HEALTH, DISEASE AND HEALING IN THE LARGER SOCIAL CONTEXT POPULATION GENETICS PROJECT IN SANTIAGO ATITLÁN, GUATEMALA

- I. Today I will present a case study of a medical project in Guatemala in the late 1960s
 - A. To illustrate several of the issues that can complicate medical research and international development projects related to health
 - 1. And to illustrate how institutional research boards have changed informed consent practices since that time
 - B. The study was concerned with the population genetics of the communities on Lake Atitlán in highland Western Guatemala
 - 1. NSF-funded project; researchers from Stanford Medical School and the Anthropology Department
 - 2. The design called for two summers of pilot projects to take place prior to the 3-year project itself
 - a. I participated during the second summer in 1966
 - b. Other participants were
 - 1) The Principal Investigator from Stanford Medical School, Howie
 - 2) A faculty member of the Anthropology Department, Cliff
 - 3) A graduate student in Anthropology who was finishing up a year of dissertation fieldwork, Bill¹
 - 4) An intern, Dave
 - 5) Me
 - c. The plan was to get established and then the two senior men would leave, Dave and I would do the work
 - C. Obtaining blood samples for clinical or research work was known to be difficult in

¹ See Bill Douglas, "Santiago Atitlán" in Seminario de Integración Social Guatemalteca, *Los Pueblos del Lago de Atitlán*, 1968: 229-276.

Population Genetics Project in Santiago Atitlán, Guatemala

Mexico and Central America

- 1. Our strategy: medical service in exchange for blood samples
 - a. Taken as part of a physical exam
- D. We experienced utter failure in the first town during the first part of the summer
 - 1. And total success in another nearby town during the second part
- E. The analysis that follows that tries to explain why such different outcomes
- F. Comparing the outcome in the two towns is an example of a *controlled comparison*
 - 1. Much was held constant
 - a. Same time period
 - b. Same research team
 - c. Same project
 - d. Almost the same place
 - 2. Controlled comparisons hold everything constant except the dependent and independent variable you're studying
 - a. This means that hypotheses about what factors made the difference are stronger
 - b. The fewer the variables that might be affecting the outcomes, the better
 - 3. The first town was Santiago Atitlán
 - a. Tzutujil-speaking (a Mayan language)
 - b. Population about 9,000, vast majority indigenous
 - 1) About 100 Ladino (non-indigenous) families
 - 4. Cerro de Oro was 10 kilometers by dirt road from Santiago
 - a. Population 1500

- b. Kachikel speakers
- c. No Ladinos except for 2 couples who were schoolteachers

II. Santiago experience

- A. We provided physical exams and took bloods for about two weeks
 - 1. We knew enough to expect difficulties
 - a. Other research projects in Mesoamerica had had problems
 - 1) Researchers had been run out of town
 - 2) Lots of rumors had circulated in these other sites
 - a) For example, the gringos were going to sell blood
 - b) Eat the blood
 - c) Do sorcery with it to steal babies and eat them
 - b. A widely held idea in Mesoamerica was that we only have so much blood
 - 1) It cannot be replaced except with transfusions
 - a) But transfusions are dangerous
 - 2. Then the remaining research assistants quit
 - a. These four men had been working all year for Bill
 - b. One had already been fired
 - 3. After 2 weeks, no one was coming to the clinic
 - a. Not even with pressuring from Catholic priests who were cooperating with us
 - b. The diocese of Oklahoma was in charge of the parish of Santiago
 - c. They'd set up a clinic and hired a physician who came in bi-weekly

from Guatemala City

- 4. We found out that lots of rumors had been circulating
 - a. Not just about our taking blood
 - b. But were saying the men were looking up the women's blouses, etc.
- 5. This was sad for Bill, who had worked there for a year
 - a. His research assistants quitting was a disappointing blow
- B. We consulted with the Catholics, and worked out another venue
 - 1. Cerro de Oro
 - 2. Which had asked for a clinic
 - a. And had built one with Alliance for Progress funds
 - 1) But still had no health care
 - 3. The basic research plan was the same
 - a. I would collect histories
 - b. Dave would do exams
 - c. We would take blood samples as part of the overall exam
- C. Tremendous success
 - 1. Delivered much-needed health care
 - 2. Collected comprehensive genealogies and blood samples from many families
 - 3. Town was very pleased with the project
- III. Factors influencing the outcomes
 - A. Cultural differences
 - 1. Santiago was the center of traditional healing, who were called *zaharines*

- a. They were also seen as sorcerers
 - 1) Although sorcerers were located in other towns
 - 2) The best black magic was considered to come from Santiago Atitlán
- b. Maxim'on, a 3 $\frac{1}{2}$ foot high statue, was a complicating figure
 - 1) Was housed in a *cofradía* (brotherhood, fraternal organization) house, and was taken care of by a *cofradía*, Santa Cruz
 - 2) Like the other saints (for example, Santiago Matamorros, the patron saint
 - a) There were 10 cofradias in all
 - 3) He was considered to be the fourth brother of Jesus
 - 4) He was in charge of shamanic healing, magic, sorcery
 - 5) A very ambivalent figure
 - 6) Can be seen as a supernatural agent of social control
 - a) For example, if women were out alone at night, they ran the risk of being raped by *Maximón*
 - 7) He was dressed like a *ladino*, in a suit coat
 - a) Big black felt hat
 - b) Big cigar in his mouth (cornhusk face)
 - 8) During Semana Santa (Holy Week) he was converted into the Judas figure
 - a) And taken into the plaza in front of the church and hanged
- c. All of this was greatly disapproved of by the Catholic priests

