J Community Genet (2017) 8:23–34
DOI 10.1007/s12687-016-0284-2

ORIGINAL ARTICLE

Leaves imitate trees: Minnesota Hmong concepts of heredity and applications to genomics research

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Received: 4 July 2016 / Accepted: 18 October 2016 / Published online: 7 November 2016

Abstract Historically, Hmong refugees in the USA were distrustful of Western medicine, medicines, and medical research due to concerns about harm and experimentation. Current Hmong concerns about genomics research are not well known. Our research aims were to identify cultural and ethical issues about conducting genomic studies in the Hmong community. Using a community-based participatory action process, the West Side Hmong Genomics Research Board conducted a qualitative exploratory research study that included semistructured interviews with five Hmong key informants and five focus groups with 42 Hmong adults near Saint Paul, Minnesota. We used a thematic analysis approach to qualitatively analyze the data. Identified concepts of heredity included characteristics that are passed between the generations: physical features; character traits; some behaviors; some diseases; and probably not response to medicines, although individual variations to medicines are known. Most participants were willing to join genomic research projects to help themselves and community. Others refused to participate: they did not want to know future disease risk; did not want doctors to know their genes; did not trust doctors with their blood; and did not know if they would benefit from results. Ethically, many participants were in favor of confidentiality, but wanted to know their personal results; many were willing to agree to genetic storage of anonymous samples; all agreed with individual consent, not family or community consent; and none were concerned about social stigma from genetic testing about chronic diseases and medications. The Hmong Genomics Board will build upon these concepts to create, conduct, and evaluate culturally-appropriate genomic and pharmacogenomic research projects relevant to community interests.

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Introduction

The results of genomic and pharmacogenomic studies can potentially improve people's health, by the anticipated era of "personalized medicine" (Green et al. 2011). All communities need to participate in order to benefit from the medical improvements that genomic research may bring (Green et al. 2011; Licinio 2001; Yu and Burke 2012; Zilinskas and Balint 2001). However, not all communities are equally participating in or are equally willing to participate (McQuillan et al. 2006; Sterling et al. 2006). It is recognized that minority and under-served communities are participating less, possibly due to their genetic knowledge, beliefs, and perceived utility of testing (Millon Underwood et al. 2013; Sterling et al. 2006; Sussner et al. 2009), and concerns about discrimination, fairness, privacy, and being used by researchers without clear benefits (George et al. 2014; Schulz et al. 2003; Skinner et al. 2015; Sterling et al. 2006; Sussner et al. 2009; Sussner et al. 2011; Zilinskas and Balint 2001). Rotimi and Marshall (2010) recommend ten social, cultural, and scientific factors

be considered in designing and obtained informed consent, particularly to include culturally and linguistically diverse communities. Including community members in the research process has the capacity to address the concerns and overturn these inequities, whether by use of community advisory boards (Quinn 2004), on-going interactions between communities and researchers (Mascalzoni et al. 2008), community consultations on ethical considerations (Dickert and Sugarman 2005), or community engagement processes (Halverson and Ross 2012; Marsh et al. 2010; Marsh et al. 2013; Tindana et al. 2012; Vreeman et al. 2012), including community-based participatory action research (CBPAR) (Johnson et al. 2009; Skinner et al. 2015).

When Hmong people first arrived in the 1970s-1980s as refugees from Laos, many people distrusted Western medical providers and researchers and were concerned about blood draws, tissue collection, research, and experimentation (Culhane-Pera and Xiong 2003; Kirton 1985; Warner and Mochel 1998). Hmong people around the word have participated in few genomic research projects (Li et al. 2007; Listman et al. 2007; Listman et al. 2011; Straka et al. 2006; Vang et al. 2007; Wen et al. 2005), and their specific concerns about genomic research are not well known. Xiong et al. (2013) recommended that focus groups with diverse Hmong people be conducted to elicit people's ideas and concerns about genomic based research.

Before conducting genomic research about the risks for developing chronic diseases (such as type 2 diabetes mellitus) and pharmacogenomic research about the action of medications for chronic diseases in the Hmong community, we created a Hmong community-based participatory action research (CBPAR) process to conduct an exploratory study. The Hmong Genomics Research Board consisted of eight Hmong community members and two non-Hmong professionals. Our research aims were to identify Hmong community's cultural beliefs about heredity, concepts of genetics, ethical concerns of genomic research, and response to logistical issues of collecting and storing genetic samples.

