Collection of Bodily Samples and Informed Consent: A Discussion with Recommendations

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The El Dorado Task Force was established in November 2000 by The Executive Board of the American Anthropological Association to conduct what the Board termed an "inquiry" into the allegations about anthropological practice among the Yanomami contained in Darkness in El Dorado, by Patrick Tierney. In an attempt to evaluate whether procedures of informed consent were adequately followed in the 1968 expedition by Chagnon, Neel, and others, I met with and interviewed Yanomami spokespersons in Brazil and Venezuela. These interviews produced further allegations of abuse related to the collection of blood samples and information, not anticipated by Tierney.

The first El Dorado Task Force, headed by Jim Peacock, raised questions of informed consent in connection with Tierney's allegations regarding biological materials collected by the Neel expedition and radioactive iodine experiments conducted by others. (The Task Force awaits material from Venezuela regarding these experiments.) Since bodily materials from that expedition have been distributed in US laboratories and are currently in use by federally-funded researchers, it is especially important to determine whether or not these materials were collected according to adequate and appropriate procedures of informed consent.

In attempts to locate the samples we have received extensive cooperation from Ken Weiss, curator of the blood samples at Penn State University, and D. Andrew Merriwether, of the University of Michigan, currently conducting research on data sets derived from DNA extracts from the Neel bloods. We have extensive information regarding the set of 3,500 under the curation of Ken Weiss at Penn State. An aliquot (subset) of Weiss' collection is with A. Merriwether but will be returned to Weiss. At least two other sets of Yanomami blood samples may exist. In addition, there may be fecal or urine samples but so far there is no evidence of these.

The samples under Weiss' curation consist of 1cc vials kept in a frozen condition (-80 degrees or liquid nitrogen). Weiss has expressed interest in continuing to work with these samples but will not do so until he is satisfied that the conditions under which they were collected were ethical (Weiss, pers. com., Oct. 2001). Following research protocols, names of individuals have been removed to protect donors in both blood and DNA samples.

The AAA Code of Ethics states the following with regard to informed consent: "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...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 project" (AAA Code of Ethics, cited in Laren Clark and Ann Kingsolver, "Briefing Paper on Informed Consent," AAA Committee on Ethics, Nov. 2001 update, italics mine).

I suggest, with Clark and Kingsolver of the AAA Committee on Ethics, that we regard Informed Consent procedures as an ongoing process, extending the application of procedures of informed consent into the present. This makes conspicuous sense in the case in question, given that studies of these materials are continuing in a context of ongoing debate and allegations of illegitimacy by many, including the Yanomami.

The strong agreement that emerged in interviews conducted by this Task Force, as well as independent interviews conducted outside the Task Force, show that many Yanomami perceive themselves as having been misled, misinformed, manipulated and otherwise wronged by investigators. By today's standards these wrongs would constitute violations of basic rights, including the right to informed consent. Yanomami spokespersons must be regarded as credible narrators of their own histories. Moreover, the Yanomami experience of events, even as it is recalled after a substantial lapse in time, must be respected and honored.

Interview Process

I met with and interviewed three Yanomami spokespersons: Davi Kopenawa (Demini village, Brazil, June 7, 2001); José Seripino, (Washington DC, October 2001; Xakita, Venezuela, Nov. 22, 2001); and Julio Wichato (Xakita, Venezuela, Nov. 22, 2001).

First, a word about the shortcomings of the interview process. The people I interviewed were were chosen for their availability and communicative abilities rather than through any rigourous procedures or attempts to meet standards of representativity. As a result, the three interviewees represent bilingual Yanomami, a distinct minority.

A different concern is the construction of memory through the passage of time and the debate itself. The events in question occurred over thirty years ago. If the interviewee had participated in the vaccinations or blood sampling, he would have been a child at the time. Seripino and Kopenawa seem to have recalled the experience, although they were then children of nine or ten. Wichato appears to base his information on reported speech from relatives in Torita who had been vaccinated by the Neel team.

Moreover, the debate itself has shaped the narratives, creating a collective past through various narrative resources. Each person interviewed had been affected by the debate generated by Tierney's book and had been drawn into the dialogue before our meeting. For example, Kopenawa reports, "An anthropologist entered Yanomami lands in Venezuela. Many people know about this. ...This book told stories about the Yanomami and it spread everywhere. So I remembered it when our friend [unnamed anthropologist] mentioned his name. When that young man spoke the name I remembered. We called him Waru. He was over there in Hasabuiteri... Shamatari...A few people -- Brazilian anthropologists -- are asking me what I think about this." Both Kopenawa and Seripino recall meeting with Tierney. My choice of Wichato, the third interviewee, was based on my attempt to find a spokesperson without ties to either Tierney or Chagnon. As I later learned, Wichato's friend Alfredo was one of Tierney's pilots. (The redundancy in persons interviewed is likely to be related, again, to issues of bilingualism and availability.)

