

**Health Disparities Due to the
Emergence of Genetic Medicine:
Perspectives from Native American
and African American Communities**

Morris W. Foster

Department of Anthropology

University of Oklahoma

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In addition to historical and existing disparities, we also should attend to the potential that new medical technologies have for creating new disparities. How might genetic medicine play out across a landscape of social differentiation and health disparities?

The promise of personalized medicine

Will it really be individualized?

Will it really be identity neutral?

Instead of customized therapies for individuals, molecular diagnostics and pharmacogenomics may just rearrange the way in which the economics of health surveillance and drug development are calculated, using both historical and marker-based groupings to categorize patients.

Existing social groups will be characterized by differing frequencies of variants that contribute to disease and promote drug response while new groupings will be based on the presence or absence of those variants.

To the extent that frequencies of those variants differ by social identity, existing health disparities may be exacerbated by the ways in which genetic medicine plays out, while additional disparities may be created among those assigned to new, marker-based groups.

This may result in two kinds of groupings: (1) social groups that are genetically stereotyped (that is, differences in frequencies are misunderstood as the presence or absence of a variant among all group members) and (2) genotyped groups that become socially identifiable and might organize as interest or identity groups.

To better understand the ways in which communities that experience health disparities may respond to the emergence of genetic medicine (including pharmacogenomics), we conducted individual interviews, focus groups, and public meetings in two rural American Indian communities and in rural and urban African American communities. We asked participants to talk both about existing disparities and about the prospect of genetic medicine.

Four common themes emerged:

1. Current problems of access;
2. An emphasis on histories of denial of access and barriers to access;
3. The use of identity to argue for greater access;
4. An emphasis on culture in talking about acceptance of new technologies.

Like many other populations that experience health disparities, AI/AN and African American populations have a lesser economic capacity to pay for access to both existing and cutting-edge diagnostics and drugs.

Overcoming barriers to access to existing diagnostics and therapies was, without exception, a higher priority than research and development of genetic medicine in all communities.

Those priorities contrast with current biomedical research budget priorities as well as with the priorities of patients who already have access to existing medical technologies. That contrast becomes, itself, a barrier to access to the extent that differences in priorities limit population-specific research and interest in adopting new clinical technologies.

AI/AN communities

- 1.5% of total U.S. population (approximately 4.5 million people)
- 1.9 million of whom receive their primary health care through IHS, which is experiencing declining appropriations
- Significantly lower life expectancy and significantly higher rates of heart disease, diabetes, etc.
- Almost twice the percentage of households below poverty as the general population

It is likely that many tribal health facilities and tribal members will be unable to afford the diagnostic tests and what will probably be the higher costs of genetic diagnostics and drugs developed in other populations.

If otherwise rare drug response variants exist at higher frequencies for some AI/AN populations, will drug companies “personalize” therapies for those variants?

Whether or not some members of AI/AN populations are pharmacogenomically unique, existing health disparities experienced by Native people will be compounded by the advent of genetic medicine.

While partly economic in nature, existing barriers to care also have long histories of social differentiation that are themselves important factors both in how contemporary community members construct their unique identities and in how they interact with others.

Social differentiation can be thought of as a basis for identity groups as well as for their specific cultural perspectives. As such, differentiation can be both a barrier to access and a means for seeking greater access.

Genetic medicine is itself the construction of a particular cultural context, and there will be barriers to its use when transferred to other cultural contexts, with respect both to world view and to historical relationships with the culture that created the technology.

Barriers perceived by some American Indian and African American study participants

■ American Indian

- Genetic population histories can undermine traditional world views;
- Genetic data can be used to argue against special legal status;
- Population-to-population comparisons;
- Expenditures on genetic medicine take away from public health budgets.

■ African American

- Concerns about forensic uses;
- Concerns about adding to burden of racism by using genetic markers to define social groups;
- Religious objections to evolution, enhancement, reproductive uses, etc.;
- Expenditures on genetic medicine take away from public health budgets.

Although not a pharmacogenomic drug, Bi-Dil is an example of the way in which identity-based disparities in the relative frequency of disease incidence and drug response can drive drug development and marketing, as well as community support.

Similarly, the most effective argument for developing drugs targeted to response variants that disproportionately are found in AI/AN populations is probably that of a shared AI/AN identity, not a shared genotype among those individuals affected.

However, if otherwise rarer variants exist at higher frequencies for some members of some AI/AN populations (as is likely the case for ALL populations), will this contribute to a perception that AI/AN people generally respond differently to drugs? That is, will differences in frequency be translated as presence or absence?

If molecular diagnostics and pharmacogenomic drugs are provided or developed for AI/AN people through that identity-specific lens, the potential for confounding the social and the biological is considerable. The same can be said for African Americans or any other social group.

A similar, but reversed, conflation might occur if genetically-defined patient groups take on social characteristics, as social involvement in those groups would be defined using a limited number of markers and so could lead to inaccurate generalizations about the relationship of a shared social identity to the rest of the genome.

An equitable distribution of the benefits of genetic medicine depends on population genetics, market economics, and, perhaps most importantly, on historical and cultural identities.

Recommendations

- Research, development, and clinical trial budgets for genetic medicine should include funding to involve those populations experiencing disparities (not just as demographically proportionate participants);
- Inclusion means paying attention to context (including social, cultural, and historical dimensions);
- Genetic medicine must be better integrated into public health and prevention;
- Should populations experiencing disparities have first priority for new clinical technologies?