Methods

The Hmong Genomics Research Board collectively designed the study, wrote the informed consent forms in English and Hmong, designed the key information and focus group questions, chose five key informants and chose five locations for focus groups, and participated in data analysis and interpretation. The co-PI (KACP) and a Hmong research assistant (both of whom speak, read, and write Hmong) conducted the key informant interviews and focus groups in Hmong and/or English, as the participants desired. The audiotaped 2–2.5 h key informant interviews were conducted in people's homes or offices; four were in Hmong and one was in English. The audiotaped 1.5–2 h focus groups were held in five diverse locations in order to recruit focus group participants who represented a range of community members: two medical clinics, a Hmong church, a Hmong college student organization, and an English Language Learners (ELL) class at a Hmong community organization. Four focus groups were in Hmong and one was in English. The key informants and focus group participants gave informed consent (either signing a written Hmong or English consent form or attesting to receiving oral consent in Hmong), answered demographic questions, and received $25 as appreciation for their involvement. The research project was approved by the University of Minnesota Committee on the Use of Human Subjects in Research (IRB 0711 M21884).

Analysis

Two research assistants directly transcribed the English and Hmong audio-tapes, and then translated the written Hmong into English. Subsequently, a Board member (PCV) read the English translations and listened to the Hmong audiotapes to ensure accuracy. The same co-PI and Hmong research assistant who conducted the interviews and focus groups analyzed the transcripts using a thematic analysis approach (Crabtree and Miller 1999). They worked together to code each written transcript, organized the codes under categories from the question guides (Table 1), and then identified key themes. A grid highlighting the key themes from the key informants and the focus group themes was shared with the board. Board members discussed the cultural meanings of the themes with the two coders until agreement was reached for the final analysis.

Results

The main themes are described in categories based on the questions (Table 1). Quotes are included to illuminate the general responses; descriptive information includes gender and age range (young is 18–20 years, middle-aged is 30–49 years, and elderly > =50 years). Demographics of the five key informants and 42 community members from the five focus groups are in Table 2. All focus groups had men and women. The two clinic focus group members were mostly elderly, animists, long-term US residents, without high school education, and with chronic diseases. The church focus group members were Christians of mixed ages, mixed formal education, and varied years in the USA. The college focus group members were young, with varied religious orientations, and long-term residents of the USA. The English Language Learners (ELL) group members were young and middle aged, mostly animists, without high school education, and new arrivals in the USA. Table 3 has further division of the five focus

Table 1 Condensed interview questions for key informants and focus groups

1. Concepts of heredity
What ideas did Hmong people have about heredity?
What types of characteristics are inherited?
Have you heard about genes, DNA, or chromosomes?
How are these ideas similar or different from Hmong ideas about heredity?
2. Concepts of chronic diseases like diabetes mellitus, type 2 (DM) and heredity
Why are people getting diseases like DM? Is it hereditary?
What helps people who have chronic diseases like DM? Should they take medicine?
3. Concepts of medicines and heredity
Do American medicines help Hmong people? Why? Why not?
Do American medicines fit Hmong people? Why? Why not?
4. Reactions to genomic research about diabetes and pharmacogenomic research about medicines for chronic diseases
Would you be willing to get these tests? Why? Why not?
Would other people be willing? Why? Why not?
Who might be more wiling? Who might be less willing?
5. Ethics about genomic and pharmacogenomic research
What about anonymity? Important? Relevant?
What about confidentiality? Important? Relevant?
Willing to allow long-term storage of DNA bank and testing?
Social consequences of test results: intra-family, intra-Hmong, external Hmong?
Should a community board be involved as advocates/ consultants to researchers?

group participants' demographics along with their responses to participation in potential future genomic research projects.

Concepts of heredity and genetics

Participants expressed similar and diverse ideas about heredity (*caj ces* in Hmong and *serr sa* in Laotian -which some people referred to more readily than the Hmong word). Everyone recognized that characteristics from both the father's side (*kwv tij*) and the mother's side (*neej tsa*) of the family can be passed onto children. This concept was described succinctly in the Hmong proverb: Leaves imitate trees- Human seeds imitate relatives (*Nplooj yoog kav - Noob yoog tsa)*. The high school- and college-educated participants were familiar with the scientific concept of genetics, genes, and DNA, with half of a child's chromosomes coming from their biological mother and father. The participants who had not attended high school were unfamiliar with these concepts. Rather, they described a traditional view that father's seed (*noob*) gives rise to baby's bones while mother's egg (*qe*) and blood (*ntshav*) results in baby's flesh (*nqaij*) and blood (*ntsahv*). Despite this concept, participants' discussion revealed that most people agreed that fathers and mothers both contribute to their children's physical and emotional characteristics, with two exceptions. One, gender is determined by mothers and not fathers (and while not in their control, mothers can influence their infant's gender by taking medicines, assuming certain positions during intercourse, and being exposed to the moon). Two, while children's ethnicity as a Hmong person is passed from generation to generation via blood, father's ethnicity is more important than mother's. Thus, children born to Hmong fathers are more likely to be considered Hmong while children born to Hmong mothers and non-Hmong fathers belong to the fathers' ethnicity (e.g., Chinese, Laotians, White Americans, or African Americans).

