures involved in blood sample collection and did not focus on any potential psychological or social risks in the study. After collection, Foster sent the blood samples to a commercial American laboratory for DNA extraction. The DNA samples were then sent to the European laboratories for Y chromosome analyses.

Table 14.1 shows the predominant Y haplotypes for the descendants of Field Jefferson, John Carr, Thomas Woodson, and Eston Hemings. Seven biallelic markers, 11 microsatellite short tandem repeat (STR) polymorphisms and the minisatellite MSY1, all located on the Y chromosome, were typed to construct the haplotypes. The Carr haplotype differed from the Jefferson haplotype at numerous places along the Y chromosome, at one bi-allelic marker, five microsatellite markers and in both the number and repeat unit sequence type in the minisatellite. The consensus Woodson haplotype did not match either the Field Jefferson or Carr Y haplotype. The Eston Hemings descendant's Y haplotype matched the Y haplotype of the Field Jefferson descendants exactly.

Ancestor	bi-allelic marker	rs microsatellites	minisatellite
Field Jefferson	0000001	15.12.4.11.3.9.11.10.15.13.7	(3)5.(1)14.(3)32.(4)16
Eston Hemings	0000001	15.12.4.11.3.9.11.10.15.13.7	(3)5.(1)14.(3)32.(4)16
Thomas Woodso	on 0000011	14.12.5.11.3.10.11.13.13.13.7	1(16).(3)27.(4)21
John Carr	0000011	14.12.5.12.3.10.11.10.13.13.7	(1)17.(3)36.(4)21

TABLE 14.1 Y Chromosome Haplotypes (adapted from Foster et al., 1998)

The Y chromosome variation within each family descent group tested was generally minimal, and the number of observed differences fell within the range predicted by random mutation, with the exception of one Woodson haplotype. Although four of the Woodson haplotypes matched each other closely, the haplotype of the fifth descendant differed at multiple bi-allelic, microsatellite, and minisatellite loci (Table 14.2). Foster and his colleagues interpreted this haplotype as evidence of nonpaternity in that participant's descent line.

The manuscript was rejected by two other journals, before it was finally accepted by Nature. While Foster was waiting for a publication date, the story was leaked to the press. After the story appeared in the U.S. News and World Report (Murray & Duffy, 1988), the publishers of Nature rushed the article into press and it appeared in print nine days later. The article's publication sparked intense public interest. Descendants of both Martha Jefferson and Sally Hemings appeared together on the "Oprah Winfrey Show" within the month and articles appeared in major newspapers across the country.

TABLE 14.2Woodson Descendant Y Chromosome Haplotypes
(adapted from Foster et al., 1998)

Participant	bi-allelic t markers	microsatellites	minisatellite
W55	0000011	14.12.5.11.3.10.11.13.13.13.7	(1)16.(3)27.(4)21
W56	0000011	14.12.5.11.3.10.11.13.13.13.7	(1)16.(3)27.(4)21
W69	0000011	14.12.5.11.3.10.11.13.13.13.7	(1)16.(3)27.(4)21
W70	1 11 0001	17.12.6.11.3.11.8.10.14.6	(0?)1.(3a)3.(1a)11.(3a)30.(4a)14.(4)2
W61	0000011	14.12.5.11.3.10.11.13.13.13.7	(1)16.(3)28.(4)20

Current Study

Background

Carolyn Moore, a descendant of Thomas Woodson and a colleague of mine at the Field Museum in Chicago, first contacted me around the time the genetic study was published. Her family was looking for someone with genetic expertise to help interpret the study's results and wanted an outside expert to evaluate the strength of its conclusions. After a series of interactions with Carolyn, I attended the Woodson family reunion in 2000 to meet with the family and their research committee in person to answer their questions. I talked informally with many Woodson family members while there, which gave me the chance to learn how individual family members were reacting to the study. It struck me that the family was upset, not only with the results themselves, but also with the manner in which the study had been handled.

Having recently attended a workshop organized to explore ethical issues in anthropological genetic research,¹ I realized that the stress the Woodsons experienced as a result of the study was attributable in part to manner in which Foster and colleagues handled several ethical issues in their work. Thus, a more detailed analysis of Foster and colleagues' research protocol and the effects of their choices on the study participants might provide other researchers with information helpful in resolving ethical issues in their own research. I undertook unstructured interviews with Eugene Foster; several of the individuals who participated in the genetic study; Robert Golden, then president of the Woodson Family Association; and various other members of the Woodson and Hemings families.

Dr. Foster was very helpful and willing to discuss the problems he had faced and the decisions he had made. He also forwarded a copy of the consent form he used in the study to me (appendix). Foster's research did not undergo a formal ethical review because he was not directly affiliated with a university at the time of the study and the research did not receive federal funding. Foster realized a consent document would be needed, however, so he wrote one in consultation with a lawyer at the University of Virginia who served on that university's institutional review board (IRB). As was fairly typical at the time, the information and assurances included in the consent document were conservative because the document was designed more to protect the researchers by informing the participants of the rights they had agreed to waive than to protect the rights of the human subjects. It focused mainly on the blood sample collection procedures and the physical harm that participants might experience during that process. It also addressed who would have ownership of samples and documents used in the study upon completion and explained the steps that would be taken to keep the genetic results confidential. The purpose of the study, the possible repercussions from the study, and any psychological or social harms the participants might experience were discussed only briefly or not at all.

Identification of Ethical Issues

After speaking with many of the people involved and learning more about the methods used in the research, I have identified four areas in which the choices Foster and colleagues made to satisfy ethical concerns resulted in unanticipated harm, real or potential conflicts, or other problems. The first two issues are related to respect for persons and beneficence, two of the core principles outlined in the Belmont Report. The report was written by the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, formed when National Research Act that was passed in 1974 in response to the public outcry over the Public Health Service Syphilis Study (Levine, 1988). The report identified three basic ethical principles used to judge the ethics of human subject research: respect for persons, beneficence, and justice. The commission initiated the process of developing guidelines for the implementation of those principles as well, and described their practical application in the areas of informed consent, risk and benefit assessment, and subject selection. The report prompted significant revision of the Code of Federal Regulations and underpins much of our current policies on ethical research. The third area of concern involves the role of group consent and community consultation in research design, an increasingly common topic in ethical training for researchers (Freeman, Romero, & Gollub, 2002). The final area addresses issues surrounding the long-term storage and use of human samples.

Respect for Persons

According to the Belmont Report, the principle of respect for persons recognizes the personal dignity and autonomy of individuals, specifically in their roles as subjects of scientific research. It also acknowledges the obligation to protect those with diminished autonomy. The requirements to obtain informed consent and to respect the privacy of research subjects are derived from this basic principle.

TRULY INFORMED CONSENT

The principle of respect for persons requires that human subjects have the opportunity to choose whether or not to participate in research. Adequate standards for informed consent must be defined in order to provide that opportunity. Sufficient information must be both provided and understood by the research subject for consent to be completely voluntary. Study participants must be made fully aware of all the variables they need to consider when making the choice, but exactly what kind of information and the level of detail needed depends on the situation and is not always easily determined.

Current consent documents usually contain more explicit information about both the study's purpose and the possible risks of harm to the participants than Foster and colleagues' document did in order to ensure that consent is "truly informed." For example, their document stated only that the researchers were "engaged in a project designed to determine whether there is scientific evidence to support the belief of a number of people that they are related to Thomas Jefferson" see appendix. Their document did not explain the purpose of the study, or even that it would involve the descendants of Sally Hemings. Foster did describe the purpose of the study more fully when he met with them in person, however.

Truly informed consent requires that all possible risks of harm to the participants be fully explained to them. Foster and colleagues' consent document described the physical risks to the participant well, but did not anticipate or adequately describe the potential risks of psychological and social harm. Their document outlined the risks associated with taking blood samples and the steps that would be taken the safeguard the health of any individuals exposed to blood products during the research. The participant was informed that he would be notified if evidence of HIV, hepatitis, or other infection was found. Possible social and psychological risks were addressed only indirectly in two statements that briefly outlined possible consequences of the study. The first statement acknowledged the fact that the press might contact the subjects and stated that each participant had the right to talk to the press if they saw fit. The second statement merely cautioned that their ancestry might not be what they thought it was. The document did not elaborate any further on what effects this knowledge might have on the participant.

ACCESS TO STUDY RESULTS

Foster wrote the consent document before he met directly with the participants and learned what they expected to receive in return for their participation. Foster then modified the assurances he gave them when he met with the participants in person to encourage their cooperation and goodwill. Most notably, although the consent form promised only that the participants would receive copies of the article at or around the time of publication, Foster promised them in person that they would receive the results before they were published. He also agreed to send prepublication copies to other interested parties, such as then Woodson Family president, Robert Golden. Later, when the participants did not receive the results beforehand, the discrepancies between the written and verbal assurances that had crept in during the process of obtaining informed consent made a difficult situation—learning that their Y haplotypes did not match Jefferson's—even more upsetting. President Clinton was embroiled in the Monica Lewinsky scandal and his impeachment trial was about to begin when Foster learned that his paper had been accepted by *Nature*. A study that addressed the sex life of a cherished former president such as Thomas Jefferson was timely and controversial, so *Nature* rushed the paper into publication when the popular press broke the story. Foster had been waiting for *Nature* to give him a publication date before sending copies of the paper to participants and other interested parties, so the hurried publication meant the participants did not receive copies ahead of time as planned. Consequently, the participants and their families first heard the results of the study either when they read it in the newspapers or when reporters called their homes. A great deal of distrust and anger was generated among the study participants and family members because they felt that "a promise was broken." Foster felt betrayed by *Nature* and the participants felt the same about Foster.

Beneficence

Beneficence is the principle that ensures the well-being of research subjects. As defined in the Belmont Report (National Commission for the Protection of Human Subjects, 1979), beneficence extends beyond the admonition to do no harm to include a responsibility to maximize any potential benefits to human subjects and to minimize all possible risks of harms to those involved in research. Researchers have become increasingly aware through time that the possible harms experienced in biomedical studies may be social, economic, psychological, as well as physical.

The person who experienced the greatest psychological and social harm in Foster and colleagues' study was the Woodson participant whose Y chromosome haplotype did not match the other Woodsons. Foster was aware of the possibility that nonpaternity might be exposed in the course of the study and tried to avoid the problem by including either fathers or sons, but not both in the study. Unfortunately, he did not anticipate that nonpaternity might be revealed through intrafamily haplotype comparison and one subject was found to have a haplotype that differed from his male relatives. Another Woodson participant represented the same line of descent, so this particular participant was not critical to the analysis. Despite the potential for psychological and social harm that publishing this information held, the participant was not removed from the study.

The participant has not responded to my request for an interview, but I believe that his willingness to participate in the original study indicates that he did not anticipate this result. To make matters worse, he had no chance to prepare for the publication of the findings because the participants first heard about the study results from the news media. Lastly, the precise genealogical information presented in Figure 14.1 of the article effectively revealed the participant's identity

to individuals familiar with Woodson genealogies (M. Woodson, 1984), so Foster and colleagues' attempts to keep each participant's genetic information confidential failed to protect him. In this case, the benefit of including the subject in the study was small in comparison to the social and psychological harms likely to be incurred by doing so, so the subject should have been removed from the study. The publication of his haplotype violates the principle of beneficence.

Group Consent

Although federal regulations do not require group consent or community consultation, the subject is now routinely treated in the IRB training provided to universities and research centers (see, for example, Hansen & Braunschweiger, 2002). The potential advantages and disadvantages of working with the community and in obtaining group consent in addition to individual consent in anthropological genetic research have been discussed in recent workshops.² One of the main benefits of obtaining group consent is that it facilitates good relations with the community or groups involved in the research.

In Foster and colleagues' case, consent could theoretically have been obtained from the Woodson Family Association and the Monticello Foundation. Individual members might not have recognized the authority of these organizations to make decisions for them though, because the groups were established for other reasons. The Woodson Family Association was originally intended to facilitate and maintain intrafamily contact, mainly through family reunions. The Thomas Woodson Family Association elects a president and board and organizes large family reunions every other year. The Monticello Association, composed of descendants of Thomas and Martha Jefferson, was established to oversee the upkeep of the Monticello cemetery (Monticello Association, 2000).

Foster did not formally request permission from the Woodson Family Association to include them in the study, but he did approach Richard Cooley III, then president of the Woodson Family Association, along with several other Woodson family members, to ask for help in recruiting participants. Foster told me he had not thought it necessary or appropriate to ask Cooley for permission to contact other Woodsons. Cooley's daughter, Michele Cooley Quille, has accused Foster of including Woodsons in the study over their objections (Lanier & Feldman, 2000, p. 45). Cooley Quille says that her father consulted with the Family Association Board and refused Foster's request for help when Foster would not agree to have the samples independently tested and the results examined by an outside geneticist appointed by the Woodsons. According to Foster, Cooley responded to his initial letter, asking questions that included whether the Woodsons could have the samples tested independently. Foster replied that larger blood samples would have to be collected in order to do so, but that it would be feasible and he would be willing to do so. An agreement was never formalized though, because Foster found a sufficient number of Woodson participants through other family members while he was waiting for Cooley's response. Although Foster did not obtain formal consent from the Woodson Family and Monticello associations, he did continue to interact with the Woodson Family Association, even after the article's publication. Foster ordered the testing of a descendant from another branch of the Woodson family after the article was submitted in order to test alternate explanations for the difference between the Thomas Woodson and Eston Hemings haplotypes. Nevertheless, disagreements within the family as to the exact nature of Foster's first interactions the Woodsons during subject recruitment have added to the general atmosphere of distrust and hard feelings.

Ownership and Disposal of Samples

When Foster wrote the consent document, he followed the conventions of the time and declared that ownership of all samples belonged solely to the research team, with future sample use and disposal method to be determined by them. The document also asserts that the samples will not be used to develop commercial products or biological techniques that could have commercial value. Although the researchers could certainly keep the guarantee that the latter commitment would be kept during their study, it would be difficult to ensure that the samples would not be used in research resulting in commercial applications or biological techniques once the samples were given to other laboratories.

Anticipating Ethical Concerns in Future Research

Foster told me that he had considered using a university laboratory to perform the DNA extractions, but decided against it because the IRB process was so time consuming. If Foster had participated in the institutional review process, the research protocol might or might not have been altered to avoid some of the problems described here. Protocol changes would likely be required now, but the ethical review process is constantly being reevaluated and updated, so holding the original genetic study to today's standards is unfair. Rather, it is hoped that the examination of Foster and colleagues attempts to deal with the ethical issues they encountered in their research, will help other researchers to anticipate the ethical issues they will face in their own work. The study illustrates a number of important issues to be considered when designing research protocols. First, it highlights the fact that concern with ethical issues remains important throughout the study. Second, the Foster and colleagues' research identifies several potential conflict of interests in nonmedical genetic studies. Finally, it raises the issues of group and individual participation in the research and encourages the discussion of the role and degree of participation both groups and individuals could or should have in this kind of research.

Ongoing Evaluation of Ethical Concerns

This particular case demonstrates the need for constant vigilance in such studies. Although Foster anticipated the possibility of nonpaternity and did not recruit father and son pairs in order to avoid inadvertently identifying cases of nonpaternity, one case was revealed. When I asked Foster about it, the idea of removing that individual seemed not to have occurred to him, so the participant was not given the chance to withdraw from the study. The subject could have been removed from the study without altering the study's conclusions, but it simply did not occur to anyone to do so.

No matter how much effort is made to anticipate every eventuality, surprises will likely occur. Flexibility and constant vigilance are required, so the necessary protocol adjustments can be made quickly when unanticipated events happen. IRBs require any researcher who experiences an unexpected or unanticipated result to report it immediately, so that the board can review the researcher's proposed plan for responding to the incident. The review process helps scientists to remain cognizant of ethical issues and concerns while the research is in progress and provides guidance in handling new or unanticipated problems.

Differing Expectations and Conflicts of Interest

Conflicts of interest and misunderstandings due to differing expectations can arise in many different situations. Three examples from Foster and colleagues' study are described here.

PARTICIPANT PRIVACY AND CONFIDENTIALITY OF DATA

The first conflict that could arise in genetic research occurs between the participant's right to privacy and the researcher's need to disclose the details needed for others to interpret and evaluate the study's findings. Foster and colleagues elected not to attempt to safeguard their subject's privacy by withholding the names of the participants in this study. The consent form stated that the researchers would refer to participants by name in publications, if they deemed it necessary. The researchers agreed to keep their participants' genetic information confidential, however, by stripping the samples of identifiers during the DNA extraction and genetic analyses, so that only Foster would know what samples belonged to which individuals. Identifiers were to

be stripped from any samples given to other researchers for future analyses as well.

The ability to protect a participant's privacy and keep participant records and genetic information confidential is a serious concern in research today because it is difficult to achieve, and may depend on circumstances and individuals outside the researchers' direct control. Fortunately, although not required to do so, Foster and colleagues have been able to protect the participants' privacy in the public arena. When the public has learned a participant's identity, it has been the participant's choice to disclose his role in the research. Unfortunately, the researchers have been unable to keep the genetic information of one participant confidential. Although they observed the standard precautions for keeping genetic information confidential by removing sample identifiers, the genealogical information provided in the article allowed family members to deduce the participant's identity.

PEER REVIEW VERSUS POPULAR PRESS

The occasionally lengthy scientific peer review process may also conflict with the popular press's commitment to report news to public as quickly as possible. In this case, the interests of the popular press accelerated the peer review process and resulted in an earlier than anticipated publication date. Foster was caught by surprise and could not distribute copies to the participants as he had planned. Some of the people I spoke with believe that the results were intentionally leaked to the press to draw more attention to the work. They believed the results were leaked, either to gain greater publicity for the journal or in an effort to help Clinton at a crucial time in his presidency by focusing attention on previous presidential scandals. Whatever the reason, it is certainly true that scientific journals are under increasing pressure to release scientific news to the popular press earlier in the publishing process. Researchers must recognize the fact that they will not have complete control over the process of publishing their work once it has been accepted and plan accordingly.

OWNERSHIP OF BIOLOGICAL SAMPLES

Finally, a potential conflict could occur between the scientists' right to control the research design and the products used in that research and the participant's right to autonomy over their body and its products. Although it was once standard practice for the researcher to decide who would have access to samples and to stipulate the conditions of that access, policies related to the tracking, and monitoring of samples are changing. Scandals surrounding previous genetic research, for example, those involving the Yanomami of South America (Mann, 2001; Wong, 2001) and the Hagahai of Papua New Guinea

(Friedlaender, 1996), have heightened awareness and concern over the long term storage and continued use of biological samples that has resulted in new policies (American Anthropological Association, 2002).

Potential participants have become more aware of the possible value of their samples in light of the great advances in biomedical technology in the last decade, and are less willing to cede rights over their body products to researchers. Arguments over who will benefit from medical advances resulting from genetic studies have resulted in several recent battles (Friedlaender, 1996). In order to make an informed decision to participate in research, human subjects need to know whether the samples they are being asked to donate are likely to result in significant financial gains for anyone involved in the study. That knowledge is a critical part of the informed consent process because it will likely affect either their decision to participate or the conditions under which they are willing to participate in the research. Universities and research institutions are also becoming increasingly concerned about the ultimate fate of samples when a genetic study is completed. Further study of such samples may require new IRB approval and additional consent forms.

Foster and colleagues could only promise the participants that the samples would not be used to develop technologies or products with commercial value while in their care. The risk that the samples will be used in ways these researchers did not anticipate increases each time the samples are used in other studies. The inherent conflict in the two statements illustrates why many are concerned about the ethics of archiving biological samples and using samples in research other than the project for which they were originally collected.

Group Participation

A small number of individuals directly participated in the research, but the members of the groups to which they belonged were affected by their actions and experienced some of the same risks. The entire Woodson family, and not just the participants themselves, have been affected by the study's publication and subsequent press coverage.

Since the study, roles of both the Woodson Family Association and the Monticello Association have changed subtly and the associations' responsibilities have expanded to include roles as spokespeople for their members. The Woodson Family Association formed a research committee and is now taking a more formal role in representing the interests of the family in this ongoing debate over the relationship between Jefferson, Hemings, and Woodson. The association has commissioned genetic studies of its own to determine whether the family Y haplotype matches those of the descendants of John Woodson, the owner of the plantation where Thomas Woodson lived as a young adult. The Monticello Association formed a membership advisory committee charged with evaluating the arguments made for the identification of Thomas Jefferson as the father of Sally Hemings's children in order to decide whether Hemings's descendants meet the criteria needed to permit burial in the cemetery (Monticello Association, 2000). In this role, the Monticello Association now represents the descendants of Martha and Thomas Jefferson in the public forum on the issue of the genetic evidence.

Foster acknowledged that the Woodsons as a group had some rights when he agreed to provide their Family Association President with a copy of the results prior to publication, but did not include them in the early stages of the research. Federal authorities currently provide little guidance in the incorporation of group and community involvement, so researchers must make their own decisions in each research context (Freeman, Romero, & Gollub, 2002). Group and community consultation is particularly important in anthropological genetic research, which often involves socially vulnerable groups and populations.

Participant Involvement

The nature and degree of participant involvement in research has been debated in ethnographic research for many years (Ablon, 1982, 1994; Hammersley & Atkinson, 1995; Hopkins, 1993; Wrobel, 1979). Participants have begun to play larger roles in modern ethnographic studies, particularly those undertaken in the United States and other western countries. That expanded role may include reading and commenting on manuscripts.

Foster might have avoided some of the ill will felt by the participants and their families if he had provided them with copies of the manuscript earlier in the publishing process, but he waited until late in the process in order to provide them with the final version. The participants and other interested parties were to be given copies ahead of time as a matter of simple courtesy, not because of any belief that they would play an active role in the research.