Nonetheless, these interviews, however flawed, provide a strong argument and consensual case that the blood sampling procedures of the Neel expedition of 1968, as recalled, did not meet criteria of informed consent by study participants. The following allegations, made by interviewees, call for concern. They hold that:

1) the collection of bodily samples was conducted without full disclosure (see below for difficulties attached

to this standard);

2) the description of study goals contained elements of deception;

3) the duration of research and preservation of materials, not explained, offends Yanomami custom and respectful treatment of the deceased;

4) the Yanomami were treated in less than a humane manner; as stated by several, they were treated "as animals."

I here present excerpts of the narratives. See complete interviews in this set of postings.

CONSENT TO WHAT?: CONFUSION OVER GOALS

Lack of Full Disclosure

All conversations were independent; yet all speakers held that explanations that accompanied blood collection were inadequate.

Davi Kopenawa is a prominent Yanomami spokesperson. He has presented the case of the Yanomami internationally for over twenty years. Davi was raised near Toototobi, where he lost his mother to the measles epidemic and where he and his family were among those whose blood was collected by the Neel/Chagnon expedition. He first learned Portuguese through contacts with missionaries and later by working for FUNAI, the Brazilian agency charged with indigenous affairs. Kopenawa returned to the Yanomami area and trained with his father-in-law as a shaman. Davi is an effective mediator who has travelled widely on behalf of the Yanomami. For example, I have met with Davi Kopenawa 4 times, once at an international conferences in New York, twice in the city of Boa Vista, and once in his village, Demini, in the Parima highlands. This is the third interview I have conducted with Davi, and the first for this Task Force.

In interview with him, recorded in Demini, June 7, 2001, Kopenawa had this to say:

Davi: "He [Chagnon] arrived, like you, making conversation, taking photos, asking about what he saw. He arrived as a friend, without any fighting. But he had a secret...."When the doctor requested something he [Chagnon] translated it... But he didn't explain the secret. We didn't know either -- no one understood the purpose of giving blood; no one knew what the blood had inside it...."

Janet: "But he didn't explain why?"

Davi: "The Yanomami were just supposed to give blood and just stand around looking. He didn't talk about malaria, flu, tuberculosis, or dysentery. ..Husband, wife, and children went as a group. They always took the blood of one family together...It was a bottle -- a big one -- like this. He put a needle in your arm and the blood came out. He paid with matihitu -- machete, fishhooks, knives."

2. José Seripino

The lack of full disclosure suggested by Kopenawa is reiterated by Seripino for the Venezuelan case. José Seripino is a Yanomami leader of Koparima village in the Upper Orinoco in Venezuela. Active in bilingual education efforts, he represents his village in SUYAO (Shabonos Unidos de los Yanomami del Alto Orinoco) and the Yanomami people in the Venezuelan National Indian Council, CONIVE. Recently he was appointed to the staff of the governor of Amazonas state in the role of Commissioner for the Upper Orinoco. Jesus Ignacio Cardozo Hernandez is head of the Venezuelan Commission to investigate the allegations of Darkness in El Dorado. He is also president of the Venezuelan Foundation for Anthropological Research (FUNVENA) and an adviser to SUYAO.

The following comments by Seripino were made in an address by him at George Washington University in conjunction with the 2001 Meetings of the Latin American Studies Association:

Seripino: "When they [the Neel team] arrived we Yanomami didn't know -- we didn't even understand Spanish at that time. I was in school. We didn't understand. But now we've learned... We began to defend our communities by educating ourseves in primary and secondary schools. So now we know all the bad things that happened. What are the bad things that went on? Taking blood. Taking skin [biopsies] [gestures]. I saw this. I was only ten years old. I thought, 'OK. This will help us. But what happened? We haven't seen the results. We were not consulted" (transcribed, Sept. 7, 2001).

3. Julio Wichato, Nov. 22, 2001 [taped]

In order to obtain an opinion from a Yanomami who was familiar with health needs and the positive uses to which blood samples may be put, I interviewed Julio Wichato, a Yanomami nurse who has worked with the Ministry of Health in the Yanomami area at Platanal for 18 years.

"They say that Chagnon took blood. I heard this...I think that Chagnon vaccinated these people to see if they would die. These people of Torita -- they say that Chagnon vaccinated to see if the medicine worked or if it was poison. Then he would go. People started to die and Chagnon left. And they died -- all of them!"

Consent to What?: Confusion over Goals

Considered together, Kopenawa and Seripino make the case that those who participated did not understand the purpose of the sampling. Wichato's version of the vaccinations, although an obvious misunderstanding, is the most troubling because it suggests the kinds of meanings and purposes that have been attributed to the collection team over time.