> *You cannot escape heredity. That is why they say (the proverb)* "*Leaves imitate trees - Human seeds imitate relatives*". *(Elderly man)*

> *It is the blood, not the spirit, which is passed (between the generations). The man provides what we call* "*sperm*" *and that is mixed with the woman's* "*blood*". *(Elderly woman)*

> *This is the way of the Hmong. My son is my blood and will carry my name until the day he dies. My daughter marries into a family and becomes part of that family. (Elderly man)*

Participants described physical characteristics as the most evident of inherited characteristic. Children physically resemble their family members with similar facial features, hair color, and height. Also, some birth defects are inherited, such as congenital deafness and blindness (which people note therefore cannot be cured). While flesh (*nqaij*) and blood (*ntshav*) are both inherited, an individual's physical essence of *roj ntshav* (literally "fat-blood" or "flesh and blood") is not just inherited; it is also affected by individuals' actions (such as diet and activity) and environmental factors beyond their control (such as weather).

Participants discussed variable ideas about behavior characteristics being passed between generations. People generally agreed that parent's characteristics such as patience or impatience (s*iab ntev/ siab luv)* and intelligence or impaired mental capacity *(ntse/ruam)* are passed to children. In addition, a few people mentioned various other characteristics that can be inherited, such as being an unproductive person *(tub nkeeg)*, opium addict (*tus quav yeeb*), spouse abuser *(tus ntaus poj niam)*, thief *(tub sab)*, polygynous man (*yuav poj niam yau*), or a bum *(neeg loj leeb)*.

> *Let me tell you how Hmong view genetics. If I know that a Xiong person has good genes I will want my children to marry their family and vice versa. ...Leprosy and limited intelligence are genetic and you do not marry into that family. (Middle-aged man)*

Table 2 Social, demographic, and disease characteristics of 47 research participants

	5 key informants	42 focus group participants
Gender—% (N)		
Women	40 % (2)	51 % (22)
Men	60 % (3)	49 % (20)
Ages		
Mean	70 years	41.4 years
Range	(45–86 years)	(18–86 years)
Age categories—% (N)		
Young (18–29 years)	0 %	45 % (19)
Middle-aged (30–49 years)	20 % (1)	26 % (11)
Elderly (50–86 years)	80 % (4)	26 % (11)
Unknown		2 % (1)
Religion—% (N)		
Hmong animism	60 % (3)	53 % (22)
Christianity	40 % (2)	40 % (27)
Both		6 % (1)
None/unknown		12 % (2)
Formal education—% (N)		
<High school grad	80 % (4)	66 % (27)
High school grad or college	20 % (1)	34 % (15)
Unknown		2 % (1)
Years in the USA		
Mean	22 years	13.8 years
Range	(15–30 years)	(1–28 years)
Birth country—% (N)		
US	0 %	11 % (5)
Southeast Asia	100 %	89 % (37)
Spoken English Skills—% (N)		
None/Poor	60 % (3)	29 % (12)
Fair/Good	20 % (1)	53 % (22)
Very Good/Excellent	20 % (1)	18 % (8)
Written English Skills—% (N)		
None/Poor	60 % (3)	47 % (20)
Fair/Good	20 % (1)	34 % (14)
Very Good/Excellent	20 % (1)	18 % (8)
Written Hmong Skills—% (N)		
None/Poor	20 % (1)	12 % (5)
Fair/Good	80 % (4)	57 % (24)
Very Good/Excellent	0	31 % (13)
Professions—% (N)		
Shaman	60 % (3)	Unknown
Khawv koob healer	20 % (1)	
Herbalist	20 % (1)	
Pharmacist	20 % (1)	
Diseases—% (N)		
Diabetes	60 % (3)	19 % (8)
Hypertension	20 % (1)	17 % (7)
Hyperlipidemia	20 % (1)	10 % (4)

Table 2 (continued)

	5 key informants	42 focus group participants
Gout	20 % (1)	2 % (1)
COPD	20 % (1)	0
Cancer	0	2 % (1)
None		50 % (21)

Concepts about diseases and heredity

While participants agreed that many diseases could be passed between generations, the only traditionally recognized inherited disease that everyone agreed upon was leprosy (*mob ruas*). While some high-school and college-educated participants had heard that leprosy was caused by bacteria, they still had heard from their families that leprosy was a disease that ran in families. As such, marriage negotiations ask about leprosy in the family, as these family members are undesirable marriage partners. Participants did not have consensus about other inherited diseases.