As people become more educated about the benefits and risks of genetic studies, they are likely to expect to be notified of results prior to publication, as these participants did. Including participants in the process requires more time, if participants are given time to respond the manuscript, and may prove stressful if the research is controversial and likely to provoke angry reactions from at least some of the participants. Furthermore, sharing study results with research subjects prior to publication may prove risky because human subjects have the right to withdraw from research at any time. If they withdraw because they disagree with the results or with the scientist's interpretation of them, publishing results obtained as a result of their initial participation, and over their objections, may prove difficult. The withdrawal of more than a few

participants from Foster and colleagues' study could have forced the researchers to withdraw their paper. When participants have agreed to participate in research because they are specifically interested in the results of that study, researchers will likely experience pressure to provide the participants with study results as soon as possible. In order to avoid this kind of situation, those researchers will need to consider carefully the degree of involvement the participants will have throughout the research and when the subjects will be notified of the results before beginning the work.

Many cultural anthropologists attempt to avoid this kind of conflict is by building strong bonds of trust with both the individual participants and the groups or communities involved. Those bonds help the participating individuals and groups to accept results that are contrary to their expectations or are otherwise difficult for them to accept. Anthropologists as a whole, need to be especially sensitive to these issues because their work frequently involves indigenous groups or socially vulnerable populations. Expending the time and commitment required to build this kind of trust with study participants has not been generally typical of previous genetic studies, but will become increasingly crucial to a study's success. Anticipating problems and preparing participants ahead of time for all possible outcomes will hopefully reduce the likelihood that participants will withdraw from the study, if they are unhappy with a study's findings or disagree with its authors' conclusions.

Conclusion

The Hemings-Jefferson study highlights some of the ethical issues in current genetic research. The principles of respect for persons and beneficence have been recognized for many years, but the discourse about how best to implement them in research is ongoing. Issues such as group consent and consultation, and the long term use of samples are receiving increasing attention. Future sample use is part of the process of informed consent and must be carefully considered by any researchers who work with human biological samples. The rights of the group members, who may be affected by, but not directly involved in, research need to be considered as well.

Foster and colleagues' study illustrates the importance of both identifying potential ethical issues ahead of time and continuing to monitor them throughout the research. Conflicts of interest or sources of potential misunderstanding should be identified to the best of the researcher's ability at the outset and strategies implemented to avoid them. Unanticipated events will occur no matter how careful the advance planning, however, so constant vigilance must be maintained throughout the study to deal effectively with unexpected results. The degree of involvement both groups and individual participants will have in the study, and the timing of the distribution of results must be determined before the research begins. Participants are given the right to withdraw from the study, and this right, when combined with any agreements made to provide them with access to prepublication results will pose risks for the researcher. These risks can be minimized by increasing the amount of time spent at the beginning of the process to build a foundation of trust through the discussion of the potential outcomes and interpretations with those involved. Incorporating these protections of research subjects requires more time and effort on the part of the researchers, but the sense of empowerment and trust engendered in the participants by this approach will increase the willingness of people to participate in future studies.

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Notes

1. Anthropology, Genetic Diversity, Ethics, sponsored by the National Science Foundation and organized by Trudy Turner, February 12–13, 1999.

2. Examples include an NSF sponsored workshop entitled "Anthropology, Genetic Diversity and Ethics," organized by Trudy Turner, February 12–13, 1999 and a workshop entitled "Health and Global Human Genetic Diversity" sponsored by The Field Museum, organized by John Terrell, September 24–26, 1998.

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Appendix: Foster and Colleagues' Consent Form Permission to Collect and Test Genetic Material and Survey Family History

1. Purpose of the Study

As you know, Dr. Eugene A. Foster and his colleagues (the research team) are engaged in a project designed to determine whether there is scientific evidence to support the belief of a number of people that they are related to Thomas Jefferson. This form explains the procedures they will use to do a scientific analysis of the family relationships in question. By signing this form you will be agreeing to cooperate with the research team by providing information about your family and permitting them to collect blood and/or cells from you to use in this study.

2. Description of the Study Procedures

The study will require collecting small amounts of your blood (about three teaspoonsful) When the blood is obtained from you, it will be put in a container that is labeled with code numbers. (A record of the code number that corresponds to your name will be kept confidential by Dr. Foster.) Portions of the sample gotten from you and other participants will be sent to one or more laboratories where the DNA they contain will be analyzed to determine which of the various people studied are blood relatives and which are also related to Thomas Jefferson. The personnel in the laboratories will see only the code numbers on the specimens and will not know the names of the people they belong to.

The blood will be collected by a medical doctor or other trained and qualified person who will insert a needle into one of your arm veins and fill a small tube. The procedure, which is just like that used to get blood for ordinary medical tests, involves a needle stick and is slightly uncomfortable. Rarely, people faint during the procedure. Occasionally bruises appear or minor soreness occurs where the needle was inserted. Very rarely, the needle stick leads to an infection even though sterilized needles and other clean materials will be used to try to prevent infection.

As part of the study you will be asked to provide as much information about your ancestors and yourself as you can, including the names and locations of your relatives as far back as you can trace. The research team may also interview some of your family members and examine public records to confirm facts about your family background. This information will form part of the record that will be studied along with your DNA.

3. Ownership and Storage of DNA Samples and/or Documents

Your DNA and the blood or cells containing it will become the property of the research team. The material will be kept indefinitely by the team and/or the laboratories where the analysis was done. Other researchers will have access to the specimens, subject to availability of sufficient quantities and the judgment of the custodians, but only with coded identification Any personal papers or records you allow the research team to review will remain your property, but you give the team permission to use and copy these materials as part of his study and to disclose the information in them to others

4. Disclosure of Results of Study

By participating in this study by providing blood and/or cells for DNA analysis, you understand that that the results of this study will be disclosed to other researchers and may be disclosed to many other people through books, articles, interviews, etc. No information about the results of the study will be given to the participants until the results are published. On or about the date of publication, copies will be sent to the participants. An interpretive note will be provided along with scientific articles.

5. Commercial Applications

Your blood and/or cells will not be used to develop any products or biological techniques that might have commercial value. If this study is successful, it is likely that one or more books describing the results will be published. By signing this form you are giving permission for your name to be used whenever study results are reported. If you wish, copies of any publications written by members of the research team as part of this project will be sent to you free of charge.

6. No Medical Testing

This is not a medical study and we do not expect the analysis of your DNA to provide any information about your health. Your blood will not be analyzed for any genetic information not related to the determination of your blood relationships. In the event anyone involved with this study is exposed to your blood or body fluids, your blood may be tested for evidence of hepatitis, AIDS, or other infections without your further consent. Should there be evidence of infection, the results will be made known to you and the exposed individual. Your identity as the source of possible infection will not be revealed to the exposed individual. If no one involved in the study has been exposed to your blood, no testing for any infection or other medical condition will be done.

7. No Compensation

You will not receive any monetary compensation for your participation in this study.

8. Possible Consequences of Participation in the Study

Participants my be approached by representatives of the media, scientists, historians or other individuals seeking more information from them. The participants are not obligated to respond to such inquiries, but are free to do so.

The study may produce evidence that a participant's ancestry is not what he thinks it is.

By signing this form you are indicating that you have read it and/or had it read to you, and had any questions concerning it answered satisfactorily.

I accept the terms and conditions of this agreement.

Signature_____

Date_____

Participant

Signature_____

Signature

Member of Research Team

Witness

Chapter 15

Psychological and Ethical Issues Related to Identity and Inferring Ancestry of African Americans *Cynthia E. Winston and Rick A. Kittles*

To rob people or countries of their name is to set in motion a psychic disturbance that can, in turn, create a permanent crisis in identity.

-Jan R. Carew

Ancestry tells a people's story in narrative form and offers a sense of identity meaning. Disparate narratives, such as those of African American ancestry and genealogy, lead to an incomplete story and fragmented identity. Most African Americans know little about their African ancestry and are unable to identify with their ancestral homeland or specific indigenous African community. In fact, many African Americans learn and come to view their history as starting during slavery in the Americas. Arguably, the identity of enslaved Africans was largely determined by his or her master (Lovejoy, 1983; Ball, 1998; Curtin, 1990). As a result, over time there have been major implications that have evolved related to the social and psychological consciousness of descendants of enslaved Africans. This type of void or disconnect in ancestry is common among African Americans, but largely absent among other groups in America. For instance, white Americans have considerable latitude in choosing ethnic identities based on ancestry. Since many whites have known mixed ancestries, from Europe, they have the choice to select from multiple ancestries. For African Americans there is but one option in choosing ethnicityblack (Nagel, 1994).

With the recent advances in science and technology, it is now possible for scientists to use genetic, historical, and cultural data to tell a narrative of the African American experience prior to slavery. The African Ancestry project uses these advances in science and genetic technology to provide a bridge to the past. Through the development of a large database of genetic information, the African Ancestry project offers insight on genetic lineages that can be used for genealogical inference. By reconstructing the past using genetic techniques, and anthropological and historical data, the African Ancestry project unravels and tells the story of a people. These stories are unique to the history of the African experience in the Americas and help shape the multidetermined concept of identity.

In this chapter, we describe the growing interest in inferring ancestry in general and the significance of inferring African ancestry among African Americans in particular. In addition, we offer an analysis of important ethical and psychological issues that emerge from inferring African ancestry by placing the research within the context of the African American community's needs, motives, goals, identity, priorities, and the history of unethical research. Most importantly, we discuss why ethics in research on African Americans is a sensitive issue. Finally, we address some of the criticism related to this work and stress the importance of African Americans having the option and opportunity to tell the story of their ancestry.

Interest in Ancestry and the African Ancestry Project

Interest in Ancestry

Popularity in ancestry and genealogical research has grown rapidly over the last 10 years as evidenced by the increased number of websites such as Ancestry.com, genealogical societies and organizations, and church sponsored genealogy projects. Recently called "America's latest obsession" (*Time,* April 19, 1999), genealogical research has become the fastest growing hobby in many different U.S. communities. Most of the genealogical research utilizes court, birth, and death records. Recently, DNA technology has been used to supplement these historical documents in order to research genealogy. The rapid accumulation of genetic data in the form of DNA polymorphisms sampled from different human populations has provided a powerful tool for the field of genetic anthropology to infer human population history and explore genealogy.

Following groundbreaking genetic research, two major surges occurred in the field of genetic anthropology. The first was after genetic variation within and between human populations was assessed for the mitochondrial genome in 1987 by Allan Wilson and colleagues at University of California, Berkley. The mtDNA molecule was attractive to geneticists primarily because it was maternally inherited and mtDNA sequences collected from individuals could be interpreted as genealogies reflecting the maternal lineage history of the human species (Cann, Stoneking, & Wilson 1987; Vigilant, Pennington, Harpending, Kocher, & Wilson, 1991). Also, mtDNA evolves more rapidly than nuclear DNA. The second major surge occurred after polymorphisms began to be identified on the non-recombining portion of the human Y chromosome (NRY), which is transmitted father to son. Presently, over 400 well characterized polymorphic loci on the NRY can be analyzed with simple PCR methodology (Jobling and Tyler-Smith, 2003). These polymorphisms consist of slowly evolving single nucleotide polymorphisms (SNPs) (Underhill et al., 2000) and the ALU insertion/deletion polymorphism (Hammer, 1994); and the highly mutable microsatellites or short tandem repeats (STRs) (Jobling, Heyer, Dielties, & Knijff, 1999; Kayser et al., 2000). Although the informative stretches of genetic information at the mtDNA and the NRPY may represent less than 1 percent of the entire human genome, they have proven to be powerful tools for identifying and defining maternal and paternal lineages that ultimately relate all humans to a common ancestor.

One group of Americans particularly intrigued with the possibility of determining ancestry is African Americans, a group disconnected from their original cultures and historical past. There are several reasons for this tremendous interest among African Americans. First, there is limited information available to African Americans about the origins of enslaved Africans brought to the Americas. From about 1619 to 1850, millions of indigenous west and central Africans were kidnapped and transported to the Americas for indentured servitude. The origins of the enslaved Africans encompassed a wide geographic range consisting of eight coastal regions from Senegal south through the Cape of Good Hope and north along eastern Africa to Cape Delgado (Curtin, 1969; Lovejoy, 1983; Klein, 1999). The eight major regions were Senegambia (Gambia and Senegal), Sierra Leone (Guinea, Sierra Leone, and parts of Liberia), Windward Coast (Ivory Coast and Liberia), Gold Coast (Ghana, west of the Volta River), Bight of Benin (between the Volta and Benin Rivers), Bight of Biafra (east of the Benin River to Gabon), Central Africa (Gabon, Congo, and Angola), and the southern coast of Africa (from the cape of Good Hope to Cape Delgado, including the island of Madagascar).

Another reason for this interest in inferring African ancestry is related to the first. Slavery initiated and over the long term, motivated the disintegration of the social organization, knowledge of family history and culture, and traditional social sanctions of the pre-slavery African family (Stampp, 1956). Enslaved Africans suffered materially, medically, psychologically, and physically. In addition, slaveholders took full advantage of enslaved African women resulting in countless illegitimate and unacknowledged children of mixed European and African ancestry. Because of the U.S. slavery system and plantation complex, significant aspects of the history, identity, and culture of the enslaved Africans were essentially wiped away and lost to succeeding generations. These lost histories are represented as gaps in the historical record such that when African Americans attempt to trace their family history many, if not most, hit a wall in the antebellum south. Records of births and deaths during the period of slavery are substandard at least and nonexistent in most cases (Burroughs, 2001). The insufficiency of the historical record hampers the ability of African Americans to trace their ancestry back to specific African populations. Genetic information on ancestry may prove to be an ideal resource to supplement historical documents and possibly extend the African American search for indigenous African ancestry.

African Americans represent a recent, yet heterogeneous macroethnic group (Jackson, 1997) with a majority of its genetic contributions from regionally and genetically diverse west and central African populations. Because of this high genetic heterogeneity it is difficult to quantify the percentage of all the different groups of indigenous African ancestry which contributed to the genome of individual African Americans. Instead, the project focuses on utilizing information on African maternal and paternal lineages in order to evaluate if these lineages are present among African Americans. The opportunity to explore genetic markers that track ancestral lineages is tantalizing and can be used to supplement other forms of research on African American genealogies.

Indeed, the opportunity to explore the genetic ancestry of Africans in America was deemed so important and practical that it was placed as one of the objectives of the African Burial Ground project. During 1991 to 1992, human remains were uncovered from an eighteenth century burial ground of enslaved Africans in lower Manhattan. The U.S. General Services Administration (GSA) was preparing to build a federal office tower on the site at Broadway and Duane Streets. Although historical maps indicated that the site had been a "Negroes Burying Ground," GSA did not anticipate the storm of controversy that arose after excavations began (LaRoche & Blakey, 1997). Ultimately, the African American community became a major contributor to a research design that specified three major research questions about the burial ground population: What are the origins of the population? What was the physical quality of life in eighteenth century New York City? What can the site reveal about the biological and cultural transition from African to African American identities? The African Burial Ground Project was a multidisciplinary research project that was shaped to a large extent by the relentless determination of the African American community (La Rouche & Blakey, 1997). The response and demands of the African American community to research on remains from their ancestors also blatantly revealed to many that "Black people do not want to work for white people's purposes at the expenses of their own empowerment, perhaps especially not when it comes to the study and interpretation of themselves" (Blakey, 1997).

These types of responses from the community revealed that the interest in inferring African ancestry is also related to identity, a normal human psychological quest to answer the question, "Who am I?" Various disciplines such as philosophy, sociology and anthropology have offered definitions of identity. Psychologists characterize identity as that part of an individual's self-concept that defines who he/she is as an individual and as a member of a group (Demo & Hughes, 1990; Stryker & Serpe, 1994; Sellers, Smith, Shelton, Shelton, Rouley, & Chavous, 1998). As such, individuals have multiple personal and social identities, which are hierarchically ordered and have distinct levels of importance and meaning (Brewer, 1991; Deaux, 1992; DeBoeck & Rosenburg, 1988; Hogg & Abrams, 1988; Markus & Sentis, 1982; McCall & Simmons, 1978; McCrae & Costa, 1988; Rosenburg, 1979, 1988; Rosenburg & Gara, 1985; Sellers et al., 1998; Stryker & Serpe, 1982, 1994). These multiple identities assume various forms and can be based on selfcategorization (Turner 1987), ascribed categorization, such as gender and race (Baldwin, 1984; Cross, 1971, 1991; Kambon, 1992; Parham & Helms, 1981; Parham, 1989; Sellers et al., 1998), and internal psychodynamic processes (Erickson, 1968).

Among the multiple identities of African Americans is one identity that has historically by custom and tradition been ascribed by larger society—in other words, that of being Black. For *all* African Americans in the United States, amid the many answers to the question "who am I?" is one common answer: I am an African American is as true an ascribed identity for Jesse Jackson as it is for Michael Jackson, yet the meaning and significance they personally attach to being African American is likely very different. Identity is multi-determined in that not merely the ascribed identity comprises who one is, nor does solely the meaning and significance the individual attaches to that ascribed identity. In addition, it is likely that one's sense of who they are is also tempered by their beliefs about their ancestry and related to a geographic origin and location. For a group like African Americans, who largely only know that their ancestors were violently removed from Africa and then legally defined as property for over a century, it is likely that a gaping ancestral void in their identity exists.

Thus, interest in inferring African ancestry among African Americans likely emanates from a quest to affirm or disconfirm the congruence between that part of their identity that has been ascribed, the meaning and significance they attach to this ascribed identity and that part of their identity that evolves from a particular African lineage. In other words, the opportunity for African Americans to choose to infer their African ancestry presents another vehicle for them to gain historical and cultural knowledge that has the potential to augment what comprises one's identity or answer to the question of "who I am" In sum, the multidimensional and hierarchical nature of identity makes it necessarily psychologically complex. As such, ignoring one aspect of identity has the potential to have negative psychological consequences for some individuals. As a psychological phenomenon, identity is an important aspect of human functioning as it has implications for the way that individuals construe their experiences and respond to different events (Higgins, King, & Marvin, 1982; Higgins, 1989, 1990; McGuire, McGuire, Child, & Fujioka, 1978; McGuire & Padawer-Singer, 1976; Stryker 1980). For many African Americans, an opportunity to gain knowledge about their ancestral origins has the potential to answer the question "who am I?" more completely than ever before in our history.

Inferring African Ancestry

As databases cataloging genetic information on ancestry increase, many critical issues will need to be addressed. The potential implications of genetic research on ancestry are multidimensional, potentially spanning a number of psychological and ethical issues.

The primary goal of the African Ancestry project is to provide DNAbased testing to determine indigenous African paternal and maternal lineages among African Americans. Over the past five years, the initial research for the project has proceeded in several stages. First, the creation of a database began by collecting data on genetic polymorphisms that define maternal and paternal lineages from indigenous west and central African countries. Historical documents on the transatlantic slave trade provided information on the populations that were selected to sample for the database. Currently, the database consists of—over 11,170 maternal (mtDNA haplotypes) and 10,386 paternal lineages (Y chromosome haplotypes) from over 120 indigenous African populations. The database is stratified according to self-reported ethnicity, geographic origin, and language.

The second stage of the research focuses on gaining through more sampling a more comprehensive representation of populations that contributed to the millions of enslaved Africans. The countries included in this second phase of sampling for the database are Angola, Gabon, Congo, and Guinea. This is critically important to understanding the genetic background of African Americans because central Africans from Angola, Gabon, and the Congo represented about 35–40% of enslaved Africans during the slave trade (Curtin, 1969; Lovejoy, 1983), yet little is known about the level of genetic variation within this region of Africa.

The third stage in the research process was the testing of a pilot sample of African Americans. The majority of participants for the pilot study were not recruited but volunteered based on information they heard about the project from the African Ancestry website (www.africanancestry.com), newspaper articles and television news shows, thus providing further evidence of the enormous interest in inferring African ancestry among African Americans.

Preliminary analyses of mtDNA and Y chromosome lineages within the indigenous west and central African populations revealed, for both genetic systems, significant clustering of lineages within geographic regions of Africa. This finding has critical importance for the objectives of the African Ancestry project. In order to reliably "estimate" lineage ancestry there must be significant genetic differentiation or "differences" between indigenous west and central African populations. Pilot studies on approximately 1,000 African Americans have revealed that the majority of African Americans resemble west and central Africans at all genetic systems: autosomal, mtDNA, and Y chromosome markers. Interestingly, the paternally inherited Y chromosome markers revealed a larger non-African contribution to the African American population than the other genetic systems. This finding is due to sex-specific gene flow into the African American population and is not surprising, especially because European male-directed gene flow into the African American population began immediately after the enslavement of Africans in the Americas. We call this the "Jefferson effect" after President Thomas Jefferson, who fathered a child with the enslaved African Sally Hemings (see Forster, Bernsten, & Carter, 1998; Gordon-Reed, 1997). Thomas Jefferson was neither the first nor last slaveholder to produce illegitimate "mulatto" children with enslaved African woman because it was common practice in the antebellum United States (Woodson, 1922; Ball, 1998; Berlin, 1998; Russell, Wilson, & Hall, 1992). It is estimated that 28-30% of African American Y-chromosomes are of European origin (Doura and Kittles, 2002). This is distinct from the pattern observed for the maternally inherited mtDNA. European mtDNA haplotypes are less frequently observed (< 3%) within the African American population (Parra et al., 2001).

