

**Janis Faye Hutchinson, Ph.D., M.P.H.**

Janis Faye Hutchinson, Ph.D., M.P.H. is a biological/medical anthropologist in the Department of Anthropology, University of Houston. I received my doctorate from the University of Kansas; master's and bachelor degrees from the University of Alabama. My research interests include condom use, HIV/AIDS, racism and health, and health issues among African Americans. Currently I am examining the impact of new genetic information on health beliefs among Indian Americans in Houston, Texas. In this endeavor I conducted focus groups to engage community members in discussions about human genetic variation research and the potential for genetic variation research to affect the community's interpretation of ethnic identities. Also, I conducted focus groups to examine peoples' beliefs about personalized medicine. These sessions focused on the pros and cons of traditional versus a personalized approach to health care. My publications focus on these topics and race as shown in "The Coexistence of Race and Racism: Can They Become Extinct Together" and "Power, Race, and Culture: The Evolution of a Black Anthropologist."

# **INDIAN/HINDU PARTICIPATION IN GENOMIC RESEARCH**

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With the mapping of the human genome and development of the HapMap Project, inclusion of diverse populations in genomic research is essential. Historically, there has been a paucity of minorities in genetic research. This has been due to a variety of reasons. However, not all minorities share the same history in terms of inclusion in medical and genetic research and not all minorities are resistant to such research. Identifying reasons why diverse ethnic groups will or will not participate in genomic research will be of great value to the HapMap and other genomic studies. The current project is a case study examining reasons why Indian/Hindu Americans are willing to participate in genomic research.

## INDIAN/HINDU PERSPECTIVES OF GENETIC RESEARCH\*

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## Affirmative Action for Clinical Trials

NIH 1993

### Reasons for not including minorities

- Time consuming
- Expensive
- Hard to recruit

### BASIC HEALTH CARE\*

- 1) Degree of benefit
- 2) Likelihood of benefit
- 3) Duration of benefit
- 4) Cost, and
- 5) Number of people who would benefit

\* American Medical Association, 1994

## Right to Fair Consideration

- African Americans
  - Tuskegee Syphilis Study
  - Racism
- American Indian/Alaskan Natives
  - Political, cultural, religious, historical issues
  - Theft and respect
  - Stigmatization

Table 1. Examples of Themes and subthemes identified through analysis of transcripts

1. Medical Information
  - a. Benefits of predictive medical tests
  - b. Concerns about privacy, stigma, discrimination
  - c. Voluntary disclosures
2. Medical (non-genetic) research
  - a. Benefits of medical research
  - b. Concerns about medical research
  - c. Conduct, practice of researchers
3. Genetics, stem cells, and society
  - a. Benefits of genetics
  - b. Concerns about genetics and society
  - c. Conduct of genetic researchers
  - d. Playing God
  - e. Cloning concerns
4. Blood and tissue donation
  - a. Benefits of donation
  - b. Concerns about, trust in donation
  - c. Conduct, practice of donation
  - d. Ownership, control, right to information

## Karma

- Our basic philosophy is trinity. Trinity means we believe there are three basic things: matter, soul and God. God to us is all pervading. It is not something that is static and sitting on one place. It is matter through which this world came out of. And the third thing is soul. Regarding soul we believe in transmigration: the circle of life and death. And that circle is according to our Karma. Our deeds become our destiny.
- The basic traditional way of life there [in India] is that if you do anything wrong in a previous life, it will come out in this life.

- "betterment of humanity"
- "benefit the human race"
- "increase the lifespan of the human race"
- "increase the quality of the offspring"

## "Knowledge is Power"

- I think it is important to know, like for example diabetes or high blood pressure. You need to know what can be done to prevent it or delay it and I think that's important. That's important that we learn what's involved with a disease.

## Reincarnation

- I asked my mother, I want to give my eyes to this. And my mother, but she said when you reincarnate after rebirth you will not have eyes if you donate eyesight.
- There are other issues involved, like, some people do not [want] parts being cut or disturbed after the body dies because they think, they believe that the soul will come around and the soul will see what the body is going through.

