

Pharmacogenomic Testing in the Hmong Community

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and Hmong Genomics Board

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Background

- Hmong patients have concerns that could be elucidated by genomic research
 - medications are too strong AND too weak for them
 - diabetes is occurring at a high rate
- Genomic testing has occurred in some communities but not in Hmong community
- Historically, Hmong community has been concerned about being researched upon

Research Aims:

- Phase 1:
 - Create a partnership with community board
 - Explore cultural concepts of heredity
 - Identify how conducting genomic research could be acceptable to Hmong adults
- Phase 2:
 - Create an informed consent process, including educational program about genetics
 - Recruit, collect samples, analyze samples
 - Bring results to the community

Hmong Pharmaco-genomics Research Board

- West Side PI: Kathie Culhane-Pera
- UMN PI: Robert Straka
- Pharmacy student: Mai Lor
- Public health nurse: MaiKia Moua
- MPH grad student: See Moua
- Pharmacist: Tzur Thong Moua
- Educator: Txiabneeb Vaj
- Community educator: Chau Vue
- Family physician: Kang Xiaaj
- Anthropologist consultant: Dr. Dia Cha
- Research Assistants: Pangdra Vang

Hmong Genomics Board

- West Side PI: Kathie Culhane-Pera
- UMN PI: Robert Straka
- Pharmacy doctor: Mai Xia Lo
- Pharmacy student: Mai Lor
- Pharmacy resident: Kanjua
- Family physician: Kang Xiaaj
- Educator: Txiabneeb Vaj
- Community educator: Chau Vue
- Research assistants: Pachia Vue, Pa Kou Yang, Yeng Yang, Caroline Lochungvu

Role of Hmong Genomics Board

1. Partner with researchers
2. Represent Hmong community's interests
3. Discuss appropriateness/ inappropriateness of research topic, research questions, and research methods
4. Ensure that informed consent process is appropriate
5. Participate in data collection and analysis
6. Discuss results, to understand the potential meaning and significant for the health of the community
7. Create plan to disseminate results, to benefit community
8. Participate in publications and presentations
9. Be involved with future research

Phase 1: Research Methods

1. Interview 5 community leaders as key informants
2. Interview 42 people in 5 focus groups
3. Qualitatively analyze interview data
4. Discuss results with Board

Phase 1 Results: Majority

1. Did not know about genetics, but knew heredity.
2. Were willing to have their blood drawn, analyzed, and stored for future testing.
3. Believed that research could benefit community .
4. Foresaw a personal benefit, especially those with diabetes or with family members with diabetes.
5. Wanted individual results, not just group results.
6. Not concerned about negative social stigma for or discrimination towards Hmong community.

Phase 1 Results: Minority

1. Did not believe that
 - diabetes or medication variation is inherited
 - saliva samples could reveal heredity-- only blood
2. Were not willing to participate
 - concerned researchers know their results
 - concerned researchers keep their DNA
 - Concerned about knowing the future
3. Willing to participate and not receive individual results
4. Concerned about discrimination towards Hmong

Phase 2: Research Methods

- 1) Provided informed consent to 263 potential participants:
 - 1 Hmong social service agency (clients and staff)
 - 2 medical clinics (patients and staff)
 - 3 colleges and
 - 2 Hmong college student conferences
- 2) Enrolled 238 adults
- 3) Collected 236 saliva samples for genomics testing
- 4) Collected 59 blood samples for chemistry testing

Phase 2 Results:

- Using the principles of CBPAR, it is feasible to conduct a genomic investigation with the Hmong
- Harder to recruit elders than college students
 - As they needed more time and education to understand what they were consenting to
 - As some desired individual rather than group results
- Only 25 people (5%) declined to participate
- 84% allowed us to keep DNA for future CVD analyses
- 81% allowed us to share DNA with other researchers
- 78% allowed us to contact them for future research

Genomic Variations (SNPs) in 3 Genes”

1. *CYP2C9**3 rs1057910 -- coumadin metabolism
SNP has decreased metabolism, so lower dose
Found more in Han Chinese than in Whites
2. *VKORC1* rs9923231 -- coumadin target
SNP has increased effectiveness, so lower dose
Found more in Han Chinese than in Whites
3. *CDKN2A* rs10811661 - DM risk
SNP - 1.2 increased odds rate of DM in Caucasians
1.3 increased in Han Chinese and 1.25 in Japanese
Risk allele present in 46% of Han vs 21% of Europeans

SNP Results

1. *CYP2C9*3* -- coumadin metabolism
19.8% have SNP on 1 or 2 alleles
5 times more prevalent than Han-Japanese
2. *VKORC1* -- coumadin target
11.4% have SNP on 1 or 2 alleles
Same prevalence as Han-Japanese
3. *CDKN2A* -- DM prevalence
43.9 % have SNP on 1 or 2 alleles
Same prevalence as Han-Japanese

Clinical Significance of Results

- Coumadin dosing:
Combining SNPs in two coumadin genes:
 - 30% need ≤ 21 mg coumadin/ week
 - 67.8% need 22- 48 mg coumadin/ week
 - 2.2% need ≥ 49 mg coumadin/ week
- Diabetes prevalence:
44% of sample have SNP with increased 1.2 - 1.3 odds ratio of developing DM
Indeed, 29.1% of sample had BMI>30

Implication of Research Results

- Uncertain of clinical implications:
 - Some Hmong people need low coumadin doses.
 - Some Hmong people at higher risk for DM.
- Uncertain of community health implications:
 - When return results to community, how will they respond?
 - Can we use result to improve the health of the community?
- Need further research:
 - Epidemiological sample
 - Test for larger number of SNPs
 - Continue to partner with Hmong Genomics Board

Implications of CBPAR for CHCs

- Involving CHCs in pursuit of knowledge can improve the health of communities.
 - We could be key partners with academic researchers and communities.
 - We have the relationship with communities to engage in important research AND to apply the information.
- Partnering with community members can improve health of communities.
 - They are necessary partners whose insights and expertise are invaluable to conduct research and apply results to community.

Thank you

- Program in Health Disparity Research at UMN for funds for CBPAR.
- Genetic Alliance for funds for patient education materials
- Questions? Contact:
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