Several arguments have emerged against the use of genetic information for ancestry testing, specifically for African Americans (Lee, Mountain, & Koenig, 2001). Lee and colleagues at Stanford University (2001) assert that the African Ancestry Project "adheres to the one drop rule" and "places African American identity solely in the realm of genetics." Interestingly, the arguments by Lee, Mountain, and Koenig (2001) were in response to several false descriptions of the project in the popular press that contained gleaming generalities of "mounting public and scientific criticisms." The first argument presented by the Stanford group is that the project implicitly adheres to the "one-drop rule" of racial classification by ignoring the potential significant degree of admixture between populations (Lee, Mountain, & Koenig, 2001). The "one-drop rule" or "hypo-descent rule" (Harris, 1964) has been a socially constructed classification system since the period of slavery in the United States (Davis, 1991). The "one-drop rule" as legislated in many states in the antebellum South proclaimed, that any person with any known African "Black" ancestry would have the same legal status as a "pure" African (Berry & Tischler, 1978, p. 97–98; Myrdal, 1944, p. 113–118; Williamson 1980, p. 1–2). No matter how "white" or "black" the person looked, he or she would be considered "Black" or African American. This racial paradigm emerged from the South and then became the nation's definition accepted by all (Bahr, Chadwick, & Stauss 1979, p. 27–28). The goal of the African Ancestry project is not to define who is African or African American but to provide an opportunity for those who define themselves as African American to infer their African ancestry. In fact there may even be those who identify themselves as European American but want to determine if west or central African lineages are present in their ancestry. The African Ancestry project does not force on any of its participants a socially constructed or legal definition of who they are.

We note that the "one-drop rule" has only been applied to U.S. "Blacks." This U.S. cultural definition of "Black" or African American contributed to the already enormous phenotypic and genetic heterogeneity that existed among early Africans in the America. However, even during this time of legislated social order, there were a few who were able to "pass for white." This was a convenient alternative for African Americans who physically resembled European Americans. Passing for white has been possible only for a small proportion of the African American population per generation. Estimates of the number of African Americans passing permanently into the European American population ranged from a few thousand to tens of thousands annually (Vanderzanden, 1983). However it is problematic to accurately estimate the number of people who pass due to the sensitive nature of the actions. Because of these social and culture practices which have contributed to the heterogeneity of the African American populations, the African Ancestry project's aim is to explicitly focus on the prominent lineages defined by the mtDNA and NRY because they directly reflect maternal and paternal lineages that coalesce to a common ancestor without any overshadowing due to genetic recombination as observed in nuclear genes. For the most part, these maternal and paternal lineages coalesce within regionally defined west and central African communities; however, for some individuals they reveal non-African ancestry.

The second criticism from the Stanford group is that the African Ancestry project geneticizes identity. It is interesting that similar criticisms have not been projected at related research such as the Oxford Ancestors project at Oxford University, which places Europeans into one of seven mtDNA lineages (Sykes, 2001). African American or Black identity, like British "Anglo-Saxon" identity is a construction based on social and biological factors. For the African Ancestry project, identity is not "geneticized" nor "racialized" because it is not placed solely in a genetic context. If genetics were the only means in which identity is based, then it will construct an identity that is without culture and history. African Ancestry does not supplant but supplements shared social and historical experiences by placing African American maternal and paternal lineages in the context of indigenous African and even non-African (European and Native American) lineages. As presented earlier in the example of the "Jefferson effect," the project neither denies nor ignores, but recognizes the interactions among human populations.

Ethical Issues Related to Inferring African Ancestry

Within the African American community there is caution and skepticism about participation in genetic studies (Jackson, 1998). One of the main reasons why African Americans distrust biomedical and genetic research is "Tuskegee." The Tuskegee Syphilis Study was a government-sponsored study, from 1932 to 1972, that denied the effective treatment for syphilis to 399 African American men in order to document the natural history of the disease (see Jones, 1993). However, the Tuskegee Syphilis Study was not the first study in which African Americans were subjected to unethical and racist research that instilled fear in the African American community. For example, during the antebellum period enslaved and free Africans in the United States were subjects in medical experimentation (see Savitt, 1982). Not surprisingly, the Tuskegee Study continues to haunt the lives of African Americans, thus ethical research in the African American community must take into account the sensitivities and complexities of the experiences of Africans in America. There are two major requirements for ethical research in the African American community. The first is that the research must be of benefit to the community (Jackson, 1997, 1998; Jonsen, 1998). The second is that it should provide a strong contribution to science. The Tuskegee Syphilis Study did neither. In fact, historically, many types of research within the African American population have done neither (Gamble, 1997). With the completion of the human genome sequence by the public and private consortiums of the Human Genome Project there now exist new potentials for unethical research on the African American population. Genetic information is transgenerational (Rothstein, 1997) and has the potential for misuse, for instance sensitive medical genetic information can be used negatively against offspring in future generations. Once genetic information began to be collected it also was used to "scientifically" justify racism, eugenics, and genocide (Kevles, 1985). In response to unethical genomic studies, some of which included or intentionally excluded African Americans, several African American social and biological scientists in 1994 formulated a document called the Manifesto on *Genomic Studies Among African Americans*. This document reflects several of the values and priorities of African Americans (Jackson, 1997, 1998).

Generally, there are three primary ethical issues that emerge that are not necessarily unique to genetic studies on ancestry: ensuring confidentiality; preventing discrimination and stigmatization based on test results; and ensuring full disclosure of the potential psychological risks and benefits during the informed consent process (OPRR 1993). These risks include those associated with access to the genetic information on African Americans and the DNA data collected on the indigenous African populations.

It is clear that some concern within the community may focus on the possibility of unacceptable research that attempts to link a particular African ancestry with negative "stigmatizing" traits, such as criminality, or diminished intelligence. Unfortunately, historical precedents (Hernstein & Murray, 1994; Jensen, 1969) have caused the African American community to be all too familiar with these types of extrapolations and their impact on social policy. Therefore, it is indeed conceivable that any database such as this, comprised primarily of genetic information on African Americans and their ancestral populations, is especially appealing to individuals seeking to perpetuate and reinforce racist attitudes.

It is also possible that individuals and/or subgroups may experience stigmatization or discrimination as a result of disclosure of their ancestral origins, particularly if these origins are linked (justifiably or unjustifiably) to certain diseases/disorders or undesirable traits. Stigmatization and discrimination may occur from outside of the African American community as well as within the community. Therefore, despite the general perception that as individuals utilize genetic technology to link back to Africa there is enormous potential for the unification of the African American community, others are concerned that use of the technology will further divide and marginalize the African American community. It certainly is conceivable that information on African ancestry could also exacerbate current concerns about employment and insurance discrimination against individuals and groups based on genetic affinities and/or potentially perceived predispositions.

The importance of full disclosure, to the participants, of the potential benefits, risks, and limitations of this DNA testing cannot be overstated. Communication of the potential benefits must be tempered with appropriate discussion of the limitations previously described. In addition, the paradigm shift in the concept of informed consent for genetic studies such as this necessitates increased emphasis on the potentially more significant psychosocial risks rather than the limited physical risks (Thomson, 1997).

The informed consent process minimizes the potential for negative outcomes in several ways. First, in terms of risk, informed consent provides individuals with information about some of the personal and psychological costs associated with participation. Second, this process can highlight specific benefits or gains emanating from the testing. Finally informed consent can illuminate the limitations of genetic testing for ancestry. Each of these components maximizes the varied types of information some may need to make an informed decision to participate.

The ability of African Americans to make an informed decision to participate in the ancestry project is also influenced by the public and private perception of the project. It is important to note that there is no single response from the community about the African Ancestry project, but a variety of perspectives. Three primary responses from the African American community are characterized by positivity, apprehension, and skepticism. In contrast to the heterogeneity of responses from the African American community, Native American communities appear to be more unified in their lack of interest in DNA studies on ancestry. The Native American response may reflect the strong nationalism produced by myths of origins many of the Native American communities possess. Although the responses from the African American community vary in respect to genetic research (Kittles & Royal, 2004; Royal et al., 2000) an underlying response warrants comment. When asked if they would participate in genetic research for common diseases such as hereditary prostate cancer, asthma, or diabetes, many African Americans decline even though the research may provide major medical and healthcare improvements in the future. The possible outcome of improved health is not deemed important enough for many African Americans to participate in the research. For many of these African Americans, it is more important to deny access to their (African American) genetic information because of possible misuse, abuse of the information and/or stigmatization (Zwillich, 2001). However when asked if they would participate in a genetic study to determine African ancestry the response is usually positive. Because of the lost connection to Africa, the African America community places value on the genetic lineage research and it is likely perceived as more important than the possibility of misuse of the genetic information.

Psychological Issues in Inferring African Ancestry

There are not only important ethical issues that have the potential to evolve from inferring African ancestry, but critical psychological ones as well. These psychological issues converge around the meaning and significance one attaches to being African American. This meaning and significance has the potential to influence an individuals' motivation to infer their African ancestry, as well as shape their responses to the results of their ancestry analysis. Both the motivation and the response to the results can interact with the meaning and significance one attaches to being an African American in such a way that an individuals' psychological well-being is influenced.

Within the psychological literature, the meaning and significance that African Americans attach to being African American is referred to as racial identity.¹ There are many conceptualizations of racial identity within the field, however the most comprehensive model of racial identity that is used in psychology to understand the meaning and significance of being African American is the Multidimensional Model of Racial Identity developed by Sellers and his colleagues (1998). Within this conceptualization of identity, the meaning and significance of being African American is defined by the following four dimensions: 1) salience-the extent to which being African American is a relevant part of one's self-concept at a particular moment or in a particular situation; 2) centrality—the extent to which a person normatively defines him or herself with regard to being an African American; 3) regard—the extent of a person's affective and evaluative judgment of African Americans in terms of negative or positive valence, (i.e., public regard-the extent to which individuals feel that others view African Americans positively or negatively, and private regard—the extent to which an individual feels positively or negatively about being and African American).; 4) ideology-an individual's beliefs, opinions, and attitudes with respect to the way he/she feels that African Americans as group members should act (i.e., a nationalist philosophy, oppressed minority philosophy, an assimilation philosophy, and humanist philosophy).

How might individuals' racial identity influence their motivation to infer their African ancestry? One possibility is that individuals with high identity centrality exhibit interest and are driven to infer their African ancestry because they want to further solidify this psychological importance with biological evidence of a particular ancestry. Another possibility is that identity centrality alone may not be a motivator for some individuals, but would be interdependent with regard or ideology. For example, for an individual with low identity centrality and negative regard for African Americans, their motivation for the test may be to provide justification for their psychological disconnection with a group they view negatively.

Although it is likely that an individuals' racial identity plays a role in their motivation to infer their African ancestry, it cannot be ruled out that for some the desire to infer their ancestry evolves out of a general interest in gaining more information about their family history that would prove valuable to pass down from one generation to another. In either case the motivation for inference is rooted in filling an important ancestral knowledge void.

Not only is it possible that individuals motivation to infer African ancestry is tempered by identity, their responses to the results of the analysis may also be linked to identity that may in turn influence their psychological wellbeing. This can be most clearly illustrated by the story of one of the subjects in the pilot sample. Dressed in an African dashiki and highly articulate about his assumed connection to the Mandinka in Senegal, an African American male who was about 48-years-old was so eager to receive the results from his DNA analyses that he showed up unannounced. For this individual two things were clear. First, his dress and the focus of his conversation on his Africaness made it apparent that being African American was central to how defined himself and it was salient in the context of inferring his ancestry, he had positive regard for African Americans and he adopted a nationalist identity the stressed the uniqueness of being an African American. Second, it was clear that in his mind his DNA analysis would serve as a mechanism to confirm what he believed he knew: he was Mandinka. In other words, it appeared that this individual was intensely interested in uncovering his African ancestry as a means of supporting the importance he attached to being African American, but also interested based on his ideology related to the meaning of being African American on which his values, behaviors, and way of life likely had rested.

However, much to his surprise the results revealed a description of his African ancestry that was different from what he expected. More specifically, his results revealed that his paternal (Y chromosome) lineage was of European ancestry. As a result of this disconnect between his motivation, identity, and results, his psychological well-being appeared to be negatively impacted. Immediately after being given his results, the gentleman quickly saddened and clearly showed signs of a depressed mood.

This is just one example, among many possibilities, of how an individual's motivation to infer ancestry and their response to analyses may both be influenced by racial identity, which collectively could contribute to psychological well-being. That is, there are any number of combinations of motivation, racial identity, and psychological well-being that could emerge across different individuals in this quest to infer African ancestry. What is important is the recognition of the possibility that for some individuals there may be profound positive (euphoria, happiness, high self esteem, sense of belongingness), as well as negative (anxiety, anger, depression, disappointment, shock, denial) psychological consequences. These potential negative psychological effects raise the following question: What will African Americans make of themselves when they do find out more about their heritage? It would be important for the project to provide useful psychological resources such as access to a clinical psychologist who specializes in identity and psychological well-being counseling.

In sum, there are psychological issues in inferring African ancestry that are rooted in the meaning and significance an individual attaches to being an African American. It is important to recognize that there are many possible ways in which identity may relate to individuals' motivation to determine their African ancestry and their response to their analysis. Further, systematic investigation is required to further understand the specific patterns and mechanisms by which this meaning and significance shapes individuals' motivation, responses, and ultimately how this may influence their psychological wellbeing. Recognizing the existence of a wide array of psychological issues in influencing African ancestry coupled with providing adequate psychological resources will ensure that an individuals' quest to fill a psychological identity void will be less likely to result in negative psychological outcomes.

Conclusion

Science and technology now provides a bridge to the past. Technological advances in DNA technology now open up new and unprecedented opportunities for African Americans to fill centuries old voids in knowledge of their family history. The African Ancestry project capitalizes upon of this new state of the art technology and is poised to increase the options available to African Americans to determine ancestry. Although inferring African Ancestry project seeks to uncover unknown and fragmented stories of the African American experience, supplementing genealogical research with DNA markers that define paternal and maternal lineages. Genealogical research, especially on African Americans, is multidisciplinary, applying many different methods, techniques, and sources in its inferences.

The potential to connect African Americans with family lineages lost during the Transatlantic Slave Trade may ultimately provide many benefits to the African American community. This is novel because historically genetic research in human populations has provided little in terms of benefit to participants. Thus far, for example, the Human Genome Project, whose monumental objective has been to sequence the entire human genome, has not generated data explicitly beneficial to the general community as a whole and especially the African American community in particular.

In addition to the question of the benefit of the research to the community, another ethical issue that has emerged is the extent to which the African American community is involved in all aspects of the research process (Blakey, 1997; Jackson, 1997). African Ancestry is a multidisciplinary collaborative project involving geneticists, psychologists, anthropologists, historians, ethicists, and science journalists from the African American community. This not only increases the likelihood that the research agenda will benefit the community and include their priorities, but also ensures the sensitivity to African American history and culture.

Despite the promise that this research holds for African Americans in search of "identity," there are various scientific limitations and psychological implications that must be considered. Efforts to achieve optimal reliability and specificity in the genetic analyses may be compromised by inherent limitations in the informativeness of the database. As such, what is promised to participants in terms of the accuracy of the testing, as well what is communicated about the meaning and applications of test results are important issues that must not be ignored. These potential limitations are not unique to the African Ancestry project. Placing the project in its proper perspective with all its advantages and limitations will continue to be challenging because there is a high level of interest and an overwhelming desire within the African American community to connect with a lost past and identity. As the work moves forward, it is likely that more ethical, social, and psychological issues will emerge. Our ability to anticipate some of these issues and formulate plans to attend to them will undoubtedly enhance the positive and reduce the negative impacts on the African American community.

Although this research has limitations and is challenging and controversial it is imperative. Many other American communities possess considerable and detailed knowledge about their ancestry, as evident from family shields and coat-of-arms that are passed on from generation to generation. These symbols instill a sense of family identity and origin. In contrast, for most African Americans all too often what exists is the horrific image of their origin that is captured in the pictures and stories about the inhumane conditions and experiences of the middle passage. Thus, it is important to pass down information on heritage and family history to future generations of African Americans. A better understanding of family history will inform individuals on hereditary diseases and other family circumstances. Most importantly, knowledge of ancestry and genealogy has the potential to enhance pride and self-esteem (Burroughs, 2001, p. 37). For so long there has been negative imagery and attitudes surrounding Africa and African culture. These negative messages are internalized early in life by African American youth and likely are the reason why some African Americans reject their biological connections (Spencer-Stracham, 1992).

In sum, African Americans' interest in genetic research on ancestry is grounded in their historical and contemporary experiences in the United States. The high levels of biological heterogeneity within the African American population make the use of DNA to infer African ancestry a promising *empirical* endeavor. However, the most reliable method for inferring African ancestry is combining empirical DNA evidence with other forms of genealogical and historical knowledge (i.e., family and court documents). We recommend this mosaic approach to inferring African ancestry as it clearly

recognizes that identity is not simply that, which is ascribed, based on phenotype or the one-drop rule but is multi-determined. Thus, the African Ancestry Project provides an unprecedented opportunity for African Americans to define who they are and have a more complete identity narrative.

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Notes

1. There has been debate within the field of psychology about the use of racial identity versus ethnic identity. Psychologists who argue for the use of racial identity do so based on importance of the concept of race in their experiences makes the term preferable (e.g., Sellers et al., 1998).

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Chapter 16

The Consent Process and aDNA Research: Contrasting Approaches in North America

Dennis H. O'Rourke, M. Geoffrey Hayes, and Shawn W. Carlyle

Introduction

Ancient (a)DNA analyses present several novel ethical and legal problems and challenges that do not always obtain for genetic studies of contemporary populations, as well as a number that are the same irrespective of age of the samples (e.g., Goldstein & Kintigh, 1990; Thornton, 1998; Simms, 1993, Greely, 2001; Anderlik & Rothstein, 2001). Among the ethical, legal, and social issues routinely encountered in the course of aDNA research are:

- 1) Research access to samples;
- 2) The consent process undertaken to obtain such access;
- 3) A realistic assessment of what risks and/or benefits might obtain, and to whom, if molecular analyses are conducted on prehistoric materials;
- 4) Results assessment issues; and
- 5) Native American Graves and Repatriation Act (NAGPRA).

There is a voluminous and growing literature on issues attendant to NAGPRA in biological anthropological research and these issues will not be described here. Rather, this chapter will focus on the first three items, paying particular attention to our diverse experiences in obtaining consent from indigenous communities in order to conduct aDNA research.

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The first challenge in many aDNA studies is definition of population. Although this can be difficult in modern groups, where the self-definition of community, ethnicity or population membership makes for a fluid communal identity, the problem is exacerbated over the temporal scales that define aDNA research. Typically, we consider archaeologically recovered human samples as members of a continuous local or regional population if they:

- 1) are from archaeological contexts characterized by a uniform material culture;
- 2) derive from identical, or at least geographically proximal, locations; and
- 3) span a relatively short time-frame.

Ignoring the genetic analytical difficulties such a definition of population creates, it also creates the expectation that as a "real" population in the past, archaeological collections must relate to "real" populations in the region in the present. This may or may not be a reasonable expectation, depending on the time frame encompassed by the samples, their geographic distribution, or known aspects of local history. Indeed, continuity between prehistoric and modern groups may or may not be a focus of the aDNA research. But possible (perceived) ancestral/descendant relationships may be an important element of the consultation/consent process in obtaining research access to the samples.

Three aDNA projects we have conducted recently are illustrative of the variety of consent processes that obtain today. Our analyses of the Fremont materials from northern Utah (Parr, Carlyle, & O'Rourke, 1996; O'Rourke, Parr, & Carlyle, 1999), ancient Aleut samples from the Aleutian islands in the western subarctic (Hayes, 2001; Hayes & O'Rourke, 2001), and Paleo-/Neo-Eskimo samples from the eastern Canadian arctic (Hayes, 2001; Hayes & O'Rourke, 2001) exemplify the diversity of local approaches to aDNA research requests.

The Great Salt Lake Fremont

Following several years of record snowfalls in the northern Utah mountains in the late 1980s, the Great Salt Lake experienced large-scale flooding. The flooding and subsequent rapid retreat of historic lake levels resulted in substantial erosion of the lake margins, exposing a large number of prehistoric human burials in a small geographic area on the lake's eastern wetlands. A minimum of 85 individuals were ultimately identified, and it rapidly became clear that vandals were routinely excavating in newly eroded burials, removing cultural artifacts as well as skeletal elements. Efforts to recover and preserve the eroding burials, as well as the negotiations and consent process undertaken has been detailed by Simms (1993) and Simms and Raymond (1999).

The negotiations for permission to excavate and study the materials eroding from the lake margin were initially under the direction of the Utah Division of State History. Following several months of discussion and debate among state representatives, archaeologists, and various tribal representatives regarding which tribal entity in the Eastern Great Basin should have responsibility for dealing with the materials, the Northwestern Band of Shoshoni Nation were ultimately given jurisdiction for deciding on the dispensation of the eroding burials. This tribal entity subsequently agreed to excavation of the skeletons, scientific analysis of the remains (including aDNA analysis and dating) over a three-year period, subsequent repatriation of the remains to the tribe, and burial in a vault to be provided by the state. The initial 18 months of discussion and debate leading to identification of the Northwestern Band of the Shoshoni as responsible parties led to the archaeological recovery of the skeletons, but the negotiations on such issues as future dispensation and repatriation continued for two more years.