These findings raise the following questions: Who is responsible for the interpretation of the researchers' explanation? Should not responsible researchers attempt to ensure that an explanation is well understood? If this is so, these interviews suggest that explanations were either insufficient or misleading. To what point in time do these responsibilities extend? Here the issue of informed consent as an ongoing process, as outlined in the Code of Ethics of the AAA, becomes relevant.

Deception: Promises Unkept

Yet another problem is the unanimous recollection of unkept promises of direct health benefits. The evidence is overwhelming that the Yanomami understood that results of the blood studies would contribute to their own well-being in combatting disease.

All three people expressed concern that results had not been provided to them. In the absense of reported results, the utility of the samples was, to them, questionable.

Davi: "...Now we are asking about this blood that was taken from us without explanation, without saying anything, without the results. We want to know the findings. What did they find in the blood -- information regarding disease? What was good? Our relatives whose blood was taken are now dead. My mother is dead; our uncles, our relatives have died. But their blood is in the United States. But some relatives are still alive. Those survivors are wondering -- 'What have the doctors that are studying our blood found? What do they think? Will they send us a message? Will they ask authorization to study and look at our blood?'"

That the collections were said to be related to health benefits is further substantiated in testimonies to the Task Force by two members of the 1968 field team, Ernesto Migliazza, a linguist specializing in the Yanomami language who accompanied the expedition, and Napoleon Chagnon. Both state that individuals were told that blood was taken so that they could look for disease inside the blood (Trudy Turner, p. 17; report to Task Force).

In a telephone interview with Jane Hill, Head of the Task Force, Migliazza stated that in each village, the Yanomami were told that the project would look for diseases that were "inside," "in the blood" (Hill transcript, June 12, 2001). In a telephone conversation with Napoleon Chagnon, conducted March 18, 2001, Ray Hames reports that "[Chagnon] said that for a year prior to Neel's arrival and during the collection phase he told the Yanomamo in all the villages to be sampled that Neel's team wanted to examine their blood in order to determine whether there were things that indicated whether or not they [had] certain kinds of diseases, especially <u>shawara</u> (epidemic diseases) and that this knowledge would help treat them more effectively."

If promises of health benefits or results were delivered, they were never kept. This is serious, since Yanomami health needs are great and medical services have been inadequate. In a different conversation I had with Davi Kopenawa in 2000, before the news of the Tieerney book, he said, "We [the Yanomami] already have an enemy among us -- it is disease." The Yanomami face serious threats to their health. Among the most serious of these are the diseases malaria and river blindness, both requiring blood collection, and, as in cases of advanced malaria, transfusions. It is therefore all the more important to ensure that collection standards are met and that promises linked to health care are not abused, in turn discrediting and thereby undermining the few health care services available.

Moreover, the possibility remains that these promises were never intended but served as instruments in motivating participation. If the Yanomami were made promises without any intent of fulfillment, this constitutes an attempt to persuade, in order to obtain samples, under false pretenses. It is a breach of ethics.

Respecting Custom: "Whatever is of the Dead"

The retention of the samples creates a potential offense to Yanomami beliefs regarding the dead and their remains.

Davi Kopenawa: "My mother gave blood. Now my mother is dead. Her blood is over there. Whatever is of the dead must be destroyed. Our custom is that when the Yanomami die, we destroy everything. To keep it, in a freezer, is not a good thing. He will get sick. He should return the Yanomami blood; if he doesn't, he [the doctor] and his children will become ill; they will suffer."

Perhaps a medical researcher cannot be expected to understand the concerns of a population not his own. This problem, however, merely underscores the importance of a participating anthropologist -- in any medical research -- whose role it is to ensure that the population has understood the goals of the procedures in which they are asked to participate. Moreover, an anthropologist, especially one who works closely with study participants over the long term, is in an opportune position to discern the concerns of participants and to address them. Indeed, I would hold that (s)he is morally compelled to do so.

Longevity of Consent

It is apparent that the Yanomami were not informed of the storage of the samples and their long-term research uses, issues that are of substantial relevance to them because of customary laws concerning death. In addition, the long-term use of samples raises questions regarding a shift in goals as explained during collection but altered over time. These concerns, again, point to the utility in approaching informed consent as a dynamic process, rather than a static procedure.

One might ask whether any investigator can anticipate the future research uses of samples? Indeed, in 1968 neither Neel nor any other collector of bodily samples could have requested and obtained consent to study DNA extracts to determine proximity of relationship or propensity for a disease. Most of the techniques currently applied to the samples were not possible in 1968. The Yanomami cannot be said to have given consent in 1968 to the uses to which DNA could be put in 2002. Not, that is, unless they gave blanket consent.

Treating the Yanomami as animals

Finally, two speakers, Kopenawa and Seripino, sum up the treatment by researchers this way:

Davi Kopenawa: "These anthropologists are treating us like animals -- as they would fish or birds."

José Seripino: "It [the blood] HAS to be destroyed! They are treating us like animals! We are human beings!

