

Ethical, Legal, and Social Issues of Toxicogenetic Research with Working Populations

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Acknowledgement

- Funded provided by the National Institutes of Health R25 ES012089

Session Overview

- Describe current trends of toxicogenomic research with working populations.
- Compare and contrast the major advantages and challenges of toxicogenomic research from the perspective of scientists and advocacy representatives.
- Describe methods of culturally appropriate genetic research with vulnerable populations.

Significance of the Study

- The number of research studies incorporating genetic markers has increased.
- Genetics has become a major part of the exposure – disease question.
- Significant ethical issues related to obtaining and applying genetic data from working populations.

Significance of the Study: Ethical Concerns

- Individual consent is a cornerstone of ethical research.

BUT....

- What is the role of community consultation and consent in gene-environmental research with vulnerable populations?

Case : PON 1 Gene Farmworker Pesticide Exposure Studies

- Paraoxonase (PON1) is a liver and plasma enzyme that hydrolyzes the active metabolites of several organophosphate insecticides.
- Low activity of the enzyme is hypothesized to result in increased risk of toxic health effects associated with exposure.

Research Design

- Qualitative/Exploratory
- Interviews with scientists (8)
 - Engaged in farmworker or pesticide research in past five years
 - Duplicate interviews from same team/institution avoided
- Interviews with farmworker advocates
 - Legal aid associations (6)
 - Trade unions (2)

Interview Questions

- Experience with research protocols exploring health effects associated with pesticide exposure
 - Familiarity with PON1
- Process of obtaining informed consent
 - Benefits and risks of knowing results of genetic studies
- Community Representation
 - Who speaks for the community?

Advocate Concerns

- Vulnerability of the population
“Research is a foreign concept to the majority of workers”
- Facilitate research by:
 - Inviting workers to meet with researchers
 - Outreach workers present the research
 - Community became part of the project with trained community members
- Many indigenous languages spoken
“Language...is the primary impediment to ...connecting to the community”

Advocate Concerns

- Only half of the advocacy groups were aware of emerging genetic research. Only one known of the PON 1 gene.
- Unclear of any benefit to the community
 - “ Will the information be used in the future to protect workers or could it be used to discriminate against workers?”
- Issues specific to community
 - Unclear benefit
 - “Assumes the workers have job choices, which is not the case in reality”
 - “They have no insurance and cannot do anything about it”

Informed Consent

- Language is a major barrier. Concern regarding the communities' ability to understand the research.
- Communities are distrustful of scientists, but trustful of healthcare providers.

Individual vs. Community Consent

- Consensus among advocacy respondents on need for more than individual consent.
- Leaders of community organizations can not speak for all the members of a community
- Strikingly little mentioned by researchers on community consent.

Researchers' Concerns

- Limited knowledge of genetics

"Most of the people we are associated with are not aware of what is going on with genetics."

One researcher revealed that the consent document is stated in broad terms so the researchers could do tests when they needed.

- Benefits vs. Burdens of research

"Concerns expressed related to research results of PON1 and if they can be used to better the conditions of vulnerable groups."

- Informed Consent

"Researchers conscientious about the process of informed consent and took measures to make sure subjects were appropriately informed."

Researchers' Concerns

- Shared Responsibilities, Trust, and Respect.
 - *“Sought counsel from community leaders, community partners and organizations who advised researchers on how to collect data, and how to approach groups of subjects.”*
 - *“Community leaders can be mistrustful”*
 - *“Respect the community’s expertise”*

Conclusions and Future Research

- No consensus on benefits/risks of incorporating genetic measures in research protocols.
- Does toxicogenetic research have to benefit the community?
- How do we use findings in toxicogenetic research, such as the case of PON1 to improve working conditions for vulnerable populations?
- More research needed on the meaning of individual vs. community consent.