Several issues are worth noting for the purposes of this paper. First, from an aDNA research perspective, it was gratifying to have formal written permission to conduct molecular analyses prior to excavation of the samples. This meant that aDNA samples could be recovered in the field at time of exposure and immediately placed in separate containers without human contact, where the newly exposed skeletal elements designated for molecular analysis could be removed directly to the laboratory. This proved most beneficial in reducing contamination problems in this suite of samples. However, it is instructive to note that the aDNA analysts had no voice in any of the negotiations. The archaeologist charged with excavation of the materials recognized the potential for aDNA analyses on this skeletal collection and suggested it to the relevant parties, but molecular laboratory personnel had no direct role in the subsequent discussion and negotiations. One other aspect of this process is worth noting. Absence of genetic data on contemporary American Indian populations of the Eastern Great Basin precludes a direct comparison with the ancient Fremont samples, and, therefore, any assessment of the likelihood of ancestral/descendant relationships. However, if the genetic profile of Western Basin Shoshonian people is representative of the modern Shoshoni population of the Eastern Basin, then the Fremont are unlikely ancestral to the latter. The political decision regarding which tribal entity receives entitlement to and jurisdiction over ancient human remains need not be related to lineal descent. Raising such issues in discussions during requests for access to research materials may be problematic, but is part of the risk/benefit considerations.

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The Prehistoric Aleutians

Our experience requesting and receiving permission to examine aDNA in prehistoric Aleut material is remarkable in its contrast. There are two political/cultural entities operated by and for the Aleut people: The Aleut Corporation (TAC) and the Aleutian/Pribilof Islands Association (A/PIA). Once we had identified a salient research problem requiring aDNA analyses, and the museum-curated samples necessary to conduct it, we contacted both native organizations by letter. We received cordial but noncommittal replies, and followed with in-person meetings to more fully explain the project, its goals, our interests, and as best we could determine them, the potential risks and benefits to the Aleut people if the research project were to go forward.

It was immediately clear that representatives of TAC and A/PIA were supportive of the proposed research, and of scientific inquiry into the history and culture of the Aleut people in general. We were given encouragement to develop the proposed project, and provide a copy of the final grant proposal before submitting it for funding. This, too, was received warmly. Permissions were secured for destructive analyses of the identified museum specimens, and subsequently, of newly discovered and excavated prehistoric burials. The principal constraints imposed were that we provide copies of any published reports to TAC and A/PIA, provide periodic updates on research progress and results, and, importantly, secure permission from local village corporations and/or local tribal councils on whose land the prehistoric skeletal material was originally recovered. This entailed additional in-person discussions to more fully explain the goals of the project, the methods of data collection and analysis, and to respond directly to questions and concerns of village members. Following these discussions, local village permissions were granted in writing.

Supportive relationships with the Aleut people and political/cultural entities were facilitated by early invitations to explain our project to the annual shareholders meeting of TAC and the annual board meeting of the A/PIA. In this way, information on the project, its goals and methods, was widely disseminated to most Aleut people directly. It was clear at these meetings that there was broad support and interest in the project (a collaboration of archaeologists and geneticists studying both the contemporary and ancient inhabitants of the islands).

The concerns raised in these meetings are informative. The two principal issues, relative to the proposed aDNA analyses, that gave people pause were 1) that skeletal samples not come from early church graveyards, nor recent time periods, and 2) the extent of skeletal destruction required for analysis. Once it was clarified that no historic burials would be considered, that only materials hundreds or thousands of years old were relevant, and that only

8–10 grams of bone was used (the equivalent of a small rib or rib fragment) and the rest of the skeleton was left intact and untouched, these concerns were generally alleviated. Our experience in this project is that early and frequent contact and discussion by all the investigators (aDNA analysts, contemporary population geneticists, and archaeologists) was most helpful to the positive outcome of our request to sample and analyze prehistoric nucleic acids. We have continued to receive support and encouragement from the local community level up, and have recently received support for an expansion of our research in the Aleutian area. Because of the local interest, we have traveled to individual communities to present preliminary results and discuss their meaning. The interest in the research project seems to be growing, as both we and our collaborators continue to receive requests to speak at functions where Aleut people may ask questions and keep abreast of the projects' progress and results.

The Prehistoric Eastern Canadian Arctic

The third major aDNA research project resulted from a consent process that in some ways is similar to, and in other ways different from, the two just discussed. We identified a problem of interest in eastern arctic prehistory that was approachable with aDNA analyses. We subsequently identified a collection of relevant skeletal material at the Canadian Museum of Civilization (CMC) in Hull, Quebec, and contacted them regarding sampling the collection. The CMC approved our request for sampling and destructive analysis, but had recently signed an agreement with the Native People of Nunavut (the newly formed territory) that precluded them from granting research access to any materials from the geographic area covered by Nunavut without the approval of the Inuit Heritage Trust, Inc. in Nunavut. A process for requesting such permission was in place, but had not yet been used for granting permission to conduct destructive analyses. Unlike the United States, Canada has no legislation in the NAGPRA mold. Instead, museums appear to be entering into collaborative research oversight agreements to stave off the political pressures for such legislation.

We offered to travel to Hull and/or Nunavut, to explain our project, scientific interests, and methods to facilitate obtaining formal permissions, but were informed this would not be necessary, as it was not required as part of the established permission granting process. Given our experiences with lag time from request to granting permission for aDNA research with the Fremont (~18 months) and Aleutian Island (~6 months) projects, we anticipated a considerable delay in learning if our request to sample the eastern Canadian arctic material would be granted. We were asked by the CMC for

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a written proposal, which we rapidly supplied, and it was forwarded to the Inuit Heritage Trust, Inc. Douglas Stenton, a Canadian archaeologist employed by the Inuit Heritage Trust, presented the proposal to the Trust's leadership as well as to the local communities closest to where the samples were archaeologically recovered. He explained the basic science behind the request, and answered questions of members of the Trust.

It is important to note that we never had direct contact with the Inuit Heritage Trust nor local communities; all correspondence was transmitted though the CMC. Upon receipt of the answers to the proffered questions, the Inuit Heritage Trust, Inc. granted permission to sample the requested skeletal material for destructive molecular analysis, placing the following three conditions on the project:

- 1. We were required to weigh each sample taken to make sure it was less than the maximum of 10 grams we requested. A listing of each sample and its exact weight was to be provided to the Trust upon completion of sampling.
- 2. We are required to file periodic progress reports to the Trust, via the CMC, indicating progress made on the project, and
- 3. We will be required to file a final report when the project is completed. The report is to be written in nontechnical language and at least one copy will be provided that is translated into the local language, Inuktituk.

The Trust provided a list of qualified translators who could provide the translation of the final project report, but the burden of cost of the translation is to be provided by the investigators. This cost was subsequently built into the project budget, and justified by the formal signed agreement with the Inuit Heritage Trust, Inc. From initiation of the sampling request to receipt of permission, this consent process took less than eight weeks.

Concluding Comments

Several contrasts in the three different consent processes reviewed above should be highlighed. The Great Salt Lake Fremont case is unique in two ways. First, this project was initiated prior to the passage of NAGPRA legislation so the nature of the discussions and negotiations were undoubtedly different than if NAGPRA issues had structured the discussion regarding research access. Almost certainly this would have altered the scope of consultation engaged in at the time. NAGPRA was passed during the excavation of these samples, and thus affected subsequent discussions, regarding their study, curation, and repatriation. Although of critical import to the archaeological researchers involved in the project, this was effectively transparent to the aDNA analysts working on the project. Second, it is the only case of the three that involved consent for aDNA analyses on newly discovered and excavated skeletal material. This too may play a role in the nature of the discussion and consent process. It is instructive to note that when permission was granted by The Aleut Corporation for limited excavation, documentation, and molecular analyses of newly discovered prehistoric burials on Corporation land in the western Aleutians, the consent process included only the archaeologists involved in the excavation. In neither this case nor the Fremont case were aDNA analysts involved in discussions that were part of the consent process. It may be typically the case that although aDNA researchers are involved in the consent process regarding museum curated materials, where they may be the primary researchers initiating the project, they are not so involved when the samples come from newly discovered and excavated sites. This, too, emphasizes the need to appreciate the diverse nature of the consent process in different contexts, and the need for close collaboration between researchers, curators and community representatives.

Based on our work, and the work of others in North America, it seems reasonable to believe that the levels of genetic variation in prehistoric populations, at least with respect to mitochondrial DNA, was comparable to that seen in contemporary groups, and that in both modern and prehistoric samples the variation is strongly geographically structured (O'Rourke, Hayes, & Carlyle, 2000). This being the case, it seems likely that aDNA analyses will become increasingly useful and powerful in testing hypotheses regarding regional population history and evolution, and hence, inferences made from aDNA analyses will be of increasing concern and import to indigenous populations. It seems equally likely that inferences drawn from aDNA analyses will be used for legal purposes, possibly including water and land right issues based on prior occupancy arguments, definition of tribal identities, and other applications. These applications may not be the goals of the original aDNA research projects, but just as genetic data from contemporary populations are used in a variety of legal and social ways, so too may aDNA results be used.

It seems to us incumbent upon aDNA researchers to anticipate these developments, incorporate them into risk/benefits discussions, and provide local communities with the best available information and tools with which to evaluate the meaning, import, and limitations of the results of aDNA analyses. It also appears that as a community of scholars, we are in many ways reinventing the concept of community consultation and consent—a process that anthropologists, including anthropological geneticists, have been using for decades. Despite this history, there is no single model for community

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consultation/consent that will be uniformly effective for all investigators or all communities. Our recent experiences suggest that communities increasingly take the lead in developing such consultation procedures, and we ignore them at our peril (cf., Foster et al., 1999; Juengst, 1998).

Securing written permission to access and analyze skeletal samples from all relevant parties (e.g., community/tribal organizations and museums) now appears to be a useful routine procedure. Such documentation demonstrates the completion of discussion, and possibly negotiation, regarding research access to collections, clearly signals the outcome of those discussions by detailing any constraints imposed on the collection or analysis of samples, and avoids needless confusion in the future. Such documentation seems advantageous for both the researcher and those granting consent for the research. It is our experience that such procedures invest both responsibility and opportunity in all parties, resulting in an amicable and productive collaboration. Finally, aDNA researchers should realize that research access to collections may not be permanent. Just as individuals may elect to withdraw from human subjects research protocols, so too may communities elect to terminate research access to skeletal collections over which they have purview (although how such purview is established is beyond the scope of this chapter). Continued communication between researchers and those who control access to research collections seems the only way to establish and maintain long-term collaborative working arrangements.

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Chapter 17

Working with ancient DNA: NAGPRA, Kennewick Man, and Other Ancient Peoples

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In 1990 the Native American Grave Protection and Repatriation Act (NAGPRA) was passed. This act requires that the disposition of Native American remains discovered on federal lands or curated by federal agencies be determined by identifying their lineal descendants or "cultural affiliation" with living Native Americans, if possible. Cultural affiliation is to be determined by "a preponderance of the evidence based upon geographical, kinship, biological, archaeological, anthropological, linguistic, folkloric, oral traditional, historical, or other relevant information or expert opinion" (NAGPRA, Section 7a(4)). Although some interpret "cultural affiliation" to mean "Native American" verses "non-Native American," most museums interpret it to be equivalent to "tribe." As a result, some freely allow study of many skeletal remains whereas others do not even wait for court rulings before they return remains to tribal representatives. In cases of remains from relatively recent time periods, lineal descendants or cultural affiliation are generally straightforward determinations, supported by the majority of the forms of evidence. Unfortunately, in the case of older remains, different lines of evidence often support conflicting hypotheses of cultural affiliation, or do not lend support to any specific cultural affiliation. In particular, cultural affiliation of extremely ancient remains is difficult to determine because there are more gaps in the archaeological record, too few cultural remains survive, population movement cannot be precluded over such large time frames, linguistic evidence becomes unreliable beyond a time depth of a few millennia, morphological changes over thousands of years cannot be ruled out, and often the range of variation among remains is unknown because only one individual is represented. In addition, several modern tribes might be descendants of a given ancient individual who is 5,000 years old. Many tribes that are closely related biologically do not recognize (or believe) that relationship. It is, of course, impossible to determine what entity, if any, the deceased individuals regarded themselves as being related to (culturally or biologically). In recent years, there has been a call to incorporate genetic evidence into the assessment of cultural affiliation, and both ancient and modern DNA analyses are being considered. In this chapter we will discuss preliminary results from some of the most ancient remains from the Americas, including success rates and factors that affect the probability of success. We will also discuss more generally what questions ancient DNA (aDNA) studies have the potential to answer. Finally, we discuss some of the problems of these types of studies and the assumptions behind them, especially in the context of NAGPRA.

The application of NAGPRA to Paleo-American remains (those older than about 7 kBP) is particularly problematic. These remains are of particular interest to anthropologists because they have the potential to address issues regarding the initial peopling of the Americas. In the past most anthropologists believed that the Americas were settled by migration(s) from northern Asia, across the Bering Land Bridge (exposed during the ice age due to lowered sea levels). However, recent studies of the craniofacial morphology have suggested that these Paleo-Americans, as a group, resemble modern southern Asians and Europeans more closely than modern Native American populations (Steele & Powell, 1992). Recent studies of a limited number of South American Paleo-Americans suggest, on the other hand, that these individuals most resemble modern Australians and Africans instead (Neves, Powell, & Ozolins, 1999). The combination of these new morphological analyses, recent genetic discoveries, and linguistic evidence has caused many anthropologists to question a simplistic view of the peopling of the Americas.

Modern Native Americans belong to one of five mitochondrial haplogroups, or maternal lineages, defined by combinations of shared mutations detected using Restriction Fragment Length Polymorphisms (RFLPs) and/or direct sequencing. Of these, four (A, B, C, and D) were identified more than a decade ago, and are also found in modern Asian populations. However, only three of these haplogroups (A, C and D) are found in modern populations of northeast Asia, often presumed to be the homeland of Native Americans (Schurr et al., 1990; see Figure 17.1, modified from Lorenz & Smith, 1996, fig. 4, p. 318). Moreover, the fifth lineage (X) was discovered among modern Native Americans only recently (Brown et al., 1998; Smith, Mahli, Eshleman, Lorenz, & Kaestle, 1999) and has been identified outside of the Americas in low frequencies among modern Europeans and Middle-Eastern peoples, and recently in one western Siberian indigenous population, the Altai (Derenko et al., 2001). Haplogroup X has not yet been identified among modern eastern Asians however. All of these lineages have since been identified in ancient Native American peoples as well (Kaestle & Smith, 2001).

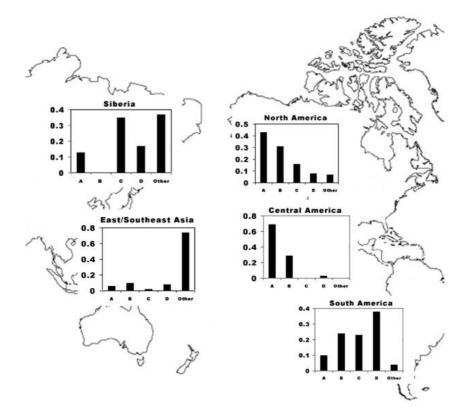


FIGURE 17.1 Distribution of Common 'Native American' Mitochondrial Haplogroups (after Lorenz and Smith, 1996).

Modern Native Americans are also linguistically extremely diverse. Recent research on the patterns of language splitting and survival (Nichols, 1990) has suggested that the remarkable level of diversity among the languages of the New World could not have evolved from a single migration into the Americas, unless the Americas were settled much earlier than radiocarbon dates suggest, and is more likely to be the result of multiple migrations of groups speaking disparate languages. Note that Nettle (1999) has created a model of language change that could explain this diversity with only a single migration. Thus many anthropologists believe that the morphological, genetic and linguistic evidence now suggests a complex pattern of multiple migrations into the Americas, perhaps from widely separate geographic regions. In contrast, some analyses have found evidence that the Archaic Native Americans, intermediate temporally between the Paleo-American and modern Native Americans, are also intermediate morphologically, suggesting some measure of biological continuity with the modern populations (Nelson, 1998; Lovvorn, Gill, Carlson, Bozell, & Steinacher, 1999). Genetic evidence from the study of mtDNA of modern and prehistoric Native American populations continues to add increasing weight to some variation of the "single migration" hypothesis (Merriwether, Rothhammer, & Ferrell, 1995; Lorenz & Smith, 1997; Stone & Stoneking, 1998;). For example, a highly derived variant of haplogroup A with a transition at nucleotide position 16111, is widespread in the New World but not found elsewhere, suggesting a single common ancestor for all of these populations (Smith et al., forthcoming). However, the ancient distribution of morphological characters and genetic markers is generally not well known and these traits can change through time. Thus, further study is required before we reject the previous model of the peopling of the Americas (Anderson & Swedlund, 1997; Goodman, 1997; Marks, 1998).

Genetic analysis of aDNA from these Paleo-American remains should greatly increase our understanding of their relationships to modern populations in both the Americas and the Old World, and the process of colonization of the Americas. Were additional mitochondrial haplogroups found among these ancient individuals, the modern geographic location of individuals possessing these haplogroups would provide strong evidence for common ancestry. Were no additional haplogroups found, this would be good evidence of genetic continuity between the oldest inhabitants of the Americas and modern Native Americans. If different haplogroups appeared to be geographically limited in distribution among the Paleo-Americans, this would have implications regarding how the first peoples moved within the Americas after colonization, and the level of genetic exchange that occurred between different ancient groups. The aDNA from the Paleo-Americans could also be compared to that from other, more recent prehistoric Native American and Asian populations, which could reveal more precise relationships between these ancient groups. The genetic analysis would also be important in testing the common assumption that groups that differ morphologically do not share a recent common ancestry. The results of such an analysis would have implications not only for the study of the peopling of the Americas, but for the study of human prehistory in general.

Additional information could be obtained from a study of the aDNA from infectious agents found in the remains of the Paleo-Americans. Recent success in identifying DNA from various diseases in ancient individuals (Braun, Cook, & Pfeiffer, 1998; Drancourt, Aboudharam, Signoli, Dutour, & Raoult, 1998) suggest the potential for a much more detailed understanding of the ancient distribution of infectious disease. This knowledge would not only have historical implication (e.g., did Europeans bring tuberculosis and/or syphilis to the New World or were they already here?), but might also have medical implications regarding disease treatment.

With these questions in mind, we have begun the extraction and analysis of aDNA from approximately 50 Paleo-American remains, one from Argentina and the remainder from North America, dating to between approximately 7400 and 10400 yBP (see Table 17.1) (Clausen, Cohen, Emeliana, Hoffman, & Stipp, 1979; Weir, 1987; Young, Patrick, & Steele, 1987; Doran & Dickel, 1988; Erlandson, 1994; Milanich 1994; Anderson & Sassaman 1996; Stone & Stoneking, 1996; Dansie, 1997; Myster & O'Connell, 1997; Carlson, 1998; Antón, Powell, & Quinn, 2000; Fagan 2000; McManamon, 2000; Dixon, 2001).

TABLE 17.1 Preliminary Results from Paleo-American aDNA studies. A '*' signifies insufficient aDNA present to type sample, a '**' signifies the presence of PCR-inhibiting substances in the extract (these samples are still undergoing analysis), a '?' signifies that the aDNA sample does not appear to belong to one of the 5 'Native American' mitochondrial haplogroups, and 'ND' indicates that testing of the sample is incomplete.

		0	•	•
Cl.e	NT	C14	Describe	C
Sample	Ν	(uncorrected)	Results	Source
Arlington Springs,				
Santa Rosa Island, CA	1	9,300	В	Current study
Browns Valley, MN	1	9,049	D	Current study
Cutler Sink, Miami, FL	3	9,620	В	Current study
Horn Shelter, Waco, TX	2	9,500-10,300	В	Current study
Little Salt Springs, FL	6	5,200-10,000	**	Current study
Los Vaqueros Reservoir,				
N. Central Valley, CA	1	7,400	В	Current study
Pelican Rapids, MN	1	7,840	С	Current study
On Your Knees Cave, Alaska	1	9,730	**	Current study
Vero Beach, Indian River Co., FL	1	late Pleistocene	**	Current study
Warm Mineral Springs, FL	3	10,260	В	Current study
Whitewater Draw,				
Sulfur Springs, FL	1	8,200-10,400	ND	Current study
Wilson-Leonard, FL	1	8,500-10,000	*	Current study
Windover, FL	25	7,400	X, 12 ?,	5 Smith et al, 1999,
			*	Hauswirth, 1994
Wizards Beach, Pyramid Lake, NV	1	9,200	С	Kaestle and Smith, 2001
Anzik, MT	2	8,000 & 10,000	ND	Anzik, n.d.
Snake River, WA	1	8,500	*	Current study
Clark Fork, ID	2	8,000	ND	Current study
Arch Lake, NM	1	10,020	ND	Current study
Hourglass Cave, CO	1	8,000	В	Stone & Stoneking, 1996
Kennewick, WA	1	8,410	*	Current study
Pintoscayoc, Argentina	1	9,080	ND	Current study

Along with Dr. Merriwether at the University of Michigan, Ann Arbor, we were asked by the Army Corps of Engineers to attempt the extraction and analysis of aDNA from one of these remains, Kennewick Man, the subject of considerable controversy. This case has been discussed in newspapers, scientific journals, television news reports (e.g., "60 Minutes," October 25, 1998), and even a science fiction magazine (Silverberg 1998). In 1996 the nearly complete skeletal remains of an individual were found eroding from the banks of the Columbia River near the town of Kennewick, Washington. Initial morphometric study of these remains suggested that Kennewick Man might be a Caucasoid from the historic period, but the presence of an archaic spear point embedded in his hip suggested otherwise (Chatters, 1997; Preston, 1997). Given the unusual combination of morphology and material remains, additional study of the individual, including C14 dating and aDNA analysis, was authorized by the local coroner (Chatters, 1997, 2001; Preston, 1997). Because modern and ancient Native Americans possess certain mitochondrial DNA mutations unique to Asians and their descendant populations (as discussed above), it was believed that a preliminary determination of the ethnic affiliation of the Kennewick remains could be made (was he a member of a typically Native American/Asian haplogroup, or a typically non-Native American haplogroup), and one of us (FAK) agreed to perform the analyses. We were forced to discontinue this analysis when we received a cease-and-desist order from the Army Corps of Engineers (COE) who exercised jurisdiction of the land on which the remains were found and had decided to repatriate the remains to local Native American tribal groups without further study. Protesting what they felt to be a premature identification of the remains as legally Native American and a denial of their rights to study the remains, a group of prominent scientists in the field of Native American prehistory filed suit against the COE to prevent repatriation. The remains are currently being held at the Burke Museum at the University of Washington pending a decision on the case (Chatters, 1997; Preston, 1997; McDonald, 1998; Chatters, 2001).