A leper's grandchildren will have leprosy. This is why it is taboo to marry a leper. (Elderly man)

When asked whether or not chronic diseases are genetically transmitted—diabetes, hypertension, cancer, kidney disease, renal failure, heart attacks, and strokes—people had varied responses. Often their initial responses were in negative, asserting their grandparents in Laos did not have these diseases. But upon further reflection, some people acknowledged that perhaps their relatives had these diseases, but were never diagnosed. Nonetheless, the majority asserted that Hmong people are developing these diseases in the USA because of changing lifestyles, not because of heredity. The lifestyle issues they cited are changes in diet (increased amount of food, increased fat, and increased sugar), activity (less sweating and less physical activity), food preparation (more chemicals and more cooking in fat), weather (less heat to help sweating), and mental health (more stress and depression).

Diabetes seems to stem from a bad diet and lack of exercise (not genetics). In the past before we were this country, we had a bad diet and we did not exercise much. It does not seem like it is a case of inheriting (diabetes) from my parents. (Middle-aged man)

Concepts about medicines and heredity

Many participants stated that American medicines work as well for Hmong people as for Americans, although some said that Hmong bodies might respond differently to American medicines than American bodies. They emphasized the individuality of response to medicines, rather than generalizing to a group response that could be genetically-based and inherited. They acknowledged that individuals can respond to medicines in variable ways, such that medicines either may not fit (*tsis haum)* people's individual bodies or that people's bodies may not fit (*tsis haum)* medicines. While participants could not state that this variability is inheritable, they also could not rule out that possibility. They acknowledged that since children receive their blood (*ntshav*) from their parents (which is an important element in their flesh-blood essence (*roj ntshav*)), then perhaps response to medicines could be inheritable. However, since flesh-blood (*roj ntshav)* can be influenced by diet, activity, and weather, then perhaps response to medicines is not inherited.

If you take some leaves and make tea out of it (herbal medicine), it could work for one person and not for the next…because everyone has their own set of flesh and blood (roj ntshav). It's not because of our ethnicity or heredity. It's a matter of individual differences. (Elderly woman)

We are all unique so we need to take what (medicine) works for us. (Middle-aged woman)

Reactions to genomic/ pharmacogenomic research

Most of the participants were overwhelmingly in favor of participating in genomic and pharmacogenomic studies and affirmed they would agree to participate in future research projects. This opinion was expressed in every focus group, thus representing a wide range of characteristics- gender, age, religion, education, chronic diseases, and length of time in the USA. They projected they would agree to having their blood drawn (particularly if only two teaspoons of blood are required), analyzed for genetic variations of diseases such as diabetes or for response to medicines and stored for future analyses. Participants also agreed to have their saliva collected, but many people were skeptical that saliva samples would be adequate since blood is the key element that is passed between generations. Their main motivations to participate were to benefit themselves and benefit their community. By

Table 3 Group characteristics and individual ideas about their participating in genomic and pharmacogenomic research studies