These statements well illustrate the ongoing insult to the Yanomami of past acts. They call for remedial action to correct wrongs.

"KEEPING THE PAST"

An important problemic that has emerged is the difference in perception of what is considered "beneficial" to a study population. When the narratives of Yanomami interviewees are compared with those collected from U.S. researchers, a fundamental misunderstanding emerges. The two groups are shown to be operating under profoundly different sets of values and assumptions.

For the researchers, the samples are important sources of information on genetic variation within Yanomami sub-populations as well as comparison with other populations around the world. The very ability to reconstruct relationships in and among populations over time is that which the researchers value, assuming it to be beneficial and advantageous universally and absolutely. These benefits extend to the Yanomami, who provided the materials.

D. Andrew Merriwether, who is currently studying DNA extracts made from the Neel bloods at the University of Michigan, discussed their importance: "These samples are an incredibly important snapshot in time. It would be a tragedy to lose them. I am hopeful the Yanomama people will be interested in maintaining this wonderful resource in some form. It is after all part of their own legacy. I am hopeful that we can discuss options that would honor the Yanomama concerns about their ancestors, without completely losing this window into the past" (correspondence D. Andrew Merriwether, 15 Oct 2001, italics mine).[1]

Ken Weiss, who curates the Yanomami blood samples at Penn State University, writes, "The samples have been used to understand the amount of genetic variation in Yanomami populations and how it differs among the many villages. The purpose was to see how that amount of variation compares with variation in studies of other populations around the world, including the United States. The samples were also studied for various traits related to health. Dr. Neel and his colleagues wanted to know how human genetic variation arises and how village life spreads variation around, over the generations, as people move during their lives, marry, and have children of their own." (Ken Weiss, Oct. 2001).

Again, Merriwether: "We are mostly interested in how behaviour and demographic history affect the pattern of genetic variation that we observe. Because the Yanomama have been so well studied, we know from their own oral history a great deal about how they have moved about and how villages have fissioned and joined over the past 100 years. We hope to make use of that information to inform our mathematical modeling of genetic variation to fine tune our methods. It may allow us to look back in time further than oral histories allow and let us (and the Yamomama) reconstruct much earlier times in South America. This is a direct extension of work I began with Dr. Neel in the five years preceding his death. We hope the data collected on the Yanomama may also aid in our studies of the initial peopling of South America" (correspondence, Merriwether, 16 Oct 2001).

Yanomami thinkers, however, may not assign positive value to reconstructions of their past. Davi Kopenawa described his objection to the work of Napoleon Chagnon this way:

Davi: "He arrived as a friend, without any fighting ... But, later what happened was this. After one or two months he started to learn our language. Then he started to ask questions, 'Where did we come from, who brought us here?' And the Yanomami answered, 'We are from right here! This is our land! This is where Omam placed us. This is our land...' He wrote a book. When people made a feast and afterward a fight happened, the anthropologist took alot of photos and also taped it. This is how it began. The anthropologist began to lose his fear -- he became fearless. When he first arrived he was afraid. Then he developed courage. He wanted to show that he was brave. If the Yanomami could beat him, he could beat them. This is what the people in Toototobi told us. I am here in Watorei, but I am from Toototobi. I am here to help these people. So I knew him. He arrived speaking Yanomami. People thought he was Yanomami. He accompanied the Yanomami in their feasts...taking [the hallucinogen] ebena, and after, at the end of the feast, the Yanomami fought. They beat on one anothers' chests with a stone, breaking the skin. This anthropologist took photos. And so he saved it, he "kept" the fight. So, after, when the fight was over, and the Yanomami lay down in their hammocks, in pain, the anthropologist recorded it all on paper. He noted it all on paper. He wrote what he saw..."

That which the researchers value in the reading of DNA may be what the Yanomami, as suggested by

Kopenawa, do not wish. DNA is a text that carries information about individuals -- their uniqueness and their relationships to other individuals. For the researcher that which is valued and assumed to be universally beneficial is the way DNA, as Merriwether puts it, provides "A window into the past." Because DNA carries the genetic code for each individual, and can be used in measuring the degree of (genetic) relatedness of individuals to one another, DNA, "keeps" the past and allows one to "read" the information it carries -- to read that past. In this sense, as a text that can be read for the meanings or information it carries about the past -- about individuals now dead, their relationships to one another as individuals and as aggregates -- DNA is analogous to the notes, books, photos, and other forms of "keeping the past" that concern Davi Kopenawa. This very conserving capability, enabling a reconstruction of past information is highly prized by the researcher. But it may be rejected by the Yanomami.