In March 1999 a group of six scientists chosen by the Department of the Interior was allowed to examine the remains in an attempt to determine whether they were Native American, and, if so, with what modern Native American group they are most closely affiliated (to whom NAGPRA stipulates they should be repatriated). Only nondestructive analyses were initially authorized, and the results of this report were released in October 1999. The scientists concluded that they could not identify the remains as definitely Native American (according to the definitions in NAGPRA) using nondestructive analysis (McManamon, 1999), and were unable to date the remains based on morphology, geochronology, or tool typology. Studies of the morphology of Kennewick Man suggest no close affinities with any modern populations (Native American or non-Native American), but show the re-

mains most closely resemble those of modern Asians and Pacific-Islanders (Powell & Rose 1999; Jantz and Owsley 2001). Comparisons with other ancient populations gave mixed results; some suggested an affinity with particular ancient Native American groups whereas others showed no resemblance to any ancient Native American groups (Powell & Rose, 1999; Jantz & Owsley, 2001). For these reasons, AMS dating was authorized and three laboratories were sent samples of the Kennewick Man remains. Results from these tests were delayed by the low protein content of the samples chosen by the Parks Service for dating, but ultimately resulted in a radiocarbon date between 5750 ± 100 and 8410±60 yBP (McManamon, 2000). Because NAGPRA defines "Native Americans" as "peoples, or cultures that resided within the area now encompassed by the United States prior to the historically documented arrival of European explorers" (McManamon, 2000, p. 1) these remains were determined to be legally "Native American." However, neither nondestructive testing nor dating of the remains allowed "cultural affiliation" as defined by NAGPRA to be determined and genetic testing was initiated (U. S. Department of the Interior, 2000). Unfortunately, none of the three laboratories involved were able to detect ancient DNA in the skeletal samples from Kennewick Man that were provided (Kaestle, 2000; Merriwether & Cabana, 2000; Smith, Malhi, Eshleman, & Kaestle, 2000).

On August 30th, 2002, U.S. Magistrate Jelderks decided in the plaintiffs' favor, ruling that the federal determination that the remains were legally Native American was in error, NAGPRA therefore did not apply, and the scientists should be allowed to study Kennewick Man under the terms of the Archaeological Resources Protection Act (ARPA) (Associated Press, 2002). In late October, 2002, this decision was appealed in the 9th District U.S. Circuit Court of Appeals, by both the U.S. Department of Justice and four Native American tribal groups (Tri-City Herald, 2002). A panel of 3 judges upheld the ruling on February 4th, 2004, but the tribes have requested a review by a larger panel of 9th District judges. They plan to appeal to the U.S. Supreme Court if their request is denied (King, 2004).

However, we have had greater success extracting and analyzing aDNA from other Paleo-American remains. Thus far we have concentrated on identifying the mitochondrial lineage to which each individual belongs (See Table 17.1). Of the 32 Paleo-American skeletal samples from which other laboratories or we have attempted to extract aDNA, 22 have yielded DNA for an initial success rate of 68.8%. Of those in which others or we have successfully amplified DNA, 10 possess markers placing them within 1 of the 5 recognized mitochondrial lineages found among modern Native Americans (B, C, D, and X), whereas 12 do not. It is possible that the samples that yielded aDNA not possessing "Native American" markers are the result of contamination of the ancient samples with modern non-Native American DNA,

a common problem in ancient DNA studies. However, although these samples are from the same site (Windover), collected by the same person at the same time, several of these samples have yielded different mtDNA hypervariable 1 region sequences that do not match those of the investigators. Thus, for contamination to explain these results there must have been multiple sources of contamination. Moreover, 5 of the 12 were extracted from teeth, which are less subject than bone to contamination prior to extraction. Excluding the non-A, B, C, D, and X results from the calculation, 10 of 20 samples yielded DNA for a success rate of 50%. Three of the "unsuccessful" samples contain substances that inhibit PCR, but may yield positive results with further processing. Although it is premature to speculate on the implications of these results for hypotheses of the peopling of the Americas until additional information on the non-A, B, C, D, and X samples is collected and the remaining samples have been analyzed, the absence of haplogroup A in this sample, the most common haplogroup among modern Native Americans, is interesting.

Based on recent ancient DNA studies, including this one, we can conclude that successful extraction and analysis of aDNA is not dependant on the age of the sample (within reason), but on other factors. Recent studies have shown that depositional characters, including pH, temperature, humidity, and oxygen exposure are important factors that affect the survival of DNA. In general, neutral to basic pH, low temperature, low moisture, anaerobic conditions, and stability of these factors over time favor the preservation of DNA. Furthermore, improved extraction and amplification techniques have greatly increased success rates with problematic samples in recent years, and are expected to continue to do so.

What are the arguments for performing ancient DNA studies on ancient samples (Native American and others)? Within anthropology, there are several major areas of research that can be informed by aDNA data. These include genetic sexing of remains, the analysis of animal, plant and pathogen aDNA, assessment of maternal and paternal kinship in prehistory, and evaluation of hypotheses of population continuity and replacement (see Table 17.2). Obviously, questions of population continuity and replacement are not only of academic interest, but are relevant to NAGPRA claims of cultural affiliation. We would like to discuss how this type of data might be used to assess these claims, and raise some issues regarding the definition of cultural continuity.

The majority of ancient DNA research involves studies of mitochondrial DNA, because 1) it exists in higher copy number per cell and therefore is more likely to survive in ancient samples; 2) mtDNA evolves more rapidly than nuclear DNA and, therefore, reveals differences between individuals whose common ancestors lived fewer than 10,0000 yBP; and 3) mtDNA does not recombine because it is solely maternally inherited and, therefore, reflects differences due to mutations that accumulate in matrilines over time. Studies

Application	Implications		
Genetic Sexing	understanding marriage and burial patterns, differential patterns by sex of disease, diet, status and material possessions, forensics		
Animal & Plant aDNA	understanding hunting and dietary patterns, ecology, domestication of animals and plants, environmental reconstruction		
Disease aDNA	trace history and patterns of prehistoric and historic diseases		
Maternal & Paternal Kinship	understanding social structure, status, marriage patterns, burial customs, migration, forensics		
Population Continuity & Replacement	trace prehistoric population movement, ancestor-descendant relationships between modern and ancient groups, relationships among ancient groups with similar/different morphology or cultural remains		

TABLE 17.2 Potential applications of aDNA studies in anthropology.

of the distribution of mitochondrial variation in modern groups have shown that some of these groups possess what appear to be private polymorphisms (mutations unique to that group) (Starikovskaya, Sukernik, Schurr, Kogelnik, & Wallace, 1998; Schurr, Sukernik, Starikovskaya, & Wallace, 1999). Were these same mutations detected in ancient individuals, an ancestor-descendant relationship could be posited. Unfortunately, our knowledge of the distribution of mitochondrial variants among modern Native American tribes is limited, because most tribes have never been sampled. Of those that have, many are represented by a small number of individuals, and thus the probability of detection of private polymorphisms that are rare is low. A sample of fewer than 30 individuals from a tribe is likely to miss any private polymorphisms present in frequencies lower than 3.3%. However, a survey of the literature on mitochondrial DNA variation in modern Native Americans (Merriwether, Rothhammer, & Ferrell, 1994, figure 17.2, our calculations) reveals that 14 of 31 South American groups, 2 of 8 Central American groups, and 17 of 46 North American groups studied were represented by 15 or fewer individuals.

Only 28 of the 85 (33%) Native American groups reported in Merriwether et al. (1994) are represented by more than 30 individuals. Although these numbers have improved in the past few years, there are still significant gaps in our knowledge.

In the absence of private polymorphisms, sequence data from the hypervariable mitochondrial regions could still be employed for repatriation purposes. The first hypervariable region (HVI) is approximately 500 nucleotides long, and the mutation rate for this region has been estimated at 7-12% per million years (Stoneking, Sherry, Redd, & Vigilant, 1992; Horai et al. 1995). Thus, over 10,000 years, the number of mutations within the first hypervariable region in one (randomly selected) lineage is expected to be 0.35 to 0.6, or less than 1. Therefore, it could be argued that modern individuals possessing identical HVI sequences to an ancient individual are likely to be direct descendants, whereas those without identical sequences are not. There are three main difficulties with this argument. First, the majority of 10,000-year-old individuals will possess basal, or underived, HVI sequences, as studies have suggested that the majority of the variation found in modern Native Americans has arisen since the peopling of the Americas (Torroni et al., 1993a; Forster, Harding, Torroni, & Bandelt, 1996). These are the same sequences that are generally found at highest frequencies throughout the Americas (Torroni et al., 1993a, 1993b). For example, were this logic to be applied to several ancient samples from the Great Basin, their HVI sequences, when compared to modern Native Americans only from the western United States, would match individuals from six different tribal groups (Washo, Chumash, Tubatulabal, Costanoan, Vanyume, and Northern Paiute) (Kaestle & Smith). Although individuals in these six groups might well share a recent common ancestor, none of them recognizes a genealogical relationship to the other. It is not clear to which group, if any, the remains should be returned. Second, genetic models of stochastic lineage extinction suggest that the majority of mitochondrial lineages present in the New World 10,000 years ago will not have survived random extinction (See figure 17.2, after Avise, 1994, p. 127). In fact, Avise (1987) has shown that if the number of daughters produced by females follows a Poisson distribution with a mean (and variance) of one surviving daughter per female, the probability that any individual mother's mtDNA will survive even 100 generations (approximately 2,000 years for humans) is lower than 2%. Conversely, the vast majority of Native Americans alive today can trace their mitochondrial lineage to a small number of women living 10,000 years ago. However, because at least some of these women will be matrilineally related to those whose lineages do not survive, matches (or near-matches) between modern Native American lineages and those derived from prehistoric remains thousands of years old can be expected to occur at a much higher frequency. Third, because mtDNA is

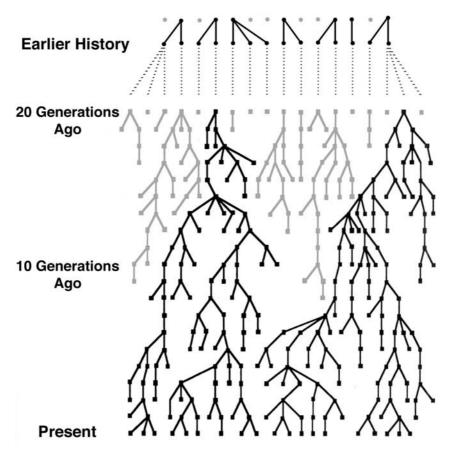


FIGURE 17.2 Example of stochastic lineage extinction of mtDNA over time (after Avise, 1994). Surviving maternal lineages in black, extinct lineages in gray. Note that all surviving daughters can trace their ancestry to two mothers who lived 20 generations ago.

inherited through the maternal line, but nuclear DNA is inherited from both parents equally, although one inherits 100% of one's mtDNA from only 1 of 16 great-great-grandparents, that particular ancestor contributed only 1/16 or about 6% of one's nuclear DNA. Thus, mitochondrial DNA is inherited from only one (female) of many ancestors and only traces that one relationship of many. Thus, *using mtDNA alone*, specific modern individuals can be included as possible descendants of a particular prehistoric individual, but no modern individual can be definitely excluded as a descendant of any given prehistoric individual. Recent advances in techniques now allow us to access nuclear

DNA from ancient human samples, and tests of ancestor/descendant relationships utilizing both Y chromosome and autosomal markers are underway. Unfortunately, because we have even less data on the modern distribution of these markers than for mtDNA, hypothesis testing will be difficult until far more data are collected.

There is another way in which examination of aDNA can help test hypotheses of population replacement or migration. Because genetic variation is inherited from a group's ancestors (each generation the genetic variants present are a random sample of those present in the previous generation), modern groups are expected to have frequencies of genetic markers that are similar to those of their ancestors, whereas ancient and modern groups with different frequencies are not likely to be closely related. In fact, the frequencies of the five common mitochondrial lineages vary significantly among modern Native American tribes, as can be seen at a gross level in Figure 17.3. Although genetic drift (the random change in gene frequency over time due to random sampling effects) can lead to differences in lineage frequency over time, recent comparisons of prehistoric and modern mtDNA from the same geographic region reveals a substantial level of regional continuity (O'Rourke et al., 2000). Moreover, these effects can be incorporated into models and accommodated in tests of hypotheses (e.g., Cabana, Hunley, & Kaestle, 2000; Kaestle & Smith, 2001).

For example, we have investigated a hypothesized population replacement, the Numic Expansion, in the U.S. Great Basin approximately 1000 yBP. Archaeological and linguistic evidence suggest that the current Native American inhabitants of the Great Basin, the Numic Speakers, expanded into the region from southern California about 1000 yBP and replaced or mixed with the previous inhabitants (Madsen & Rhode, 1994) (See figure 17.4). Examination of the frequencies of mitochondrial lineages of the ancient and modern inhabitants of the Great Basin reveal significant differences in lineage frequency indicative of a major population replacement (Kaestle, Lorenz, & Smith, 1999; Kaestle & Smith, 2001). In combination with the archaeological, linguistic, and morphological evidence, the Nevada State Office of the Bureau of Land Management has utilized these results in their determination that the Spirit Cave remains, which include an individual dated to more than 9000 yBP with morphology similar to that of Kennewick Man, are culturally "unaffiliated" (Barker, Ellis, & Damadio, 2000). Similar evidence for or against the cultural affiliation of Kennewick Man with local tribal groups in the middle Columbia River Valley is lacking. The assessment of ancestral/descendant relationships requires a relatively large number of samples from both the ancient and modern populations of interest. The sample size of remains from such ancient time periods is often too small, and the consequences of both

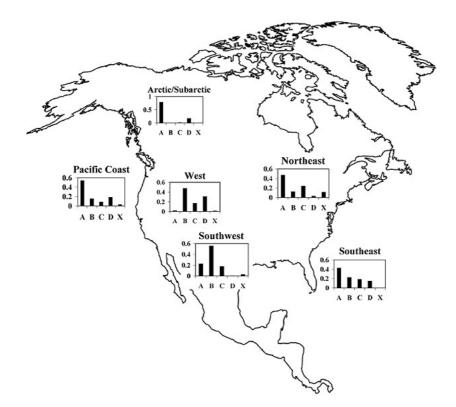
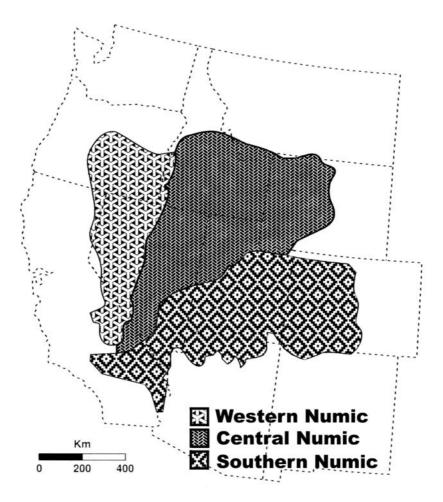


FIGURE 17.3 Distribution of mitochondrial haplogroups in modern Native Americans. The Arctic/Subarctic includes Old Harbor Eskimo, Ouzinkie Eskimo, Gambell Eskimo, Savoonga Eskimo, St. Paul Aleut, Dogrib, Haida and Inuit individuals (N=621). The Pacific Coast includes Bella Coola, Nuu-Chah-Nulth, Chinook, Costanoan, Chumash, Yurok, Salinan and Diegueno individuals (N=254). The West includes Yakima, Yokut, Miwok, Cahuilla, Patwin, Washo, Northern Paiute and Shoshoni individuals (N=398). The Southwest includes Navajo, Apache, Pima, Papago, Zuni, Jemez, Hopi and Yuman individuals (N=252). The Northeast includes Micmac, Chippewa (Wisconsin and Turtle Mountain), Ojibwa (Manitoba Island and Northern Ontario), Sioux (Sisseton/Wahpeton), Mohawk, Norris Farms, and Cheyenne/Arapaho individuals (N=358). The Southeast includes Cherokee, Pawnee, Seminole, Creek, Chickasaw, Choctaw, and Muskoke individuals (N=167). (Torroni et al., 1992, 1993a and b; Shields et al., 1993; Ward et al., 1993; Merriwether et al., 1995; Lorenz and Smith, 1996; Scozzari et al. 1997; Kaestle, 1998; Stone and Stoneking, 1998; Smith et al., 1999; Malhi et al. 2001, 2002, 2003, 2004; Bolnick and Smith 2003; Eshleman et al., 2003, 2004)



sampling effect and genetic drift too great, to directly assess hypotheses of local population replacement (except in the case of Windover, Florida, where more than 150 individuals are available for analysis).

A final point that warrants attention is the correlation between culture and genes. The NAGPRA status of human remains is determined by their "cultural affiliation" with one or more modern Native American groups. The law appears to accept both biological evidence in general, and molecular genetic evidence specifically, for cultural affiliation. For example, genetic data is discussed in the context of establishing cultural affiliation between Kennewick Man and some modern Native American group(s) (Hackenberger et al., 2000). In addition, in a discussion of how an "identifiable group" might be evidenced in the past, the Department of the Interior states that "such evidence may relate to identified cultural characteristics of an earlier group, or it also may be possible to establish the existence of the earlier group as a biologically distinct population by examining the chemical, genetic, or physical characteristics of skeletal remains (43 CFR 10.14 (c)(2)(i)-(iii))" and later states that "genetic evidence is a kind of biological evidence that may be relevant in determining cultural affiliation" (U. S. Department of the Interior, 2000).

Although genetic data often correlate with cultural data (in the form of material culture, language, symbolic beliefs, spiritual/religious beliefs, legal systems, etc.) because all of these variables can be effective barriers to gene flow, they do not always do so. For example, both modern and prehistoric Uto-Aztecan speaking groups of Mexico's Central Valley and those from the arid U.S. southwest share(d) many cultural traits in common, yet remain(ed) genetically distinct, at least maternally (Smith et al., forthcoming, note that nuclear markers are now being examined to test the hypothesis that the Uto-Aztecan migration was comprised primarily of males). In contrast, other groups in the U.S. southwest with different cultures and unrelated languages, such as the Jemez Pueblo, Pima and Yuman-speaking groups, appear genetically similar to each other (again maternally). In general, however, genetic discontinuities provide more reliable indicators of cultural discontinuities than the reverse. NAGPRA defines cultural affiliation as "a relationship of shared group identity that may be reasonably traced" between an ancient and modern group (43 C.f.R.10.14(c), as quoted in Babbitt 2000). Unfortunately, it is impossible to predict whether genetic (or, for that matter, cultural) relationships entered into any given prehistoric group's notion of shared group identity, nor is any definition of "group" offered. Moreover, the common ancestry shared by some modern groups is often not acknowledged by these groups. Thus, a genetic discontinuity provides scientific evidence of cultural discontinuity, but evidence of genetic continuity alone is difficult to interpret. Nevertheless, the federal government has determined that NAGPRA "claimants do not have to establish cultural affiliation with scientific certainty" (Department of the Interior, May 28, 1993, 31132). In fact, the government offers little advice regarding cultural affiliation decisions that are not clear-cut, other than that "ambiguities . . . must be resolved liberally in favor of Indian interests" (Babbitt, 2000). Under these guidelines, genetic evidence for continuity should be interpreted as evidence for cultural continuity.

The federal government has painted scientists into a corner by requiring them to incorporate the results of scientific investigations of prehistory in their recommendations, the consideration of which will ultimately not be determined by scientific method. In doing so, they have painted themselves into the same corner; although the scientific method can ultimately be used to satisfactorily explain contradictory scientific data, given sufficient research, conflicts arising from contradictory oral histories or creation beliefs that result in multiple tribes filing for repatriation of the same remains can never be resolved. How does one define "preponderance," as in "preponderance of evidence"? If we follow Babbitt's instructions to resolve ambiguities in favor of Indian interests and absent any guidelines regarding the relative weights to be given to scientific and nonscientific evidence, it seems that in all cases nonscientific evidence of continuity will overwhelm scientific evidence of noncontinuity. This begs the question, "why ask scientists at all?" If additional scientific evidence contradicts previous dispositions of Native American remains, will redisposition be permitted? One is reminded of the ongoing strife in the Middle East over control of Jerusalem—all concerned parties have apparently legitimate claims to the land based on oral history and religious beliefs. Ultimately, ownership is a philosophical, not a scientific issue.

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Chapter 18

Commentary: Changing Standards of Informed Consent: Raising the Bar

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The chapters in this section provide a variety of special views from anthropological perspectives on ethical issues in human research. Some issues are identical to all biomedical research. We can all easily agree that the Belmont Report's principles of beneficence, justice, and respect are excellent reference points for researchers to adhere to, no matter the particulars or their situations. Obtaining (and deserving) the trust and continuing confidence of subjects, preferably as active participants in the project, is a corollary.