Characteristics— % (N)	Key informants $N=5$	Clinic group $N=4$	Clinic group $N=4$	Church group $N=12$	College group $N=11$	New arrival group $N=11$
Gender						
Women	40 % (2)	50 % (2)	50 % (2)	42 % (5)	36 % (4)	64 % (7)
Men	60 % (3)	50 % (2)	50 % (2)	58 % (7)	64 % (7)	36 % (4)
Age categories						
Young (18–29 years)	0	0	0	33 % (4)	100 % (11)	36 % (4)
Middle-aged (30–49 years)	20 % (1)	0	25 % (1)	33 % (4)	0	55 % (6)
Elderly (50–86 years)	80 % (4)	100 % (4)	75 % (3)	33 % (4)	0	0
Unknown	0	0	0	0	0	9 % (1)
Religion						
Hmong animism	60 % (3)	75 % (3)	75 % (3)	0	55 % (6)	91 % (10)
Christianity	40 % (2)	25 % (1)	25 % (1)	100 % (12)	18 % (2)	9 % (1)
Other/none	0	0	0	0	27 % (3)	0
Years in the USA						
<5 years	0	0		17 % (2)	0	0
5–15 years	0	0	0	17 % (2)	0	0
>15 years	100 % (5)	100 % (4)	50 % (2)	50 % (6)	100 % (11)	100 % (1)
Unknown	0	0	50 % (2)	17 % (2)	0	0
Formal education in the USA or SEAsia						
<High school	80 % (4)	100 % (4)	100 % (4)	58 % (7)	0	100 % (11)
High school grad or college	20 % (1)	0	0	33 % (4)	100 % (11)	0
Unknown	0	0	0	8 % (1)	0	0
Chronic diseases						
Yes		100 % (4)	100 % (4)	8 % (1)		
No		0	0	92 % (11)	100 % (11)	100 % (11)
Agree to genomic study for chronic diseases, like DM?						
Yes		100 % (4)	100 % (4)	92 % (11)	82 % (9)	82 % (9)
No		0	0	0	28 % (2)	28 % (2)
No response				8 % (1)		
If yes, accept general genomic results?						
Yes, general		0	0	45 % (5)	78 % (7)	0
No, want individual		100 % (4)	100 % (4)	55 % (6)	22 % (2)	100 % (9)
Agree to pharmacogenomic study?						
Yes		100 % (4)	100 % (4)	92 % (11)		
No		0	0	0	64 % (7)	100 % (9)
No response				8 % (1)	36 % (4)	0
If yes, accept general pharmaco-genomic results?						
Yes, general		0	50 % (2)	45 % (5)	100 % (7)	0
No, want individual		100 % (4)	50 % (2)	55 % (6)	0	100 % (9)
If yes to genomic, agree to store DNA sample?						
Yes		100 % (4)	100 % (4)	100 % (11)	100 % (9)	100 % (9)
No		0	0	0	0	0
If yes to genomic, agree to future genomic testing?						
Yes		100 % (4)	100 % (4)	100 % (11)	100 % (9)	91 % (10)
No		0	0	0	0	9 % (1)

knowing their genetic risks for diseases, they speculated that individuals could avoid harmful behaviors. By knowing their pharmacogenomic results, they assumed they could avoid ineffective medicines. They surmised that other Hmong people would agree to participate if they understood about genetics, how the results would help them and how the research was conducted. They predicted that young people would more likely join than older people, and people at increased risk for chronic diseases (like diabetes because of their family history) would more likely agree to participate. Finally, they stated that people's knowing and trusting the researchers can make it easier for people to agree to participate.

Yes (I would participate). I want to know what was given to me and what I have given to my children. (Middle-aged woman)

I think the youth will be more likely to consent. They may be unsure of their future and want to learn more about their DNA. (Elderly man)

Not everyone shared these opinions. A few participants said they would personally refuse to join genomic or pharmacogenomic studies; these people were in the focus groups conducted in the college and ELL class, thus represent a range of years in formal education and the USA. The discussions revealed that many participants thought that other people would refuse to participate. People's reasons for refusing and people's thoughts about why others would refuse can be categorized into five reasons. (1) People are afraid of knowing the future; if people have a genetic risk for a disease that could not be cured or that they have to change their lifestyle to accommodate, they would prefer to not know their genetic risk. (2) People do not want other others (doctors, researchers, general Americans, or Hmong) to know about their blood, or genes. (3) People are concerned that researchers could take advantage of them in various, although as of yet unknown, ways. Some people expressed distrust of researchers, expressing suspicion about researchers' motivations for doing research, asserting that researchers might conduct the study for their own personal (although unspecified) gain and feeling vulnerable that researchers could take advantage of their genes (although in unknown ways). (4) People do not want to participate in hypothetical research that does not have a known end point, or which might not benefit them, especially if they feel they were too old to benefit from the results. (5) A few people mentioned fear of needles, fainting when losing blood, or not wanting to be bothered.

I think they may fear it because if they know they have diabetes in their DNA, they will worry themselves sick. (Young man)

Those who do not consent are fearful of what they will learn. (Middle-aged woman.)

I am now old.. ..the elderly are different. They are more fearful, paranoid and their outlook on life is less energetic. If it is found that a family has a tendency to get a certain illness it would be very distasteful (to them). (Elderly man)

Hmong fear the blood may be used for reasons other than research. (Elderly man)

They may not consent. If there is nothing to be gained from this research such as a prevention or cure, it is unlikely that people will consent. (Elderly man)

Overall, participants predicted that the people most likely to participate were young or middle-aged adults with good English skills, written language skills, formal science education, long-term US residence, trusting relationships with doctors, and/or risks for chronic diseases and needing chronic medications. They predicted these elements would help people understand the research process and goals, trust the researchers, and be more likely to envision that the results would help themselves or the community.