In a document (November 11 2001) intended for presentation to the Yanomami at theNovember meeting in Shakita village, Merriwether described his work this way:

"Over the past ten years I have worked with DNA extracted from blood samples collected from Yanomama people from Venezuela and Brazil, by Dr. James V. Neel and coworkers, and Dr. Doug Crews and coworkers. I have been interested in studying population movements and population history and evolution by looking at the patterns of genetic variation in Native American peoples. While people may only recall their history for a few generations, or even tens of generations, a person's DNA holds clues to the entire history of a person's ancestors. I have been especially interested in using genetic variation to try and infer the early histories of indigenous populations, and to use genetic variation to try and learn more about the distant pasts of these peoples. We do this by studying the populations present today, and seeing how their life-ways affect the pattern of genetic variation we find, and then use modeling and statistical approaches to see what kinds of patterns in the past could give rise to the variation we see today. Because the history of Yanomama village fissioning and mergers is well known for the past 50-100 years, and because ethnologists and biological anthropologists have studied the Yanomama culture and history, we can see how well these genetic techniques can capture the events that we know to have happened. This detailed knowledge of population movements and village histories make the Neel collection of Yanomama bloods and DNAs unique. Further, because most of these samples were collected before much of the recent upheavals by disease and violence, they represent a critical snapshot in time of the Yanomama people. Maintenance of this genetic resource will also help ensure that this important documentation of Yanomama history will not be lost" (Merriwether, Nov. 11, 2001).[2]

The Ethics of Collection: Researchers' Viewpoints

Both Ken Weiss and Andrew Merriwether have expressed interest in continued work with the samples. Both have said that they assume the samples were collected in accordance with ethical norms.

For example, Ken Weiss writes, "My understanding has been that these samples were obtained from Yanomami who volunteered to participate in Dr Neel's studies, and that the samples were exchanged in a fair way for various goods that were of value to the Yanomami as the blood samples were of value to Dr Neel. I also believe that his general explanation of the use of the samples was honest and reflects what has been done with the samples." In a different correspondence, Weiss writes, "I believe that my use of the samples has been completely proper, dignified, and respectful of the Yanomami" (October 2001).

Weiss has expressed opposition to the ongoing study of the bloods without adequate and authorizations from the Yanomami. Weiss limited his research in ways he thought protected Yanomami rights: "These samples have been analyzed by many scientists. I have done some of that work, but I have not studied questions that I thought would not be right to study. For example, I have a student who wanted to study some of the specific genealogies (families). But my understanding is that the names of ancestors that we would to use for such work were obtained in a way that may not have been proper, such as by paying enemies of a person to provide names of that person's ancestors. So I did not allow my student to use the genealogical information in his work" (Weiss Oct. 2001).

Weiss describes the conditions under which he would continue studying the Neel samples: "I would like to have the Yanomami's permission to continue to study these samples. I would not to reveal the names of specific individuals (I do not know these names). If there were any way in which these samples would be of monetary value, I would either refuse to do that, or would make arrangements so that the Yanomami would receive benefits, but I do not think this is likely to happen (and as far as I know, nobody has made money from these samples)."

On another occasion, he writes, "I would like to keep able to use these samples, and I think I have not done anything questionable in using them. But I also realize that the Yanomami have had a rough time and that they attribute many evil things that happened to them to the trips that were made there 25 years ago. I have no interest in offending them, nor can I defend (or assail) those who collected the samples, since I was in no way involved" (Ken Weiss 30 Sep 2001).

In addition, Weiss has offered the following statement: "I and other scientists who have these samples would like to be able to continue studying them. But if this is not the wish of the Yanomami, I would not do so. I would also be willing to return samples to the Yanomami to do the ceremonies that honor the individuals who were sampled. But these samples are mostly anonymous, and were collected so long ago (and not by me) that I might not be able to identify which samples belonged to which people. I wonder if it would be most appropriate, and most honoring of the Yanomami whose blood made a contribution to science, to send back to the Yanomami a representative set of samples that could be honored in the name of all the individuals whose blood was taken, over so many villages and so many years. Even if I cannot identify each individual, I could for example return a sample from each of the villages that were visited. But before I could do this, we would need to work out an understanding of which samples should be returned, how they should be prepared and sent, and whether other laboratories need to participate in this symbolic gesture of tribute to the Yanomami and their contribution to world science."

Merriwether ensures participant protections. Samples were given ID numbers upon collection and again in the laboratory, making it impossible for anyone (other than Merriwether) to connect the genetic information with a specific person or family. Merriwether explains, "I keep the records in a locked office, in locked filing cabinets, that only I have the key for. The computer records do not contain any names at all. The names are only connected to the ID numbers on the original hard-copy participant sheets" (Merriwether Nov. 11). (It should be noted that the very anonymity of the sample intended to protect the individual precludes his receiving any benefits from the collection.)

Merriwether intends to return the bloods, now in his care in the department of anthropology at the University of Michigan, to Ken Weiss, at Penn State, and to continue working only with the DNA extractions. He writes, "I am, and always have been willing and eager to discuss my research and my field of research with the native peoples I study, and if this commission allows a dialogue to open up between the two groups, then this is likely to be a good thing" (Merriwether, 14 Oct 2001).