However, biological anthropological researchers often find themselves in complex ethical situations, primarily because of their increased distance from their research subjects, culturally, socially, and spatially. They are often foreigners in language and culture, not able to keep in constant contact with participants, and they almost always have significantly more access to wealth, education, or information. Although the power of the researcher in anthropological situations is obvious enough, he or she is simultaneously dependent as an isolated guest vis-à-vis the subject population. The ideal is certainly to minimize the asymmetry and maximize the mutual collaboration. But this ideal is difficult to approach in many peripheralized populations that anthropologists typically study. Besides the specific relationship between the fieldworker and local populace, other contextual dynamics play important complicating roles. Not only are the central governments of the foreign countries in a dependent or antagonistic relationship with the United States, but the local populations under study are in a similar relationship with their governments. This inevitably molds the attitudes of those in a position to grant research permissions as well as those who must grant consent as participants.

Although these have been obvious problems in biological anthropological research, I believe people are becoming aware of their relevance, perhaps to a less obvious degree, in human research undertaken in more conventional settings. The following is a short summary list of some of the specific problem areas that derive from this basic imbalance.

Obtaining community or group consent, in addition to individual informed consent, has been a central concern. As essentially all of the contributors point out, group or community consent is an important additional level of permission that biological anthropological researchers usually have to address, and have had to address for decades. A strict blinder-like focus on the individuation of participation and consent is a particularly modern Western notion, and our IRBs have ignored wider community issues for too long, although this is changing (e.g., growing Askenazi malaise over their characterization as a population with a wide variety of deleterious neurological Mendelian genetic disorders). However, the culturally appropriate levels of group consent and participation are often highly variable, and single standards do not apply.

The active participation of illiterate or poorly educated people in the definition or refinement of project goals is another special problem. It is little wonder that this was not a major consideration in anthropological research until recently. Our research objectives are difficult to explain to nonscientists in any language. How to explain one's intent in a comprehensible fashion, while asking for input to improve project goals, is difficult in such situations. Subject expectations are usually poorly informed and often greatly inflated.

An accurate assessment of the local effects of the research or its likely outcomes is particularly difficult to do well. This is hard enough to manage in the "standard" situation in the United States and Western Europe, as shown by the Sally Hemmings/Sloan Williams case. With dramatic future changes assured in genetics, the best one can often manage is continuous involvement with subject groups or their representatives.

Issues of public policy and political ramifications can also intrude. Although IRBs have been restricted in the consideration of this issue, it is frequently impossible to ignore in many societies and situations, especially where the foreign researcher stands out as a person of particular curiosity and a fount of special knowledge.

Proper compensation for participants is also a particularly nettlesome problem in areas where health care delivery systems are poorly developed, where expectations may be particularly unreasonable, and where cash payment/ compensation for "time lost" in participation has a questionable rationale.

My argument in this chapter is that, although guiding ethical principles may well remain roughly constant, their proper actualization is subject to considerable modification over time and in different contexts. What I consider to be satisfactory ethical and work situations are heavily time- and placespecific. How to obtain and retain trust and support from a research popula-

tion is often difficult and sometimes impossible. And because it is almost guaranteed that there will be unanticipated critics and problems, one must be scrupulous in adhering to standards of behavior that may, at the time, seem totally unnecessary.

I will not rehash the formal development of bioethical standards in the West during the post-World War II era, which has been covered so well in other sections of this volume. Rather, I will provide an historical illustration using my own bioethical experiences in Papua New Guinea, Solomon Islands, and Indonesia, showing how I attempted to cope with these different issues and circumstances over the past 36 years, and how these have changed.

A Personal History of Bioethics in the Southwest Pacific

About 10 years ago, I was asked by a National Academy of Sciences Panel that was exploring the ethical issues surrounding human genetic research in simple societies what I had used to guide my ethical standards during my 35 years of field research: How had I dealt with permissions and collaborations with other governments and their ministries? How had I obtained satisfactory informed consent from illiterate subjects? Had I obtained written consent? What role did group consent play? Was there adequate confidentiality? I said, almost without thinking, that the major point I always kept in mind was that I always intended to return at future times to carry on follow-up investigations. I had to do my utmost to ensure people and entire communities continued to feel comfortable and supportive of my presence and my research. This may sound too self-interested, but in the end, I believe appropriate ethical standards and behaviors for particular situations stem from this sense of continuing engagement. It forces the researcher to be constantly aware of the subject's concerns, welfare, and attitude, which should produce a mutually beneficial (or at least harmless) result. However, there is always a considerable risk that no matter how well-intentioned or considerate the researcher is, political and social situations may develop that make subjects change their minds about the suitability of the project. We should be aware that projects might have to be substantially modified or even abandoned in the face of changing attitudes.

For most of my career as a fieldworker in the Pacific, I was fortunate in my acceptance by most study populations. I believe most of the people I worked with in the past have either a neutral or positive attitude towards my stay in their communities and to what I did. However, there have been major exceptions and a number of groups and individuals have refused to participate. But refusals should not be taken as failure, but often are a sign of the opposite—by informing people adequately of the proposed work, it is hardly to be expected that consent will always be obtained. I am suspicious of any project where there is 100% consent, especially in traditional and non-Western societies.

My first field season was in 1966. I was a graduate student involved in the Harvard Solomon Islands Project, originally organized by Albert Damon. Papua New Guinea then was not an independent country (it became so in 1975), but was administered by Australia as a U.N. Trust Territory. Many ethical issues were simpler in those semi-colonial days-we would say too simple now. I only had to gain permission to do research from the Australian administration in the first instance, and local authorities in the second (local government councils or village elders). In my interview with the primary Australian government official, he said that my research did not present too many problems, but there were two concerns I must be aware of. First, I could say nothing unfavorable about the Australian administration, as people were likely to ask me for advice on everything in dealing with the outside world, and specifically their prospects for independence. He said that being an American in Melanesia meant that I might be subject to magical Cargo Cult expectations, and I had to be careful not to become a focus of anti-Australian sentiment. And second, because I was planning to take blood samples, I must not pay people for their cooperation. If I did, this would make problems for the malaria control officers when they gathered blood smears-people would demand money for their blood smears. Of course, I said I would avoid both these issues. I had no choice.

With the help of local Catholic missionaries, I identified a set of villages where I wanted to collect biological and demographic information. I was introduced to a mission catechist who suggested I come and discuss my research with his community, so one evening we walked to his village and I tried to describe my work and objectives to a group of adults there in rudimentary New Guinea pidgin English (Tok Pisin). With his help in translating, I did the best I could to explain my research goals and what I wanted to do in their village during the following two weeks.

The basic speech went something like this. I told the community I hoped to find out if there were differences in the way people looked and in their blood factors inherited from their parents from one village and language group to the next in the island of Bougainville. I would identify families I hoped to include, carry out some simple anthropometry, collect dermatoglyphics, hair samples, and add a dental examination on eruption sequences of children. The last day, I would take 10 cc of blood from everyone over about 10 years in the sample, and give everyone a Polaroid photo as a gift. Then, I planned to go down the path to nearby villages and do the same thing during the following months. At the end of my stay, I planned to write a "report" (a.k.a. doctoral dissertation) for my teachers that should enable me to get a

job as a teacher myself. I might write up the report as a book or articles in magazines, but they were unlikely to make significant money for me—the real payoff was a job.

People almost invariably appreciated this frankness with regard to my motivation. Although there have been village meetings where people told me they were not interested in participating, the great majority of meetings ended with acceptance, usually after three or more hours of discussion. Many individuals decided not to participate, for a variety of different reasons. Usually, non-participants were simply afraid of what I was doing, particularly taking blood and hair samples.

There also were times when village leaders attempted to browbeat reluctant individuals to participate, because the village had agreed as a group. One village nurse, for example, tried to shame people into participating, because he was likely to get my sphygmomanometer, stethoscope, baby scale, and supply of bandages when I left. Although I remember allowing this to happen at first, I quickly realized this was an unsatisfactory way to operate. I decided that whenever I became aware of this happening, I had to remind all parties that it was perfectly acceptable for them not to participate. I did try to emphasize at the preliminary meeting that a group decision to cooperate implied a sizeable percentage of those present were morally obligated to participate.

All this was done, in the 1960s and early 1970s, without written consent forms, and without any formal government approval within Papua New Guinea or Solomon Islands. It worked in a satisfactory manner for a number of reasons. The Australian administration was not interested in basic research, and was preoccupied with how (or how not) to transfer political power to local authorities. Melanesian communities had relatively diffuse decisionmaking structures, and people were accustomed to long (sometimes interminable) community meetings concerning important issues. Coercion was difficult for anyone to achieve and skepticism was a common reaction to most novelty. People thought foreigners were generally after their land and tended to be suspicious of anything that could possibly be interpreted as laying a foundation for claims on land ownership (archaeologists sometimes had problems on this score).

My being an American was both a great asset and detriment. Americans have had a special, even magical, attraction for Melanesians throughout the last 100 years, even preceding World War II. Revitalization and millenarian movements there, called Cargo Cults, often named "Merika" as the origin place of all modern machines and modern material wealth (or "Cargo"), so that if people could only gain special access to "Merika" or their representatives, they could gain all the wealth of white people. U.S. activity in the Solomons and Papua New Guinea during World War II only reinforced this belief of unimaginable wealth and power. For the Melanesians, Americans had demonstrated their power by driving out the Japanese, who had already driven out the British and Australian plantation colonialists. Also, a number of the U.S. soldiers were black brothers, and appeared to be treated better (even in a segregated army) than Melanesians felt they had been by colonial plantation owners. And they had never seen anything like the innumerable planes, ships, trucks, and supplies that the U.S. Navy had at its disposal. There have been many instances where local groups have wanted to secede from local governments and become annexed to the United States. For example, magical attempts were made to capture President Johnson and make him king in New Hanover Island.

For me, this meant that people were initially very well disposed to my living in their village and to the work I undertook. But clearly, I had to be careful what I promised or what I suggested we were doing, because there was always the possibility of being badly misinterpreted or being used in local political machinations. In one early circumstance, I was told that certain people had spread a rumor that I was a secret agent for the United States and was surreptitiously registering people for U.S. citizenship (fingerprinting, photographing, and taking blood). This was in preparation for the anticipated U.S. invasion—those people who I had signed up as citizens would be put in privileged positions. As soon as I heard this, I issued a strong denial and tried to incorporate a denial of any such activity in subsequent community presentations.

I also had an unpleasant encounter with a Cargo Cult leader later on, in the 1980s. I led a group of seven researchers to a remote part of Bougainville. I had sent word ahead that we wanted to come there, and received word back that we would be welcome. After we had trekked up the mountains for eight hours, we were met by villagers singing and dancing in an elaborate welcome. After about 45 minutes had passed, we were introduced to the village leader, "John God." He had established paramilitary control over the village. There was a great deal of saluting, marching, and ordering going on. He told us that he had been expecting us for months (!). He was preparing to declare his independence from Papua New Guinea and was sending a letter to the U.S. president to become a new state in the United States, and expected us to build a hospital and take up permanent residence there as doctors. This was clearly a particularly dangerous situation. After spending the night there huddled together in a rat infested shack (not wanting to accept any more hospitality than we could do without), we left the next morning after mass, where I gave my often-used sermon on the unity of humankind. I also made it clear we could not get them a hospital or aid their attempt at independence. This was a case of misinformed and misguided consent!

Recently, driven by the development of new ethical standards for research and IRBs in industrialized countries, I have had to develop written and

signed individual informed consent documents for use in surveys of largely illiterate villagers. The normal procedure we now follow is a modified version of the initial "town meeting" approach. Prior to carrying out a survey in a village, we visit the village in the late afternoon and discuss the project with responsible adults that we can locate (teachers, elected officials, or businessmen). If they are reasonably interested, we agree on a date, ordinarily two or three days later, where we will appear early in the morning to present our proposal to the community. If there are no major objections at the presentation, we commence the survey, and attempt to complete the work in that same morning. One team member's time is now devoted to obtaining written individual consents, often after reading the form to each subject.

We are now completing a video describing the history and objectives of our research in the southwest Pacific. We intend to show it to prospective participant groups to aid them in understanding the purposes of the project and the accomplishments to date. We want especially to emphasize the nonmedical purpose of the research, since this is often misunderstood.

Since independence came to Papua New Guinea and Solomon Islands, permissions at the governmental level have become another major ethical focus. At first, this simply was a matter of gaining research visa approval and trying to keep officials in the ministries of health and cultural affairs notified of work in progress, and sending along books and reprints to those officials as they were published. This really meant presenting an entire packet of published materials to the officials at every visit, because there was no effective local repository for such documents, and most officials held their positions for only a few years.

Also, as the infrastructure of modern society was superimposed on these developing nations, it became possible to let wider audiences in reach of radio and newsprint know about the research and what its aims were. This became an important part of establishing a working relationship with local people.

During the past two decades in Papua New Guinea, governmental policy has dictated that all biomedical researchers be formally affiliated with the Papua New Guinea Institute for Medical Research. Although at first I viewed this as yet another bureaucratic hurdle to muddle through, this affiliation has become an invaluable aid in my research. As our local government sponsor and collaborator, the IMR has guided us through difficult research visa approvals; has helped us obtain provincial health ministry approvals and support (including truck and boat hire and accommodations); has recommended competent local scientists for participation and training in the research; and has been a source of previously collected plasma samples. This has become a full research collaboration of equals. Scientists from the IMR appear as coauthors on our publications. Our reception in local communities in Papua New Guinea has become more enthusiastic since PNG nationals became directly involved in the field research, especially in phlebotomy. I am doing what I can to encourage at least a few local scientists to continue and expand our research on their own, even though their jobs will not directly support such esoteric work. As described below, this association with the IMR has also offered something of a protection against anti-science and anti-Western politics.

My one venture outside Melanesia for fieldwork was an instructive disaster. In 1973, I attempted to initiate a similar field collection in Indonesian (western) Timor. Although I had excellent contacts through a respected cultural anthropologist who had worked extensively in the region, I found it difficult to navigate the unfamiliar Indonesian bureaucracy for visas and permissions. What is relevant for the discussion here is that the essentially feudal society that prevailed in Timor made the notion of an individual informed consent impossible to obtain. I was instructed by the cultural anthropologist that the appropriate mode of operation locally was to give a gift to the local pasha (a Filipino shirt was his suggestion). Discussion with him, and obtaining his permission, was all that was required locally. The pasha could (and did) then order everyone to appear before me to be included in the survey. No further explanations or compensations were required or wanted. I felt uncomfortable in this situation, which lacked the basic Melanesian democratic elements of community discussion and group decision. For this and other reasons, I left Timor quickly.

Consultation in Research Design

As regional governments became more active in promoting their own agendas, I have necessarily had to involve them in the development of research agendas. In the 1970s, this primarily meant notification and consultation in the application for research visas, but more recently it has meant more real give and take.

In one instance in the mid-1980s in Solomon Islands, a researcher in the Ministry of Health said he wanted us to add an HIV survey as part of our expedition (this was his interest). We had a virologist as part of our expedition, and were focussing on HTLV-1. Although I advised the minister that, because HIV was not yet identified in the port city of Solomon Islands, it was most unlikely to be found in rural communities, he said he would still like verification. We complied with a testing of samples we took for the HTLV-1 work (there were no positives).

In our more recent collaboration with the Papua New Guinea IMR, suggestions go back and forth as to what tests should be included, what the

timing of the project should be, where it should be carried out, and so on. This "consultation" is of an entirely different degree and has been most satisfactory to date. In the future, it may be that we take a supportive and even peripheral role in any fieldwork, and become restricted to specialized laboratory analyses as more local scientists become interested in such projects and appropriately trained.

Local village groups have provided a different sort of help. Once they were adequately informed on the purposes of the research work, which was primarily historical, people often offered suggestions on which groups and villages might be the most interesting for us to cover. They had their own versions of local migrations and history.

Appropriate Compensation

What to use as appropriate compensation for collaboration in surveys of this sort has always been a difficult issue for me, stemming from the asymmetry of wealth between subjects and our research team. I have tried different approaches, almost none of which I think is entirely satisfactory. The Harvard Solomon Islands Expeditions in the 1960s and 1970s routinely did two things. First, they held open medical clinics for anyone in the area, participating in the survey or not. This was relatively easy to do because they had numerous participating medical doctors. On one notable occasion, they saved a number of lives with their store of antibiotics, stemming an outbreak of pneumonia. Second, they gave gifts or some form of compensation to survey participants because people had to give up a day's work to be involved. A cultural anthropologist who had been in the area for the preceding year decided upon the type of compensation. This varied from machetes to lengths of cloth to a simple cash payment.

I tried variations on both these themes. I often have had clinicians on our expeditions. Holding a free open clinic is an attractive idea, but in the end misleading. Rather few patients can be identified or helped by a one-time visit to a physician who has no access to a full pharmacological armamentarium or hospital. Referral to local hospitals for major problems was probably the greatest single health benefit we provided.

Direct monetary payment (or compensation for participation, which is a familiar concept in Melanesia) has its own problems, as suggested at the outset. At one time, I discussed with communities what they thought was the appropriate approach. I would say that so many dollars or kina were available to compensate the community for their participation, and they could decide how that should be used—individually, or to purchase some item of community benefit. In one instance, people wanted to use the money to purchase a

16-mm film projector. The idea was to show films at fundraisers for the local PTA. In another, the money was used to support the training of a local young man as a health orderly in the community, which I thought was an excellent solution. Usually, however, people preferred cash. More recently, I have gone back to giving people family pictures of themselves as mementos, along with a food treat as a "replenishment."

RAFI and the Problem of Unanticipated Consequences

I never expected my research to become sensationalized or the subject of outrage. I did think that it might be widely cited as evidence that humans cannot be neatly classified into discrete, homogeneous racial categories or types. However, in the fall of 1995, much to my amazement and horror, I discovered I was being accused of being a "missing link" in a federally sponsored effort to clone Papua New Guineans and Solomon Islanders.

The group responsible was Rural Advancement Federation International (RAFI), then based in Ottowa. RAFI, which had been primarily interested in opposing the patenting of plant and animal genes, found that The National Institute of Health had applied for patents on viral genes (HTLV-1) carried in the transformed cell lines of people from Panama, the Hagahai of Papua New Guinea, and Solomon Islanders. This "patenting of humans" was decried by them in a variety of media, but especially on the World Wide Web. Through conversations with various people in Papua New Guinea and Solomon Islands, they learned that I had recently visited those areas as a biomedical researcher and was also an employee of the federal government (I was the director of the Physical Anthropology Program at the National Science Foundation for three years—not the NIH, but certainly a government organization). They had put two and two together and came up with six.

I did know the principals in the NIH application for the Hagahai cell lines. The samples were collected by Carol Jenkins while she was working for the PNG Institute for Medical Research, and they were analyzed by Richard Yanagihara at the U.S. NINDS. At the time, it was official NIH policy, under Dr. B. Healy's direction, to apply for patents on any new discoveries made by government scientists that could conceivably be put to commercial use in the future. Jenkins had told the Hagahai of the patent application at the time it was made. She told them that in the event any money was made from the patent, that she would donate her own portion of the royalties and have them distributed to the Hagahai (Jenkins, 1996; Malau, O'Leary, Jenkins, & Faraclas, 1994; Yanagihara et al., 1990a; Yanagihara et al., 1990b; Yanagihara et al., 1991).

Jenkins and I were accused by RAFI of being human gene patenters sponsored by the U.S. government. These accusations led to a number of

sensational newspaper stories on the scientific exploitation of unwitting and innocent humans in underdeveloped cultures. I responded on the Web as best I could, with some help from Henry Greely, a Stanford University health lawyer. In a few months, the tempest began to exhaust itself, but not before substantial damage had been done to Jenkins's reputation within Papua New Guinea, where she had done excellent work in AIDS education/prevention and sexual behavior, besides the work with the Hagahai. I was asked to edit an issue of *Cultural Survival Quarterly* on the subject of human gene patenting, which was well received (Friedlaender, 1996). The NIH reversed its policy after Healy left, dropping the patent that had been awarded on the Hagahai and Panamanian cell line, and dropping the application on the Solomon Island cell line (again, Yanagihara had been the laboratory scientist involved).

At the time of the accusations, I was able to get testimonials from Solomon Island and Papua New Guinea health officers to the effect that I was not involved in the alleged activities and was a researcher in good standing with their governments and people. This was extremely important to me, and gratifying. Jenkins, who had been the focus of the attack by RAFI, was successful in defending herself for similar reasons. She had the support of the Hagahai and the Institute for Medical Research. There were, of course, many people in Papua New Guinea, as well as international sympathizers with indigenous peoples' exploitation who assumed the worst about the allegations. These suspicions were largely diffused because those intimately involved were able (and willing) to correct the misimpressions. In the end, trusting and informed relationships in the region were the critical elements in protecting us from the attacks alleging unethical behaviors.

The message for establishing ethical guidelines more generally is clear, if not absolute. Although we may have specific protocols for assuring privacy and anonymity in carrying out research reporting, for subject safety, and for obtaining (increasingly) informed consent, there is no simple recipe for establishing a mutually beneficial, trusting relationship between researcher and subject population. In situations where the subject population feels exploited and powerless in the face of outside forces, it is likely to be impossible to develop such a relationship. However, it is essential to work toward such an objective for the protection of all concerned. The borderline between ethical and political rectitude is sometimes unclear.

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Chapter 19

Commentary: An Overview of Human Subjects Research in Biological Anthropology

Jeffrey C. Long

Ethical practice of research involving human subjects has become increasingly topical over the past several decades. This trend began with the recognition of egregious violations of human rights in Nazi medical experiments. It was also sparked by serious human rights violations in the United States, as exemplified by the Tuskegee Syphilis Experiment. However, the concern for research ethics arises from more than these failures. It also owes to the fact that there is more research funding available now than ever before, and that research is inextricably bound to public interest because it is paid for by the public and embedded in public education and health. Research in all disciplines of physical, natural, and social sciences has an impact on individuals and society, and no aspect of science or research is exempt from ethical concerns. It is appropriate that physical anthropologists hold symposia and identify both crucial ethical concerns and state of the art practices.