Despite this prediction, some focus group participants made different assertions for themselves. All people in the clinic and church groups said they would participate. This group included people of middle to older ages, those with less than high school education and those without chronic diseases. The only people who said they would not personally participate were in the college and English Language Learners groups, which includes people of young and middle ages, high and low education levels as well as long-term and recent residents.

They (healthy people) probably would refuse because they are not sick. Those of us who are sick would consent to whatever studies. (Elderly woman)

Doctors are the ones to fix us. We are just the patients. ...I've been with this doctor for a long time so would consent. (Elderly man)

Reactions to research ethics

Regardless if participants would agree or refuse to participate, they had specific ideas about how to ethically conduct this type of research. They made a clear distinction between confidential results and anonymous results. The vast majority was in favor of confidential but not anonymous results; while they did not want others to know their personal results, they

themselves wanted to their personal results so they could benefit from having participated. The minority was willing to accept anonymous testing as long as the study's general results were available to them. Indeed, most of the people in the focus groups (particularly the elderly in the clinic groups and all of the recent arrivals in the ELL group) wanted personal results, while some people in the church and college groups said they could accept general results. Overall, the desire for personal results was slightly higher for genomic studies done about diseases than about medications. Finally, a small group of people refused confidentiality; they wanted their names to be publicized as having contributed to the worthwhile effort, from which the community could benefit.

I am the one that decides to give you my blood so I would like to know all the good and bad that are associated with my genes. I don't have any knowledge about my grandparents' genes so I would like to know (my genetic) information. (Middle-aged man)

If you take my blood but you don't list my name or tell me the results, then there's no meaning. There has to be a name on it (the sample) and you should give us the results. That is the right thing to do. (Elderly woman)

Since this research is new I don't mind if our names are not listed. We are willing to be the first ones to donate our blood and volunteer to be subjects. As time passes, more and more people will be less fearful and (will be willing to) participate in research such as this one. I want my data to be on record with you. My children should be able to come to you one day and you would have my genetic data to help take care of them. (Middle-aged man)

As long as (the sample) is listed as (coming from a) Hmong then there is no need for names. (Young man)

I would consent. If it is to be … research, then I don't want my name on it. .... I don't want anyone to know what I have. (Young man)

I want you to tell everyone that I, (name), participated in this study … so they know that I helped. (Elderly man)

The majority of participants stated they would give permission for researchers to keep the DNA sample available in a DNA bank for future testing, in order to save time and money from having to draw blood and analyze the DNA sequence again. Most of these people were even willing to give blanket permission to any testing that could become available in the future, while some people wanted to give specific permission to only conduct specific tests. A minority would refuse to give permission for their DNA to be held in a DNA bank.

It's a good idea to store blood because it will save time. (Young man)

I believe it won't matter too much for the younger folks (about saving DNA) but there might be some concern among the older folks. (Young woman)

I think most people would also disagree to having their blood stored. ..... If it is stored without having my name on it, then I don't agree. (Elderly woman)

We also inquired about potential social stigma from genetic test results, whether between the American and Hmong communities, between Hmong clans, and within families. Overall, participants were not concerned about social stigma that might arise from the results of studies about chronic diseases and medicines for chronic diseases. People explained that all communities (American and Hmong) and all clans within the Hmong community have these chronic diseases and are taking these medicines, so having a higher or lower probability of a disease or medication metabolism would not stigmatize any person, family, clan, or ethnic community.

People can know about my blood result. I am Hmong, so of course my blood is Hmong. (Middle-aged woman)

Americans have diabetes and high blood pressure, so there is no stigma or shame if Americans learn that Hmong have diabetes and high blood pressure. (Young man)

When encouraged to consider potential conflicts between the generations if the elders refused and the youth accepted, people replied that youth can make their own decisions, given their familiar with English language and American society, regardless of the elders' opinion. Most people asserted that individuals can make their own decisions, regardless of what others decide, even if other family members refuse. When pushed to consider analyzing for stigmatized diseases (such as leprosy since that was culturally considered inherited), people could foresee potential untoward consequences and could imagine that increased knowledge could increase discrimination. However, people could not envision risks of stigmatization for chronic diseases like diabetes or testing for metabolism of medicines.