The Ethics of Collection: The Task Force Viewpoint

Whether the individuals subject to allegations acted for honorable motives or not, the point remains that with the passage of time thoughtful anthropologists and the Association itself have come to view those actions (including methods of collecting information) as reprehensible and unjustifiable -- acts that may have wronged, intentionally or not, the Yanomami. The strong agreement that emerged in interviews conducted by this Task Force, as well as independent interviews conducted outside the Task Force, show that many Yanomami perceive themselves as having been misled, misinformed, manipulated and otherwise wronged by investigators. By today's standards these wrongs would constitute violations of basic rights, including the right to informed consent. Yanomami spokespersons must be regarded as credible narrators of their own histories. Moreover, the Yanomami experience of events, even as it is recalled after a substantial lapse in time, must be respected and honored.

In Trudy Turner's report to the AAA Task Force on El Dorado, she writes, "We believe that the informed consent techniques used by the 1968 expedition would not measure up to contemporary standards" (Turner/Task Force 2002).

Turner, who interviewed medical researchers practicing similar methodologies at the same time points out, "It was not until the 1970s that additional clarifications and standards were set [in Infomant Consent Codes]." I would argue, however, that it would be wrong to condone past abuses on the basis of their commonality. I draw upon the language of the AAA Code of Ethics (Clark and Kingsolver, Nov. 2001) to reiterate that Informed Consent may be, indeed, should be, treated as an ongoing process, extending the application of procedures of informed consent into the present.

Discussion and Recommendations

It should be understood that the uses to which these samples can be put is limited. Neither the blood samples nor the DNA extracts contain living cells. they cannot, therefore, be cloned. That the individual samples have been separated from the names of the donors suggests that linking genetic with behavioral data would be difficult, if not impossible. So, for example, these samples could not be used to test a hypothesis regarding killings per person and reproductive success. While a reproductively-successful male could be identified by number it would be nearly impossible to link this finding to any behavioral, i.e., ethnographic, data. However, the samples are identified at the level of "village" or "community," and could easily be used to measure genetic relationships among groups and populations of several levels. They can also be used to compare the Yanomami, as a population, with other populations. It should also be known that no patens or profits have been made from the blood samples.

At the same time, the possibility remains that the Yanomami have not, to this day, received adequate and comprehensive information regarding the uses of their blood samples. It is here that the issue of informed consent as an ongoing process becomes relevant.

The Yanomami interviewed drew a distinction between sampling for purposes of health and sampling for purposes of investigation. They favored the first but objected to the latter. Testimonies collected from Yanomami by the Task force are unanimous in opposing further investigative research use of the samples at this time.

For the scientists involved, the benefits of knowledge to be gained are here assumed to have universal value. The crime of the anthropologist, however, according to Davi Kopenawa, is keeping the past -- a crime of keeping unauthorized information. This presents a dilemma that affects not one researcher, but the discipline.

Suggestions

The suggestions raised in the three interviews were (these choices are not mutually exclusive): 1) to return the blood; 2) to destroy the blood; 3) to compensate for research use.

Return or Destroy

Julio Wichato's suggestion is that the samples be destroyed: "They can never use this blood. They can never study it. They should send the results or destroy it or send it back. But they cannot study it. Never." Even with compensation, Wichato does not allow for continued research use. This is surprising, perhaps, since Wichato, of all the Yanomami interviewed, is the most accustomed to drawing and freezing blood for medical purposes.

José Seripino: "ONLY if it is impossible to send should it be destroyed here. It HAS to be destroyed! They are treating us like animals! We are human beings!

Davi: "The blood of the Yanomami can't stay in the United States. It can't. It's not their blood. [Janet: So this is a request for those who have stored the blood?] "I am speaking to them. You take this recording to them. You should explain this to them. You should ask them, "What do you Nabu think?" In those days no one knew anything. Even I didn't know anything. But now I am wanting to return to the issue."

Respecting Custom: "Whatever is of the Dead"

The retention of the samples creates a potential offense to Yanomami beliefs regarding respect for the dead and the treatment of their remains.

Davi: The blood of the Yanomami can't stay in the United States. It can't. It's not their blood. [Janet: So this is a request for those who have stored the blood?] "I am speaking to them. You take this recording to them. You should explain this to them. You should ask them, "What do you Nabu think?" In those days no one knew anything. Even I didn't know anything. But now I am wanting to return to the issue." "My mother gave blood. Now my mother is dead. Her blood is over there. Whatever is of the dead must be destroyed. Our customs is that when the Yanomami die, we destroy everything. To keep it, in a freezer, is not a good thing. He will get sick. He should return the Yanomami blood; if he doesn't, he [the doctor] and his children will become ill; they will suffer."