There are three ethical principles that guide human subjects regulations in the United States today: justice, beneficence, and respect. These principles are fully articulated in 1979 in the Belmont Report to Congress. Succinctly stated, *justice* requires that the benefits and burdens of research are fairly distributed; *beneficence* requires that benefits are maximized and harms are minimized; *respect* requires that subjects are informed about the particular protocol and participation is voluntary. These principles provide a framework for understanding the broader implications of the individual contributions to this volume.

It is immediately apparent from reading these papers that anthropological research presents unique challenges. There is often a large gap between researcher and research subject in education and socioeconomic status. This translates into several difficulties. First, it is difficult to explain research goals and methods outside of the university and our own cultural setting, but informed consent is a vital aspect of respect and a necessary component of ethical research. Second, researchers must prevent subtle use of their nationality, university affiliation, or access to material goods to influence participation. Third, researchers must ensure that the distribution of risks and benefits is equitable. New knowledge should serve to benefit those studied as well as those studying. Finally, the researcher may not be adequately prepared to assess the unique constellation of cultural and environmental circumstances that translate into risks and benefits to the research participant.

The chapter by Sara Stinson presents an informative overview of the principles of ethics, the workings of an institutional review board (IRB), and her practical experience as a human biologist. She accurately points out that behavioral research encompasses dangers that are generally under appreciated. These include the potential for loss of confidentiality, which can ultimately lead to embarrassment or stigmatization. This risk may be greater in the anthropological setting where it is impossible to conduct private interviews or a language barrier necessitates using a translator. In addition to the dangers pointed out by Dr. Stinson, it should be noted that the topics and questions central to behavioral interviews contain sensitive questions that are culturally inappropriate or can trigger severe emotional distress. These may detect evidence of illegal activity or child abuse that the researcher is required to report to legal authorities. Both the researcher and the participant should be aware of these possibilities.

The project reported by Cynthia Winston and Rick Kittles stands out well in regard to serving the community of research participants. It combines the expertise of a psychologist, an ethicist, and a geneticist to study the use of genetic markers for tracing the ancestry of African Americans to their African homeland. The project is ambitious because genetic markers record history imperfectly and the ultimate psychosocial impact is presently uncertain. Yet, the research is directly aimed at benefiting the participants. It is extremely interesting that the African American respondents in their study were more interested in issues related to ancestry than in issues related to health. This project is a nearly unique example of anthropological genetic research being conducted in the context of African American defined goals, priorities, and values.

Sloan R. Williams deftly illustrates that unforeseen research risks can arise. She achieves this in the context of a recent genetic paternity analysis that examined the putative relationship between Thomas Jefferson and Sally Hemings. This is an emotional topic because Hemings was Jefferson's slave and his deceased wife's half-sister. The analysis indicated that Thomas Jefferson

fathered at least one child with Sally Hemings, but that at least one of her other children was not fathered by Jefferson. The ultimate impact of the findings was scattershot. Some who believed that they are Jefferson's descendants must now question how they understand their family history. By contrast, others who had no knowledge of a connection to Jefferson may now identify him as an ancestor. Unfortunately, these surprising findings were leaked to the press before the family could be advised or counseled, and it became abundantly clear that many of the participants did not understand the nature of the research. Perhaps more importantly, these results had an impact on putative relatives of Jefferson who did not choose to participate in the study. In ethical research, risks must be minimized and benefits maximized. We should seriously ask, what is the benefit gained by publicly exposing Jefferson? Indeed it demonstrates hypocrisy at many levels and some deficiencies of Jefferson's character. Perhaps we benefit by knowing that blemishes and flaws can accompany the contributions of a founding father and public figure, but it seems that this could also be accomplished without disrupting the lives of his living relatives.

This leads us to a large issue in anthropological research: group consent. The Belmont principles protect individual research participants, but the findings of population-based studies often affect all members of the population. Greater protections to small and/or isolated populations may be necessary, and consultation with recognized group leaders is a straightforward extension of the principle of respect. In fact, many such populations (e.g., Native American Tribes) have political and legal autonomy and no research can be conducted on their lands without approval. The chapter by Dennis O'Rourke, M. Geoffrey Hayes, and Shawn W. Carlyle describes a successful effort by researchers to study DNA extracted from the skeletal remains of American Indians, Alaskan Natives, and the Canadian Thule/Dorset. The questions are largely anthropological but the researchers have worked out a plan with each population to report back specific results and scientific findings. Nevertheless, the standard practice of group consent is now individualized and O'Rourke and colleagues point out there is not a single model for group consent or community consultation. The process of group consent and community consultation becomes far more problematic when the groups of interest are less well defined. For example, how could Irish- or Hispanic Americans be contacted as a group and who could fairly represent them? The uses and application of the principle of group consent will require further development.

Although government regulations expressly forbid IRBs from considering public policy, as Sara Stinson points out, anthropological research may have a negative public policy impact for the participants. This is indeed a fear of Native Americans who are concerned that genetic studies of migration and group membership will be used against them for land claims, legal disputes, and interpretation of treaties. Frederika Kaestle and David Smith address the issue of repatriating the Kennewick remains. Their article is an optimistic prolegomenon for ancient DNA studies but they present several lines of population genetic reasoning that leave one pessimistic about being able to make a direct link between a modern group and an ancient specimen. Moreover, they note that the effort is futile for repatriation because cultural affiliation—not genetic descent—is the determining criterion for the Native American Grave Protection and Repatriation Act.

Stacy Zamudio introduces a different tone, frustration with the process of obtaining IRB approval. Perhaps her most cogent observation is that there is a great deal of variability in execution of requirements across IRBs. This is logically dissatisfying and it complicates multisite projects. However, Zamudio has other concerns that are less compelling. She believes that IRB approvals should be honored across institutions. Yet each institution bears the ultimate responsibility for the research conducted within its bounds. It is unimaginable to me that an organization would accept this responsibility without direct review and periodic monitoring of research protocols. Zamudio also points to several difficulties in conducting research in traditional anthropological settings. For example, local IRBs may not be present in foreign localities, individual autonomy may not be the cultural norm, and the assent of children may not be acceptable to some traditional parents. Each of these situations enhances the risk faced by the research participant. The investigator contemplating such research should ask several questions at precisely this juncture. Can studying a less vulnerable group fulfill the research goal? What additional precautions can be taken to protect these subjects? Is the benefit to these subjects likely to outweigh their increased risk? As a general rule, investigators should simultaneously meet the highest standards of both our own culture and those of the research subjects' culture.

In conclusion, these chapters present a good introduction to the challenges faced in anthropological research and they point to several directions for future progress. The need to identify potential risks and develop protections will intensify as information and medical technologies move forward. We will need to avoid cultural hegemony in recruiting participants and we will need to assess mechanisms to deliver benefits from the research back to participants' communities. The development of models for group consent and community consultation will be helpful in these endeavors. Anthropologists will have to develop standards to deal with ethical issues related to the implications of their research for public policy. Fortunately, there are now good online resources for basic ethics training and many departments are integrating ethics training into the early stages of their graduate curriculum. Indeed, federal guidelines now mandate that,

among other things, the researcher is responsible for proper scientific design, monitoring participant rights and welfare in the course of research, and ensuring that all personnel on the research team are qualified and trained in human subjects protections. It seems that to fully meet these standards and goals, the annual physical anthropology meetings would be enhanced by a regularly held research ethics workshop.

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Chapter 20

Commentary: Data Sharing and Access to Information

Trudy R. Turner

The U.S. Office of Management and Budget stipulates in Circular A-110 that data obtained through grants awarded by federal agencies such as National Science Foundation and National Institute of Health are public and may be obtained through the Freedom of Information Act. NSF, NIH, and other federal agencies encourage the rapid and broad dissemination of research data throughout the scientific community. This reflects a scientific ideal of a community of scholars producing and sharing information. Sharing data promotes "open scientific inquiry, encourages diversity of analysis and opinion, promotes new research, makes possible the testing of new or alternative hypotheses and methods of analysis, supports studies on data collection methods and measurement, facilitates the education of new researchers, enables the exploration of topics not envisioned by the initial investigators, and permits the creation of new datasets when data from multiple sources are combined." (http://grants2.nih.gov/grants/policy/data_sharing/data_sharing_guidance.htm#goals)

The application of this ideal to real situations, however, is anything but clear and easy. The timely sharing of information is one of the issues that is important in a multitude of scientific disciplines. Many disciplines are currently wrestling with the ways to establish real time data sharing plans (see for example Lindstrom & Briscoe, 1999, which proposes a new model for data sharing among oceanographers). This issue, as well as others that concern nonreproducibility of basic data, are particularly relevant for biological anthropologists.

Much of the data of biological anthropologists are unique. There may only be a single representative fossil. Even if a researcher obtains full funding and support for a lengthy field expedition, a second representative fossil may not be available. Obtaining a second blood sample may not be possible if animals are wild and/or endangered. Consent and confidentiality are particularly important when attempting to replicate a study or work on samples from human populations that were obtained for a different research project.

In this commentary I raise some of the questions that our discipline confronts concerning data sharing without providing specific answers. These questions exist on many levels—legal, ethical, and international. We hope answers will emerge with continued dialogue. Some of the questions we must address include: What exactly are the data that become public information? The *Federal Register* provides a definition of data that applies in the circumstance of federally funded research, however, it is not the only available definition of data. What is fair use for the person who originally obtained the data? There may be patentable products that may alter a timetable for sharing of information. What if information is obtained from individuals who were guaranteed confidentiality? How are the data to be made available to everyone?¹

Some of the chapters in this volume have specifically addressed aspects of the sharing of data. The chapter by Monge and Mann is concerned with maintaining access to fossil resources through appropriate casting techniques. Lehn discusses a new resource for providing access to rare primate genetic materials. Much of the work discussed in this volume has been funded by federal agencies. New technologies, particularly the Internet, have made data sharing easier. The implications of A-110 will affect everyone and must be addressed by the biological anthropology community.

What Constitutes Data?

A researcher receives a grant to study the genetics of a nonhuman primate population as part of a larger study on primate life history. Or a researcher obtains funding to study the history of a human population through mtDNA analysis. The researcher spends over a year in the field obtaining biological samples (blood, tissue, hair). The researcher returns to the laboratory to amplify and analyze the data. What are the data—the original sample? the PCR product? the lab notebooks? the gene frequency information?

Another researcher spends years at a paleontological site in a foreign country and finds, processes, and describes a fossil primate. Does the researcher negotiate with the host country for temporary removal of the fossil from the country for further study and analysis? Who curates the material? Who has access to the material? Which particular government body or agency gives permission to remove the fossil? What is the obligation of the researcher working on U.S. federal grant money and what is the responsibility to the host country and collaborators in the host country?

What is Fair Use?

A researcher spends time crafting a proposal and doing the research project. Most researchers are associated with universities that require publication of research findings as part of the condition for promotion and tenure. But how long can the researcher maintain control over the material without sharing it with others? Does publication constitute sharing of information? Can information be embargoed for individual use? How long can this embargo last? What about material that is patentable? NIH has provided guidelines for data sharing that address these issues.

Confidentiality

There has been considerable discussion in this volume about informed consent and confidentiality. What happens to this promise when there is a requirement to share data? Who controls the original data and who monitors who has access? Major research projects must guard against breeches of confidentiality and consent. Genetic material can be stored for considerable lengths of time. Can a researcher do another project on the same sample without consent of the population? Certainly this was is an issue of great concern to the Yanomami (see chapter 13). The current ethic is that a population must be reapproached for consent for all additional projected on already collected samples. But what about data, such as gene frequencies, derived from the original sample?

Making Data Broadly Available

During the past 10 years there has been a revolution in information technology. The Internet has made material available to a vast audience. Journals and data that were once only available in print form are now available on-line. There are some journals that are now available only on-line. Researchers at institutions that do not readily provide all journals in print can now have access to the journals electronically. Complex databases providing easy access and the potential for rapid dissemination of information are only available with on-line resources. One of the earliest data banks available electronically was GenBank.

GenBank is the NIH genetic sequence database, an annotated collection of all publicly available DNA sequences. A new release is made every two months. GenBank is part of the International Nucleotide Sequence Database Collaboration, which is comprised of the DNA DataBank of Japan (DDBJ), the European Molecular Biology Laboratory (EMBL), and GenBank at the National Center for Biotechnology Information. These three organizations exchange data on a daily basis. Information available at http://www.ncbi.nlm.nih.gov/genbank/ index.html.

The National Center for Biotechnology Information (NCBI) that administers GenBank creates public databases and conducts research in computational biology to better disseminate biomedical information. Other NCBI databases include PubMed, Blast, Mendelian Inheritance in Man, and information useful for taxonomy and structure of genetic systems. The information is available to anyone with access to the Internet.

NSF has also been actively involved in funding infrastructure projects. Again, the hope is to make data more readily available to scholars around the world. ALFRED (an acronym for ALlele FRequency Data) is a data base run out of Ken Kidd's laboratory at Yale University.

ALFRED has been designed to make allele frequency data on anthropologically defined human population samples readily available to the scientific community and to link these polymorphism data to the molecular genetics-human genome databases. Initially, ALFRED contained primarily data generated in the laboratories of K. K. and J. R. Kidd in the Department of Genetics at Yale, including extensive unpublished data. Data from the published literature are now being entered into ALFRED in a more systematic way, with a focus on polymorphisms studies in many different populations... All of the data in ALFRED are considered to be in the public domain and available for use in research and teaching. (from overview of Alfred or Kidd, 2004 available at http://alfred.med.yale.edu/alfred/).

ALFRED provides a way for molecular anthropology to study human variation through a variety of new polymorphisms (see Osier, Cheung, Kidd, Pakstis, Miller, & Kidd, 2002; Rajeevan et al., 2003 for more information on ALFRED). There are currently over 11,000 frequency tables available for researchers using this system.

In the past print journals published gene frequency data for a few markers on a small number of populations. With modern technology it is possible to collect dozens of markers on dozens of populations. More often than not, these data are available on Web sites noted in journals rather than in print in the journals. However, these sites may or may not be permanent, depending on whether they are the journals sites or sites of individual researchers. The developers of ALFRED hope to provide a greater permanency with this system as well as provide a source of information for the study of human variation.

Commentary

Another infrastructure project funded by NSF is different from GenBank and ALFRED. The Integrated Primate Biomaterials and Information Resource (IPBIR) supplies material capable of genetic analysis instead of sequence or frequency information.

The purpose of the IPBIR is to assemble, characterize, and distribute high-quality DNA samples of known provenance with accompanying demographic, geographic, and behavioral information in order to stimulate and facilitate research in primate genetic diversity and evolution, comparative genomics, and population genetics. Further research in these areas will advance our understanding of human origins, the biological basis of cognitive processes, evolutionary history and relationships, and social structure, and will provide critical scientific information needed to facilitate conservation of biological diversity. The derived DNA will be openly available to the broad scientific community who agree to restrict use to noncommercial purposes. (http://ipbir.org/) (Coriell Institute for Medical Research, 2004).

This resource has participation from zoos, universities, and other research foundations. Because IPBIR deals with original materials there is the need for curation and storage. NSF sponsors the curation of the material at the Coriell Institute in Camden, NJ.² It is expected that the data generated from material at IPBIR will be shared with the scientific community—sequence data will be placed in GenBank, appropriate molecular markers will be available for species identification, and microsatellite markers will be available for individual identification within species.

These two new infrastructure examples illustrate a new type of data sharing—whether it is sequence information or original samples. Genetic data are more easily shared than fossil data. Access to original fossil material can be controlled either by the country of origin or the researcher. A recent issue of *The Scientist* (February 24, 2003) describes a proposal by Bernard Wood of George Washington University to create an electronic database similar to GenBank for hominid fossils. The data bank could include high-resolution and three-dimensional images and measurements. This type of data would allow for comparison of samples housed around the world and would further democratize the discipline (Soures, 2003). This approach is not without its critics. It does, however, indicate the realization of the scholarly community of the need for better access to information.

The question of access to information and the sharing of data will be one of the many that our discipline will address in the future. This volume has posed many such questions for students and practitioners in the field. We all recognize that there remains much to be accomplished. An open and continuing dialogue over time will contribute to the ways in which these crucial questions will be answered.

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I am deeply indebted to Jeanne Beck, Ken Kidd, and Mark Weiss for their thoughtful discussions and comments on this paper.

Notes

1. It is not the intent of this commentary to address the issue of reproducible results. Reproductibility is critical to scientific inquiry. Reproducibility is based on the sharing of methodology and data. Without it nothing can be accepted. There is, however, a harder edge to reproducibility that does not involve methods or interpretation. There are rare times when there is misconduct in scientific research. The pages of *Science* detail careers that are derailed or destroyed by accusations of misconduct of real misconduct (see chapter 2 for an overview of scientific ethics). Although this issue is not discussed in this commentary, scientific openness provides a check on this system. This commentary is concerned with the overwhelming majority of scientists that adhere to the standards and principles of sharing information in the pursuit of knowledge.

2. Information on the Coriell Institute can be found at their Web site http:// www.coriell.org. A brief overview includes:

The Coriell Institute for Medical Research is an internationally-known not-for-profit, basic biomedical research institution.... In addition to conducting its own research in cancer (including breast cancer and leukemia), human genetic variation, mechanisms of cellular differentiation, and other genetic disorders, the Coriell Institute for Medical Research also serves the entire scientific community by maintaining the world's largest collection of human cells for research.... The Coriell Cell Repositories also provide support for the *Human Genome Project*, a world-wide program to map the entire human genome.

In their work with human populations they have conducted community consultations with named groups in the United States under the guidelines presented in the "Points to consider when conducting a genetic study that involves members of named populations" (http://www.nih.gov/sigs/bioethics/named_populations.html)

Commentary

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Code of Ethics of the American Anthropological Association

Approved June 1998

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I. Preamble

Anthropological researchers, teachers and practitioners are members of many different communities, each with its own moral rules or codes of ethics. Anthropologists have moral obligations as members of other groups, such as the family, religion, and community, as well as the profession. They also have obligations to the scholarly discipline, to the wider society and culture, and to the human species, other species, and the environment. Furthermore, fieldworkers may develop close relationships with persons or animals with whom they work, generating an additional level of ethical considerations.

In a field of such complex involvements and obligations, it is inevitable that misunderstandings, conflicts, and the need to make choices among apparently incompatible values will arise. Anthropologists are responsible for grappling with such difficulties and struggling to resolve them in ways compatible with the principles stated here. The purpose of this Code is to foster discussion and education. The American Anthropological Association (AAA) does not adjudicate claims for unethical behavior.

The principles and guidelines in this Code provide the anthropologist with tools to engage in developing and maintaining an ethical framework for all anthropological work.

II. Introduction

Anthropology is a multidisciplinary field of science and scholarship, which includes the study of all aspects of humankind—archaeological, biological, linguistic, and sociocultural. Anthropology has roots in the natural and social sciences and in the humanities, ranging in approach from basic to applied research and to scholarly interpretation.

As the principal organization representing the breadth of anthropology, the American Anthropological Association (AAA) starts from the position that generating and appropriately utilizing knowledge (i.e., publishing, teaching, developing programs, and informing policy) of the peoples of the world, past and present, is a worthy goal; that the generation of anthropological knowledge is a dynamic process using many different and ever-evolving approaches; and that for moral and practical reasons, the generation and utilization of knowledge should be achieved in an ethical manner.

The mission of American Anthropological Association is to advance all aspects of anthropological research and to foster dissemination of anthropological knowledge through publications, teaching, public education, and application. An important part of that mission is to help educate AAA members about ethical obligations and challenges involved in the generation, dissemination, and utilization of anthropological knowledge.

The purpose of this Code is to provide AAA members and other interested persons with guidelines for making ethical choices in the conduct of their anthropological work. Because can find themselves in complex situations and subject to more than one code of ethics, the AAA Code of Ethics provides a framework, not an ironclad formula, for making decisions.

Persons using the Code as a guideline for making ethical choices or for teaching are encouraged to seek out illustrative examples and appropriate case studies to enrich their knowledge base.

Anthropologists have a duty to be informed about ethical codes relating to their work, and ought periodically to receive training on current research activities and ethical issues. In addition, departments offering anthropology degrees should include and require ethical training in their curriculums.

No code or set of guidelines can anticipate unique circumstances or direct actions in specific situations. The individual anthropologist must be willing to make carefully considered ethical choices and be prepared to make clear the assumptions, facts and issues on which those choices are based. These guidelines therefore address *general* contexts, priorities and relationships which should be considered in ethical decision making in anthropological work.

III. Research

In both proposing and carrying out research, anthropological researchers must be open about the purpose(s), potential impacts, and source(s) of support for research projects with funders, colleagues, persons studied or providing information, and with relevant parties affected by the research. Researchers must expect to utilize the results of their work in an appropriate fashion and disseminate the results through appropriate and timely activities. Research fulfilling these expectations is ethical, regardless of the source of funding (public or private) or purpose (i.e., "applied," "basic," "pure," or "proprietary").

Anthropological researchers should be alert to the danger of compromising anthropological ethics as a condition to engage in research, yet also be alert to proper demands of good citizenship or host-guest relations. Active contribution and leadership in seeking to shape public or private sector actions and policies may be as ethically justifiable as inaction, detachment, or noncooperation, depending on circumstances. Similar principles hold for anthropological researchers employed or otherwise affiliated with nonanthropological institutions, public institutions, or private enterprises.