- 1) A book, *The Scandals of Maximón*² as written about a conflict with the Catholic clergy in 1948
 - a) The priests hated this "saint's" *cofradía*; forbade them to bring the saint into the church—as they could do with other saints
 - b) The priests arranged to have Maximón stolen, and he was taken to the Musée de L'Homme in Paris
 - c) But there was such an outcry that he was finally returned
- 2) This conflict had not been forgotten by the inhabitants of the lake's towns and villages in 1966
- 2. Western medicine practitioners were to some degree in competition with local healers
 - a. And there had been serious conflicts between non-Catholic beliefs and practices, and orthodox Catholicism
 - b. Perhaps the non-Catholic aspects of the very syncretistic religion were stronger in Santiago Atitlán than in Cerro de Oro
- B. Second difference: How project was introduced
 - 1. Cerro de Oro had a felt need for Western medicine
 - a. Whereas Santiago had many highly respected native healers
 - 1) As well as the Catholic clinic
 - a) With whom we were seen to compete, although we tried to minimize this appearance
 - b. The people of Cerro de Oro were certainly getting more of what they'd asked for
 - 1) This case underlines the importance of "felt need" in all interventions, all development projects

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² Michael Mendelson, *The Scandals of Maximón*, 1966. Originally published in French in 1952

- 2) We provided medical service in the town
- c. We arranged for permanent local health care delivery after we left
 - 1) The Catholics agreed to supervise it: make weekly visits
 - 2) You can't set up a temporary clinic
 - 3) If you leave after several months, people are worse off
- C. 3rd difference: How the project was evaluated by the community
 - 1. There was a competition problem in Santiago:
 - a. "We can go to the Catholic mission clinic when we're sick"
 - b. No competition in Cerro de Oro, quite the opposite
 - 2. In Santiago, precisely in order to not appear to be competing
 - a. We were providing medical exams, preventive medicine
 - 1) Not acute care
 - 2) When someone was found with something wrong, we sent them to the Catholic clinic
 - b. But this discredited our M.D.s
 - 1) Since they were just diagnosing, they weren't seen as proper doctors
 - c. We gave out little pills (for iron), but Latin Americans know injections are far more effective
 - d. Howie would give out the pills saying "hierro" (iron)
 - 1) To make you strong, build up your blood
 - a) Didn't fit into local understanding of blood
 - 3. In contrast, although Cerro de Oro didn't really buy the notion of preventive physical examinations either

- a. We had plenty of opportunity to demonstrate our treatment contributions
- b. Right at the beginning a very serious case of scabies was brought in that cleared up right away with penicillin
- c. Worm medicine, etc.
- d. And several advanced cases of T.B.
 - 1) Which improved a great deal over the course of the summer
- D. The fourth reason is the effects of the trajectory of our stay
 - 1. First, early on in Santiago Atitlán Howie took blood from a 1-yr. old baby—ill-advised
 - 2. Second, the Cerro de Oro experience followed the Santiago one, and we'd learned from our mistakes
 - 3. Third, a possible additional factor might be the other project I was carrying out in Santiago Atitlán:
 - a. I was interviewing midwives
 - 1) And interviewing 2 samples of women: those with large families, and women who were "spacers" in their reproductive histories
 - b. Possibly rumors went around about overly inquisitive gringos, asking too-personal questions
 - c. And my research assistant in Santiago was a Protestant
 - 1) And there was a lot of conflict between Catholics and evangelical Protestants
 - 4. Fourth, Santiago was simply less of a homogeneous town
 - a. Much bigger
 - 1) More factions, less face-to-face interaction, many more outsiders (the boat stopped there; buses came up from tropical lowlands)

- b. May have contributed to the outcome
- E. Social Differences is the fifth analytic category in our controlled comparison
 - 1. The men with the most authority in Cerro de Oro were identified with the project
 - a. The Mayor (show photograph)
 - b. Whereas this was not true in Santiago at all
- F. Sixth: Relations with outsider Guatemalans
 - 1. The schoolteachers in Cerro de Oro were Ladinos (non-indigenous)
 - a. But were very respected and appreciated
 - 2. Whereas Ladino-Indian relations in Santiago were very conflictual

IV. Discuss:

- A. Institutional Review Boards and Informed Consent
 - 1. What would be different about our research protocol today, do you think?
 - 2. Inhabitants of both towns who came to our clinic were not told about the nature of the project
 - 3. No institutions required informed consent forms to be signed by indigenous people from third world countries at that time
 - a. How would you explain the project to a resident if you were doing this kind of research?
- B. Discuss: the Yanomami (Venezuela and Brazil indigenous groups) scandals
 - 1. Following publication of Patrick Tierney's *Darkness in El Dorado*
 - 2. In the fall of 2000
 - 3. Also population genetics research
 - a. James V. Neel, Napoleon Chagnon
- V. Final, very sad note
 - A. Everyone we worked with was killed in the repression during the civil war of the 1970s and 1980s that resulted in 200,000 deaths
 - 1. Santiago Atitlán was hit very hard