The Brazilian NGO, Comissao Pro-Yanomami published this statement in its Dec. 20, 2001, Boletim Yanomami:

Regarding the Yanomami blood that is deposited in U. S. laboratories, especially Penn State, Davi Kopenawa sent this message to participants of the annual meeting of the American Anthropological Association: "I would like to speak about this book and to talk about the blood of my relatives that was carried [all the way] over there and that is today kept in freezers. I don't know what they want to do with this blood, why they are keeping it. But I don't want to go there merely to talk -- I want to decide something. I want them to return the blood to me or to bring it to Brazil and pour the blood in the river so that the spirit of the xapori (shaman) is content." (Dec. 20, 2001)

Met with under separate and independent circumstances, Davi Kopenawa, of Brazil, and José Seripino and Julio Wichato, of Venezuela, all state that the samples must be returned or destroyed. All emphasized the importance of "knowing" the status of the samples.

Compensation

Davi, "I think that Yanomami blood is O positive. Is it useful in their bodies? If that's the case, and our blood is good for their bodies -- then they'll have to pay....If it helped cure a disease over there, then they should compensate us. If they don't want to pay, then they should consider returning our blood. To return our blood for our terahonomi. If he doesn't want to return anything, then lawyers will have to resolve the issue. I am trying to think of a word that whites do...sue. If he doesn't want to pay, then we should sue. If he doesn't want a suit, then he should pay. Whoever wants to use it, can use it. But they'll have to pay. It's not their blood. We're asking for our blood back. If they are going to use our blood then they have to pay us."

José Seripino: "Chagnon ... never kept his promise to the community. Xakita -- with the founder -- he worked with this man closely. Now -- he died three weeks ago -- he promised this person a motor and he disappeared without giving it. He never paid that debt."

Weiss: "If there were any way in which these samples would be of monetary value, I would either refuse to do that, or would make arrangements so that the Yanomami would receive benefits, but I do not think this is likely to happen (and as far as I know, nobody has made money from these samples)."

Suggested forms of compensation

The missionary, Mike Dawson, who served as Yanomami translator at the Shakita conference, reported that a recent meeting was held among Venezuelan Yanomami in which they elected to request compensation in the form of collective health benefits (correspondence, Jan. 2002). Dawson writes that he was asked to transmit this decision to the Association. I have asked for details on this meeting, but Dawson is temporarily out of contact.

While at the conference in Shakita, I interviewed Guillermo Domingo Torres, Coordinating Physician for the Orinoco District with the Ministry of Health. Here is our conversation (Nov. 24, 2001, Shakita, Upper Orinoco, Venezuela):

Torres: "Regarding the question of the Yanomami and obtaining samples, I think the best at this moment is to only take samples when there is a specific problem to resolve. We call this "operational investigation" or "applied research." We are only [carrying out research that is related] to solving a current problem. If they will continue research and want to continue their presence it must be in order to solve problems, not to gather knowledge about ethnicity. But there are times, as in the year 1996, when there was an epidemic and 15-20 died it was necessary to draw blood to test for malaria, [inaud], hemorragic viruses. This is justified. Also, in 1998 it was also justifiable to take samples. It is justifiable when it is used to solve a specific problem. When there is a special problem, they ask for help and they [the Yanomami] will give the authorization. This is different from when investigators/researchers arrive with a large research project that they have. If the Yanomami don't think it responds to a problem they have now and in the future. The Yanomami feel that they have been unjustly treated -- they have been studied alot, alot of blood has been taken, but this hasn't resulted in improvements in their health conditions. There are books of information, registers of antibodies, genomic sequences.... But, in sum, there haven't been any direct repercussions [for them] of these studies. But not in function of resolving problems and they feel that they want responses, to say epidemics -- prevention, application. I also think they want to restrict the extraction of blood to people of the Ministry of Health or others in which they have confidence."

Chernela: "And if this experience were to be transformed into something positive -- what would that be? Could that happen? Let's imagine that they are not going to continue. If there is a way to fransform this "flawed" (bad) experience into a good one -- what could be done? Could, for example, there be a transference of resources to assist in Yanomami health?"

Torres: "Yes. I think so. I suggest going through CAICET...because they have the most experience...and the Yanomami would be most directly affected by assistance going through CAICET."

Conclusions and Recommendations

If we treat Informed Consent as a process, rather than a framed, discrete, occurrence, the negligence in the 1968 collection procedures might be remedied. This would involve extending the application of procedures of informed consent into the present. A committee might be established to look into the terms of (1) returning and destroying samples, as well as offering (2) reparations. I have outlined a case for repartions in a separate document.