You should ask everyone (in the family for permission) but it is still up to the individual. If (young) individuals agree, the parents would allow them to do it. It is up to each person. (Elderly woman)

(Since) cancer and stroke are isolated incidences (and will not affect marriage prospects), it is OK to know. (Middle-aged man)

Discussion

These qualitative research results with 47 Hmong adults near St Paul, Minnesota indicate that conducting a genomic research project could be possible with a wide range of people in the Minnesota Hmong community. While participants predicted that people with younger ages, more education, more years in the USA, and chronic diseases would be more likely to participate, most of the participants themselves said they would participate, irrespective of their age, gender, education, religion, health, and years if living in the USA. This uncertainty about who will and who will not participate in genomic research based on demographic characteristics was also found in a 2006 literature review (Sterling et al. 2006).

Although few of this study's participants knew much about genetics, all were familiar with Hmong concepts of heredity, which could be built upon to explain genetics and genetic research. Some of the identified heredity concepts are inconsistent with scientific concepts of genetics and genetic research. For example, people said 'leprosy is genetically transmitted', 'baby's gender is determined by mothers', 'baby's bones come from fathers while flesh comes from mothers', and 'saliva cannot be used to genetic differences'. However, the main heredity concept is consistent with genetics: physical characteristics arise from both parents, as the proverb indicates: Leaves imitate trees—Human seeds imitate relatives (*Nplooj yoog kav - Noob yoog tsa)*. These and other discovered concepts can be built upon to explain future genomic and pharmacogenomic research endeavors: heredity, behavior, and environment can influence people's susceptibility to chronic diseases, and individual people may respond to medicines differently. Using traditional concepts of heredity to build an informed consent process for a genetic study has been used and advocated in other studies (Rodriguez et al. 2016; Sandberg et al. 2015; Tong et al. 2014).

The majority of Hmong study participants stated they would be willing to join genomics research projects and surmised that others would be also, including having blood drawn, analyzed, and stored for future testing, because genomic tests could benefit the research subjects as well as the Hmong community. Exploratory research done with other under-represented minorities have also identified a desire for some members to participate, including African Americans (Buseh et al. 2013a; Carmichael et al. 2016; Dash et al. 2014; Halverson and Ross 2012; Sanderson et al. 2013; Sussner et al. 2011; Underwood et al. 2013), African immigrants (Buseh et al. 2013b), Hispanics/Latinos (Carmichael et al. 2016; Hamilton et al. 2016; Sandberg et al. 2015; Sanderson et al. 2013; Sussner et al. 2009) and Cantonese-speaking Chinese Americans (Tong et al. 2014). Participants asserted that most Hmong people would want their individual results and not just aggregated results, a desire expressed by other populations (Buseh et al. 2013a; Carmichael et al. 2016; Hamilton et al. 2016; Sanderson et al. 2013). However, whether or not individual participants or the community will benefit from the results of genomics research is unknown. At this stage of genomics research, the results are descriptive and may not be directly applicable to improving the health of individuals or the community. Indeed, for common and complex genetically influenced diseases like diabetes, knowing one's family history can be more instructive of risk than identifying some of the genetic variations (Do et al. 2012; Valdez et al. 2010). But given that Hmong do not have access to accurate family histories of biomedical diseases due to lack of biomedical diagnostic capabilities in Laos, the value of risk stratification based on family history is limited. Other researchers have found that research participants do not always understand the distinction between research and medical care; since participants can confuse the two, and assume the testing results have clear implications for them, the distinction between the two and explanation of results need to be emphasized (Berkman et al. 2014; Burke et al. 2014; Smith-Morris 2007). This type of confusion could be a concern for our study participants also. Participants' assertions that they want to participate in order to help themselves and their community may indicate there is confusion about the value of genomic results. Researchers will need to clearly state that research results may not have clear or immediately translatable applications and may not help the participants or the community, particularly in this early stage of genomic research.

A minority of study participants was not in favor of genomic research, and each focus group envisioned that some Hmong people would not participate. Some people would not want to know if they were at increased risk of developing chronic diseases, such as diabetes. Other people would be uncomfortable with researchers knowing parts of themselves called "genes" (which could be a nebulous concept, although tied with heredity), and they would be concerned that researchers could take advantage of them or the community in some unknown ways. These concerns were raised in other studies (Buseh et al. 2013a and 2013b; Carmichael et al. 2016; Dash et al. 2014; George et al. 2014; Hamilton et al. 2016; Sanderson et al. 2013; Schulz et al. 2003; Sterling et al. 2006; Underwood et al. 2013). Participants' inability to articulate what potential dangers might lie ahead is understandable; without specific results, without historical context, and without experience with genomics results, it can be difficult to imagine what kinds of consequences could arise, what significance these could have for individuals and the community, and

how individuals and the community might react. Indeed, the interview questions inquiring about potential negative impacts and potential stigmatization were hypothetical to participants. Certainly, other communities have had concerns about being stigmatized, conflicts about ownership of the results and concerns or disagreements with how they were characterized (Buseh et al. 2013a; Garrison 2013; George et al. 2014; Schulz et al. 2003; Smith-Morris 2007; Underwood et al. 2013). Once the genomic results are obtained, the possibility exists that the Hmong community will have concerns about the results, or the meaning of the results. This potential needs to be explored through the Board's continued involvement.