A. Responsibility to people and animals with whom anthropological researchers work and whose lives and cultures they study.

- 1. Anthropological researchers have primary ethical obligations to the people, species, and materials they study and to the people with whom they work. These obligations can supersede the goal of seeking new knowledge, and can lead to decisions not to undertake or to discontinue a research project when the primary obligation conflicts with other responsibilities, such as those owed to sponsors or clients. These ethical obligations include:
 - To avoid harm or wrong, understanding that the development of knowledge can lead to change which may be positive or negative for the people or animals worked with or studied
 - To respect the well-being of humans and nonhuman primates
 - To work for the long-term conservation of the archaeological, fossil, and historical records
 - To consult actively with the affected individuals or group(s), with the goal of establishing a working relationship that can be beneficial to all parties involved

- 2. Anthropological researchers must do everything in their power to ensure that their research does not harm the safety, dignity, or privacy of the people with whom they work, conduct research, or perform other professional activities. Anthropological researchers working with animals must do everything in their power to ensure that the research does not harm the safety, psychological well-being or survival of the animals or species with which they work.
- 3. Anthropological researchers must determine in advance whether their hosts/providers of information wish to remain anonymous or receive recognition, and make every effort to comply with those wishes. Researchers must present to their research participants the possible impacts of the choices, and make clear that despite their best efforts, anonymity may be compromised or recognition fail to materialize.
- 4. Anthropological researchers should obtain in advance the informed consent of persons being studied, providing information, owning or controlling access to material being studied, or otherwise identified as having interests which might be impacted by the research. It is understood that the degree and breadth of informed consent required will depend on the nature of the project and may be affected by requirements of other codes, laws, and ethics of the country or community in which the research is pursued. Further, it is understood that the informed consent process is dynamic and continuous; the process should be initiated in the project design and continue through implementation by way of dialogue and negotiation with those studied. Researchers are responsible for identifying and complying with the various informed consent codes, laws and regulations affecting their projects. Informed consent, for the purposes of this code, does not necessarily imply or require a particular written or signed form. It is the quality of the consent, not the format, that is relevant.
- 5. Anthropological researchers who have developed close and enduring relationships (i.e., covenantal relationships) with either individual persons providing information or with hosts must adhere to the obligations of openness and informed consent, while carefully and respectfully negotiating the limits of the relationship.
- 6. While anthropologists may gain personally from their work, they must not exploit individuals, groups, animals, or cultural or biological materials. They should recognize their debt to the societies in which they work and their obligation to reciprocate with people studied in appropriate ways.

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B. Responsibility to scholarship and science

- Anthropological researchers must expect to encounter ethical dilemmas at every stage of their work, and must make good-faith efforts to identify potential ethical claims and conflicts in advance when preparing proposals and as projects proceed. A section raising and responding to potential ethical issues should be part of every research proposal.
- 2. Anthropological researchers bear responsibility for the integrity and reputation of their discipline, of scholarship, and of science. Thus, anthropological researchers are subject to the general moral rules of scientific and scholarly conduct: they should not deceive or knowingly misrepresent (i.e., fabricate evidence, falsify, plagiarize), or attempt to prevent reporting of misconduct, or obstruct the scientific/scholarly research of others.
- 3. Anthropological researchers should do all they can to preserve opportunities for future fieldworkers to follow them to the field.
- 4. Anthropological researchers should utilize the results of their work in an appropriate fashion, and whenever possible disseminate their findings to the scientific and scholarly community.
- 5. Anthropological researchers should seriously consider all reasonable requests for access to their data and other research materials for purposes of research. They should also make every effort to insure preservation of their fieldwork data for use by posterity.

C. Responsibility to the public

1. Anthropological researchers should make the results of their research appropriately available to sponsors, students, decision makers, and other nonanthropologists. In so doing, they must be truthful; they are not only responsible for the factual content of their statements but also must consider carefully the social and political implications of the information they disseminate. They must do everything in their power to insure that such information is well understood, properly contextualized, and responsibly utilized. They should make clear the empirical bases upon which their reports stand, be candid about their qualifications and philosophical or political biases, and recognize and make clear the limits of anthropological expertise. At the same time, they must be alert to possible harm their information may cause people with whom they work or colleagues.

2. Anthropologists may choose to move beyond disseminating research results to a position of advocacy. This is an individual decision, but not an ethical responsibility.

IV. Teaching

Responsibility to students and trainees

While adhering to ethical and legal codes governing relations between teachers/mentors and students/trainees at their educational institutions or as members of wider organizations, anthropological teachers should be particularly sensitive to the ways such codes apply in their discipline (for example, when teaching involves close contact with students/trainees in field situations). Among the widely recognized precepts which anthropological teachers, like other teachers/mentors, should follow are:

- 1. Teachers/mentors should conduct their programs in ways that preclude discrimination on the basis of sex, marital status, "race," social class, political convictions, disability, religion, ethnic background, national origin, sexual orientation, age, or other criteria irrelevant to academic performance.
- 2. Teachers'/mentors' duties include continually striving to improve their teaching/training techniques; being available and responsive to student/trainee interests; counseling students/ trainees realistically regarding career opportunities; conscientiously supervising, encouraging, and supporting students'/trainees' studies; being fair, prompt, and reliable in communicating evaluations; assisting students/trainees in securing research support; and helping students/trainees when they seek professional placement.
- 3. Teachers/mentors should impress upon students/trainees the ethical challenges involved in every phase of anthropological work; encourage them to reflect upon this and other codes; encourage dialogue with colleagues on ethical issues; and discourage participation in ethically questionable projects.
- 4. Teachers/mentors should publicly acknowledge student/trainee assistance in research and preparation of their work; give appropriate credit for coauthorship to students/trainees; encourage publication of worthy student/trainee papers; and compensate students/trainees justly for their participation in all professional activities.

5. Teachers/mentors should beware of the exploitation and serious conflicts of interest which may result if they engage in sexual relations with students/trainees. They must avoid sexual liaisons with students/trainees for whose education and professional training they are in any way responsible.

V. Application

- 1. The same ethical guidelines apply to all anthropological work. That is, in both proposing and carrying out research, anthropologists must be open with funders, colleagues, persons studied or providing information, and relevant parties affected by the work about the purpose(s), potential impacts, and source(s) of support for the work. Applied anthropologists must intend and expect to utilize the results of their work appropriately (i.e., publication, teaching, program and policy development) within a reasonable time. In situations in which anthropological knowledge is applied, anthropologists bear the same responsibility to be open and candid about their skills and intentions, and monitor the effects of their work on all persons affected. Anthropologists may be involved in many types of work, frequently affecting individuals and groups with diverse and sometimes conflicting interests. The individual anthropologist must make carefully considered ethical choices and be prepared to make clear the assumptions, facts and issues on which those choices are based.
- 2. In all dealings with employers, persons hired to pursue anthropological research or apply anthropological knowledge should be honest about their qualifications, capabilities, and aims. Prior to making any professional commitments, they must review the purposes of prospective employers, taking into consideration the employer's past activities and future goals. In working for governmental agencies or private businesses, they should be especially careful not to promise or imply acceptance of conditions contrary to professional ethics or competing commitments.
- 3. Applied anthropologists, as any anthropologist, should be alert to the danger of compromising anthropological ethics as a condition for engaging in research or practice. They should also be alert to proper demands of hospitality, good citizenship and guest status. Proactive contribution and leadership in shaping public or private sector actions and policies may be as ethically justifiable as inaction, detachment, or noncooperation, depending on circumstances.

VI. Epilogue

Anthropological research, teaching, and application, like any human actions, pose choices for which anthropologists individually and collectively bear ethical responsibility. Since anthropologists are members of a variety of groups and subject to a variety of ethical codes, choices must sometimes be made not only between the varied obligations presented in this code but also between those of this code and those incurred in other statuses or roles. This statement does not dictate choice or propose sanctions. Rather, it is designed to promote discussion and provide general guidelines for ethically responsible decisions.

VII. Acknowledgments

This Code was drafted by the Commission to Review the AAA Statements on Ethics during the period January 1995-March 1997. The Commission members were James Peacock (Chair), Carolyn Fluehr-Lobban, Barbara Frankel, Kathleen Gibson, Janet Levy, and Murray Wax. In addition, the following individuals participated in the Commission meetings: philosopher Bernard Gert, anthropologists Cathleen Crain, Shirley Fiske, David Freyer, Felix Moos, Yolanda Moses, and Niel Tashima; and members of the American Sociological Association Committee on Ethics. Open hearings on the Code were held at the 1995 and 1996 annual meetings of the American Anthropological Association. The Commission solicited comments from all AAA Sections. The first draft of the AAA Code of Ethics was discussed at the May 1995 AAA Section Assembly meeting; the second draft was briefly discussed at the November 1996 meeting of the AAA Section Assembly. The Final Report of the Commission was published in the September 1995 edition of the Anthropology Newsletter and on the AAA web site (http://www.aaanet.org). Drafts of the Code were published in the April 1996 and 1996 annual meeting edition of the Anthropology Newsletter and the AAA web site, and comments were solicited from the membership. The Commission considered all comments from the membership in formulating the final draft in February 1997. The Commission gratefully acknowledge the use of some language from the codes of ethics of the National Association for the Practice of Anthropology and the Society for American Archaeology.

VIII. Other Relevant Codes of Ethics

The following list of other Codes of Ethics may be useful to anthropological researchers, teachers and practitioners:

Animal Behavior Society

1991 Guidelines for the Use of Animals in Research. *Animal Behavior*, *41*, 183–186.

American Board of Forensic Examiners

n.d. *Code of Ethical Conduct.* (American Board of Forensic Examiners, 300 South Jefferson Avenue, Suite 411, Springfield, MO 65806).

Archaeological Institute of America

1991 Code of Ethics. American Journal of Archaeology, 95, 285.

1994 *Code of Professional Standards*. (Archaeological Institute of America, 675 Commonwealth Ave, Boston, MA 02215-1401. Supplements and expands but does not replace the earlier Code of Ethics).

National Academy of Sciences

1995 On Being a Scientist: Responsible Conduct in Research. 2nd edition. Washington, D.C.: National Academy Press (2121 Constitution Avenue, NW, Washington, D.C. 20418).

National Association for the Practice of Anthropology

1988 Ethical Guidelines for Practitioners.

Sigma Xi

1992 Sigma Xi Statement on the Use of Animals in Research. *American Scientist* 80:73-76.

Society for American Archaeology

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Society for Applied Anthropology

1983 Professional and Ethical Responsibilities. (Revised 1983).

Society of Professional Archaeologists

1976 Code of Ethics, Standards of Research Performance and Institutional Standards. (Society of Professional Archaeologists, PO Box 60911, Oklahoma City, OK 73146-0911).

United Nations

1948 Universal Declaration of Human Rights.

1983 United Nations Convention on the Elimination of All Forms of Discrimination Against Women.

1987 United Nations Convention on the Rights of the Child.

Forthcoming United Nations Declaration on Rights of Indigenous Peoples.

Code of Ethics of the American Association of Physical Anthropologists

(Approved by the AAPA Membership at the annual business meeting on April 25, 2003)

Reprinted by permission of the American Association of Physical Anthropologists from their Website, www.physanth.org

I. Preamble

Physical anthropologists are part of the anthropology community and members of many other different communities each with its own moral rules or codes of ethics. Physical anthropologists have obligations to their scholarly discipline, the wider society, and the environment. Furthermore, field workers may develop close relationships with the people with whom they work, generating an additional level of ethical considerations.

In a field of such complex involvement and obligations, it is inevitable that misunderstanding, conflicts, and the need to make choices among apparently incompatible values will arise. Physical anthropologists are responsible for grappling with such difficulties and struggling to resolve them in ways compatible with the principles stated here. The purpose of this Code is to foster discussion and education. The American Association of Physical Anthropologists (AAPA) does not adjudicate claims of unethical behavior.

The principles and guidelines in this Code provide physical anthropologists with the tools to engage in developing and maintaining an ethical framework, as they engage in their work. This Code is based on the Code developed and approved by the American Anthropological Association (AAA). The AAPA has the permission of the AAA to use and modify the AAA Code as needed. In sections III, IV, V, VI, VII, and VIII anthropology or anthropologists refers to physical anthropology or physical anthropologists.

II. Introduction

Physical anthropology is a multidisciplinary field of science and scholarship, which includes the study of biological aspects of humankind and nonhuman primates. Physical anthropology has roots in the natural and social sciences, ranging in approach from basic to applied research and to scholarly interpretation. The purpose of the AAPA is the advancement of the science of physical anthropology. The Code holds the position that generating and appropriately utilizing knowledge (i.e., publishing, teaching, developing programs, and informing policy) of the peoples of the world, past and present, is a worthy goal; that general knowledge is a dynamic process using many different and ever-evolving approaches; and that for moral and practical reasons, the generation and utilization of knowledge should be achieved in an ethical manner.

The purpose of this Code is to provide AAPA members and other interested persons with guidelines for making ethical choices in the conduct of their physical anthropological work. Because physical anthropologists can find themselves in complex situations and subject to more than one code of ethics, the AAPA Code of Ethics provides a framework, not an ironclad formula, for making decisions.

Physical anthropologists have a duty to be informed about ethical codes relating to their work and ought periodically to receive training on ethical issues. In addition, departments offering anthropology degrees should include and require ethical training in their curriculums.

No code or set of guidelines can anticipate unique circumstances or direct actions required in any specific situation. The individual physical anthropologist must be willing to make carefully considered ethical choices and be prepared to make clear the assumptions, facts and issues on which those choices are based. These guidelines therefore address general contexts, priorities and relationships that should be considered in ethical decision making in physical anthropological work.

III. Research

In both proposing and carrying out research, anthropological researchers must be open about the purpose(s), potential impacts, and source(s) of support for research projects with funders, colleagues, persons studied or providing information, and with relevant parties affected by the research. Researchers must expect to utilize the results of their work in an appropriate fashion and disseminate the results through appropriate and timely activities. Research fulfilling these expectations is ethical, regardless of the source of funding (public or private) or purpose (i.e., "applied," "basic," "pure," or "proprietary").

Anthropological researchers should be alert to the danger of compromising anthropological ethics as a condition to engage in research, yet also be alert to proper demands of good citizenship or host-guest relations. Active contribution and leadership in seeking to shape public or private sector actions and policies may be as ethically justifiable as inaction, detachment, or noncooperation, depending on circumstances. Similar principles hold for anthropological researchers employed or otherwise affiliated with nonanthropological institutions, public institutions, or private enterprises.

A. Responsibility to people and animals with whom anthropological researchers work and whose lives and cultures they study.

1. Anthropological researchers have primary ethical obligations to the people, species, and materials they study and to the people with whom they work. These obligations can supersede the goal of seeking new knowledge, and can lead to decisions not to undertake or to discontinue a research project when the primary obligation conflicts with other responsibilities, such as those owed to sponsors or clients. These ethical obligations include:

To respect the well-being of humans and nonhuman primates

To work for the long-term conservation of the archaeological, fossil, and historical records

To consult actively with the affected individuals or group(s), with the goal of establishing a working relationship that can be beneficial to all parties involved

- 2. Anthropological researchers must do everything in their power to ensure that their research does not harm the safety, dignity, or privacy of the people with whom they work, conduct research, or perform other professional activities
- 3. Anthropological researchers must determine in advance whether their hosts/providers of information wish to remain anonymous or receive recognition, and make every effort to comply with those wishes. Researchers must present to their research participants the possible impacts of the choices, and make clear that despite their best efforts, anonymity may be compromised or recognition fail to materialize.
- 4. Anthropological researchers should obtain in advance the informed consent of persons being studied, providing information, owning or controlling access to material being studied, or otherwise identified as

having interests which might be impacted by the research. It is understood that the degree and breadth of informed consent required will depend on the nature of the project and may be affected by requirements of other codes, laws, and ethics of the country or community in which the research is pursued. Further, it is understood that the informed consent process is dynamic and continuous; the process should be initiated in the project design and continue through implementation by way of dialogue and negotiation with those studied. Researchers are responsible for identifying and complying with the various informed consent codes, laws and regulations affecting their projects. Informed consent, for the purposes of this code, does not necessarily imply or require a particular written or signed form. It is the quality of the consent, not the format, that is relevant.

- 5. Anthropological researchers who have developed close and enduring relationships (i.e., covenantal relationships) with either individual persons providing information or with hosts must adhere to the obligations of openness and informed consent, while carefully and respectfully negotiating the limits of the relationship.
- 6. While anthropologists may gain personally from their work, they must not exploit individuals, groups, animals, or cultural or biological materials. They should recognize their debt to the societies in which they work and their obligation to reciprocate with people studied in appropriate ways.

B. Responsibility to scholarship and science

- Anthropological researchers must expect to encounter ethical dilemmas at every stage of their work, and must make good-faith efforts to identify potential ethical claims and conflicts in advance when preparing proposals and as projects proceed.
- 2. Anthropological researchers bear responsibility for the integrity and reputation of their discipline, of scholarship, and of science. Thus, anthropological researchers are subject to the general moral rules of scientific and scholarly conduct: they should not deceive or knowingly misrepresent (i.e., fabricate evidence, falsify, plagiarize), or attempt to prevent reporting of misconduct, or obstruct the scientific/scholarly research of others.
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C. Responsibility to the public

- 1. Anthropological researchers should make the results of their research appropriately available to sponsors, students, decision makers, and other nonanthropologists. In so doing, they must be truthful; they are not only responsible for the factual content of their statements but also must consider carefully the social and political implications of the information they disseminate. They must do everything in their power to insure that such information is well understood, properly contextualized, and responsibly utilized. They should make clear the empirical bases upon which their reports stand, be candid about their qualifications and philosophical or political biases, and recognize and make clear the limits of anthropological expertise. At the same time, they must be alert to possible harm their information may cause people with whom they work or colleagues.
- 2. Anthropologists may choose to move beyond disseminating research results to a position of advocacy. This is an individual decision, but not an ethical responsibility.

IV. Teaching

Responsibility to students and trainees

While adhering to ethical and legal codes governing relations between teachers/mentors and students/trainees at their educational institutions or as members of wider organizations, anthropological teachers should be particularly sensitive to the ways such codes apply in their discipline (for example, when teaching involves close contact with students/trainees in field situations). Among the widely recognized precepts which anthropological teachers, like other teachers/mentors, should follow are:

1. Teachers/mentors should conduct their programs in ways that preclude discrimination on the basis of sex, marital status, "race," social class, political convictions, disability, religion, ethnic background, national origin, sexual orientation, age, or other criteria irrelevant to academic performance.

- 2. Teachers'/mentors' duties include continually striving to improve their teaching/training techniques; being available and responsive to student/trainee interests; counseling students/ trainees realistically regarding career opportunities; conscientiously supervising, encouraging, and supporting students'/trainees' studies; being fair, prompt, and reliable in communicating evaluations; assisting students/trainees in securing research support; and helping students/trainees when they seek professional placement.
- 3. Teachers/mentors should impress upon students/trainees the ethical challenges involved in every phase of anthropological work; encourage them to reflect upon this and other codes; encourage dialogue with colleagues on ethical issues; and discourage participation in ethically questionable projects.
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- 5. Teachers/mentors should beware of the exploitation and serious conflicts of interest which may result if they engage in sexual relations with students/trainees. They must avoid sexual liaisons with students/trainees for whose education and professional training they are in any way responsible.

V. Application

1. The same ethical guidelines apply to all anthropological work. That is, in both proposing and carrying out research, anthropologists must be open with funders, colleagues, persons studied or providing information, and relevant parties affected by the work about the purpose(s), potential impacts, and source(s) of support for the work. Applied anthropologists must intend and expect to utilize the results of their work appropriately (i.e., publication, teaching, program and policy development) within a reasonable time. In situations in which anthropological knowledge is applied, anthropologists bear the same responsibility to be open and candid about their skills and intentions, and

monitor the effects of their work on all persons affected. Anthropologists may be involved in many types of work, frequently affecting individuals and groups with diverse and sometimes conflicting interests. The individual anthropologist must make carefully considered ethical choices and be prepared to make clear the assumptions, facts and issues on which those choices are based.

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- 3. Applied anthropologists, as any anthropologist, should be alert to the danger of compromising anthropological ethics as a condition for engaging in research or practice. They should also be alert to proper demands of hospitality, good citizenship and guest status. Proactive contribution and leadership in shaping public or private sector actions and policies may be as ethically justifiable as inaction, detachment, or noncooperation, depending on circumstances.

VI. Epilogue

Anthropological research, teaching, and application, like any human actions, pose choices for which anthropologists individually and collectively bear ethical responsibility. Since anthropologists are members of a variety of groups and subject to a variety of ethical codes, choices must sometimes be made not only between the varied obligations presented in this code but also between those of this code and those incurred in other statuses or roles. This statement does not dictate choice or propose sanctions. Rather, it is designed to promote discussion and provide general guidelines for ethically responsible decisions.

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The AAPA committee members were Linda D. Wolfe (chair), Alan Swedlund, Trudy Turner, Phillip Walker, and Mark Weiss.

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Society for Applied Anthropology 1983 Professional and Ethical Responsibilities. (Revised 1983).

Society of Professional Archaeologists

1976 Code of Ethics, Standards of Research Performance and Institutional Standards. (Society of Professional Archaeologists, PO Box 60911, Oklahoma City, OK 73146-0911).

United Nations 1948 Universal Declaration of Human Rights, 1983 United Nations Convention on the Elimination of All Forms of Discrimination Against Women. 1987 United Nations Convention on the Rights of the Child. Forthcoming United Nations Declaration on Rights of Indigenous Peoples. This page intentionally left blank.

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