I close this report with a citation from Davi Kopenawa, in which he addresses the American Anthropological Association:

Davi Kopenawa Yanomami to the American Anthropological Association

"I don't like this, no. I don't like these anthropologists who use the name of the Yanomami on paper, in books.... For us Yanomami, this isn't good. They are using our name as if we were children. The name Yanomami has to be respected. It's not like a ball to throw around, to play with, hitting from one side to another. The name Yanomami refers to the indigenous peoples of Brazil and Venezuela. It must be respected. This name is authority. It is an old name. It is an ancient name.

"Anthropologists who enter the Yanomami area -- whether Brazil or Venezuela -- should speak with the people first to establish friendships; speak to the headman to ask for permissions; arrange money for flights.

"An anthropologist should really help, as a friend. He shouldn't deceive. He should defend...defend him when he is sick, and defend the land as well...saying "You should not come here -- the Yanomami are sick." If a Yanomami gets a cold, he can die.

"So now I think that the Yanomami should no longer accept this. The Yanomami should not authorize every and all anthropologist who appears. Because these books already came out in public.

"If it helped cure a disease over there, then they should compensate us. If they don't want to pay, then they should consider returning our blood. To return our blood for our terahonomi. If he doesn't want to return anything, then lawyers will have to resolve the issue. I am trying to think of a word that whites do...sue. If he doesn't want to pay, then we should sue. If he doesn't want a suit, then he should pay. Whoever wants to use it, can use it. But they'll have to pay. It's not their blood. We're asking for our blood back. If they are going to use our blood then they have to pay us.

"The blood of the Yanomami can't stay in the United States. It can't. It's not their blood.

Janet: "So this is a request for those who have stored the blood?"

Davi: "I am speaking to them. You take this recording to them. You should explain this to them. You should ask them, 'What do you Nabu think?' In those days no one knew anything. Even I didn't know anything. But now I am wanting to return to the issue. My mother gave blood. Now my mother is dead. Her blood is over there. Whatever is of the dead must be destroyed. Our customs is that when the Yanomami die, we destroy everything. To keep it, in a freezer, is not a good thing. He will get sick. He should return the Yanomami blood; if he doesn't, he [the doctor] and his children will become ill; they will suffer.

[I ask if he has message.]

"I don't know the anthropologists of the United States. If they want to help, if ...you whites use the judicial process .."

Janet: "Would you like to send a message to the American Anthropology Association?"

Davi: "I would like to speak to the young generation of anthropologists. Not to the old ones who have already studied and think in the old ways. I want to speak to the anthropologists who love nature, who like indigenous people -- who favor the planet earth and indigenous peoples. This I would like. This is new, clean, thinking. To write a new book that anyone would like, instead of speaking badly about indigenous peoples. There must be born a new anthropologist who is in favor of a new future. And the message I have for him is to work with great care. If a young anthropologist enters here in Brazil or Venezuela, he should work like a friend. Arrive here in the <u>shabono</u> (longhouse). He should say, "I am an anthropologist; I would like to learn your language. After, I would like to teach you." Tell us something of the world of the whites. The world of the whites is not good. It is good, but it is not all good. There are good people and bad people. So, "I am an anthropologist here in the shabono (longhouse), defending your rights and your land, your culture, your language, don't fight among yourselves, don't kill your own relatives.

"We already have an enemy among us -- it is disease. This enemy kills indeed. It is disease that kills. We are all enemies of disease. So the anthropologist can bring good messages to the Indian. They can understand what we are doing, we can understand what they are doing. We can throw out ideas to defend the Yanomami, even by helping the Yanomami understand the ways of the whites to protect ourselves. They cannot speak bad of the Yanomami. They can say, "The Yanomami are there in the forest. Let's defend them. Let's not allow invasions. Let's not let them die of disease." But not to use the name of the indian to gain money. The name of the Indian is more valuable than paper. The soul of the Indian that you capture in your image is more expensive than the camera with which you shoot it. You have to work calmly. You have to work the way nature works. You see how nature works.

It rains a little. The rain stops. The world clears. This is how you have to work, you anthropologists of the United States.

"I never studied anything. But I am a shaman, hekura. So I have a capacity to speak in Yanomami and to speak in Portuguese. But I can't remember all the Portuguese words."

NOTES

References Cited

Merriwether, D.A., Kemp, B.M., Crews, D.E., and Neel, J.V.

2000 'Gene flow and genetic Variation in the Yanomama as revealed by mitochondrial DNA', in America Past, America Present: Genes and Languages in the Americas and Beyond, ed. C. Renfrew. (Papers in the Prehistory of Languages.) Cambridge: McDonald Institute for Archaeological Research, 89-124.

1.Merriwether has used the DNAs in NSF-funded research relating to the molecular evolution of the Yanomami (Merriwether, correspondence, Oct 16, 2001). One paper on these findings has been published (Merriwether et al. 2000) and others are underway. One graduate student is writing a dissertation on the findings.

2.The organizers of the Shakita conference requested no public discussion of collection of blood samples, fearing it would endanger their own health efforts.