- The reincarnation of our sense, of our body parts, that really goes to blood, if you donate eyes, our eyes. That's a kind of reincarnation.
- And if it's a tissue which, while I'm living, if I end up donating a tissue that's fine. But I don't want to do anything after I am dead. So I'm possessive of my dead body in a way. I don't want it to be messed up.

## CONFIDENTIALITY

- And also that's why confidentiality I feel is extremely important in the research of any type because you don't want anything going back to the people who contributed towards the research because you don't know what's going on in individual lives but what once that has been contributed, the names of the people I feel should not even be revealed to anyone.

## "quality of the relationship"

- But there is always a taboo, you know, maybe the first circle I have no problems, my parents, my brothers. Anybody outside, I don't care for it [for them to know].

- I don't want my mom to know that I am at the highest risk of cardiovascular disease, and I, I have a highest risk, and I am also going to have it because she will go. She's eighty-seven, ninety years old. I don't want her to know that I have it because it will hurt her feelings. I mean, she will be thinking and depressed.

- The father has a disease to hide, the mother doesn't know. Generally if the mother has, the father will come to know. Whatever father has, mother doesn't know.
- I would tell all things to my wife. And it's all things. Yeah, it's always better to tell them everything. Honestly.

## THE RESEARCH ORGANIZATION

- I think the organization plays a much greater role than an individual in that organization because I know once the blood is gone it is going to touch multiple lives so it is not going to be an issue of who the individual is involved because there is no way I can now who it is individually but if you know an organization, you may have a history of that organization and realize that this is the kind of stuff that they have done in the past and this is what they are capable of doing and you may have a better idea of how well they handle their data and how well they are able to control what they produce.

## RESEARCHER

- An Indian bodied person is going to help a lot within the community because the outside, particularly the scientist as a white person or just an outsider from the community. For an outsider to come in and do it alone you'd have a little more opposition.

- I would like to know the spirituality of the practitioner, whether he be Hindu, Christian, Muslim or whatever. I would like to see his broad set of values that he believes in, irrespective of what faith he is in.

- I think the responsibility of the researcher should be to make sure there is no negative impacts of the input you receive. It is the responsibility of the researcher or the research organization to ensure that our interests are protected.

## CONDUCT OF RESEARCH

- The motivation should be, you know, to help the humankind. Not to make money, you know? Of course, making money as a by-product is okay but for the sole purpose of making money, no I don't think so.
- We wouldn't want, like, our blood to be used on a commercial basis. Yes, because it's essentially a donation. I'm not selling my blood.

- And a lot of times the problem has been when they didn't report adverse outcomes.
- When you are doing research, be honest and put everything on the table. And just because you saw a few positives and a lot negative, hide the negative data or else risk factors outside and keep only so called only good things out whatever you are planning, what you are planning to show. They are not good. That's how the Pfizer got into trouble and Merck got into trouble because it is nothing but the money went into the business.

## GENE THERAPY

- Most striking thing what he said is in Hinduism the belief is if you are doing in genetic remodeling or whatever for improving somebody's condition, this process, Hindus are okay with them.

## STEM CELL RESEARCH

- it is acceptable within our religious practice to perform this type of scientific research because life wasn't sacrificed, as long as the life wasn't sacrificed for the intent of doing research. So as a Hindu I am comfortable with the idea that you know if it was like embryos produced for fertilization or embryos that would be discarded post abortion if scientists want to perform research on those embryos I am perfectly comfortable with that.

## OWNERSHIP OF DONATED SAMPLES

- But once we are alive and we are giving our blood to anybody then we own our body and our blood.
- But when other people need it, we need to give it. But this is my blood, and I basically own my blood.

## OWNERSHIP OF DONATED SAMPLES

- If our blood is going to the criminal or it is up to God. We give it as a donation.
- Because once you donate, it's gone. It's gone. It doesn't matter, you know, who has got it.
- Once it is outside of my system.

## CONCLUSIONS

- Spiritual beliefs
- Confidentiality and disclosure
- Genomic Medicine fits into traditional beliefs
- Not all minorities are the same