Limitations

As with all qualitative focus group research, there are limits to correlating individual characteristics with individual responses given in a group setting. This is because an individual's responses may be affected by the responses of people around them (Crabtree and Miller 1999). Also, there are limits in generalizing from this qualitative data to other Hmong communities around the country or around the world. Nonetheless, we have elicited opinions from a range of Hmong participants in Minnesota, including both genders, and a range of ages, education levels, religions, and years in the USA. Without a quantitative survey of a representative sample, it is not possible to know to what extent these opinions represent the Hmong community in Minnesota or the USA. Finally, whether or not people will really participate will not be known until we conduct a genomics project. There may be a limited relationship between what people say they will do and what people do. For instance, people predicted that the elderly would be less likely to participate, but the elderly in these focus groups said they would participate. Whether they agree to participate or not remains to be seen.

Application

On a subsequent genomics project with the Hmong community, we plan to use a community-based participatory action research (CBPAR) approach that partners with community leaders and professionals to build upon these results, which have been proposed or has been successful with other populations (Buseh et al. 2013a and 2013b; Johnson et al. 2009; Skinner et al. 2015; Underwood et al. 2013; Woodahl et al. 2014). We will need to create an informed consent process that takes into account people's language preferences, literacy competencies, education exposure to basic genetic knowledge, familiarity with traditional concepts of heredity, and concerns for harm (Rotimi and Marshall 2010). We can build upon traditional heredity concepts that parents transmit information to their children, illustrating that father's seed and mother's eggs each contribute 23 chromosomes to their children's 46 chromosomes, that this information develops bones, flesh, organs, and blood together, which along with behavior and environment can influence susceptibility to diseases and response to medicines. We will need to explain federal research requirements about consent, confidentiality, and anonymity; describe current requirements to provide aggregate and not individual results; emphasize the difference between clinical services and research; and give choices about storing un-identified DNA for future additional analyses. We will attempt to increase trust in the research process (National Academies of Sciences, Engineering, and Medicine 2016) by being transparent, and partnering with trusted Hmong medical professionals, community leaders, and community researchers to design and conduct the research as well as analyze and disseminate the results in CBPAR fashion.

Conclusion

The West Side Genomics Board's qualitative research project explored and identified important social, cultural, and ethical issues that are pertinent to conducting genomics research. In a CBPAR process, the academic and community member Board can use these results to plan, recruit, and conduct genomics and pharamacogenomic research projects with a wide variety of people from the Hmong community. We envision expanding the informed consent process to include in-depth information about genetics, genomics, and pharmacogenomics built on traditional heredity concepts that can support educated and non-educated Hmong adults' understanding so they can make informed decisions about participating in genomics and pharmacogenomics research projects.

Acknowledgments We acknowledge University of Minnesota's Program in Health Disparity Research for funding in 2007–2008 (Grant# PHDR-2007-005). And we gratefully acknowledge all people who helped the West Side Genomics Board including See Moua, Tzur Thong Moua, Pangdra Vang, Tzianeng Vang, and Chau Vue.

Compliance with ethical standards

Funding This study was funded by University of Minnesota's Program in Health Disparity Research for funding in 2007–2008 (Grant# PHDR-2007-005).

Conflict of interest Kathleen A. Culhane-Pera MD MA declares that she has no conflict of interest.

MaiKia Moua RN MPH PHN declares that she has no conflict of interest.

Pachia Vue MPH declares that she has no conflict of interest.

Kang Xiaaj MD declares that she has no conflict of interest.

May Xia Lo Pharm D declares that she has no conflict of interest.

Robert J. Straka Pharm D declares that he has no conflict of interest.

Ethical approval for research involving human participants All procedures performed in studies involving human participants were in accordance with the ethical standards of the University of Minnesota institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. The research project was approved by the University of Minnesota Committee on the Use of Human Subjects in Research (IRB 0711 M21884).

Informed consent Informed consent was obtained from all individual participants included in the study.

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