

Understanding Genomic Knowledge in Rural Appalachia: The West Virginia Genome

Community Project

Jennifer A Mallow, PhD, FNP-BC ¹

Laurie A Theeke, PhD, FNP ²

Patricia Crawford, MS, CHES ³

Elizabeth Prendergast, MS, CHES ⁴

Chuck Conner ⁵

Tony Richards ⁶

Barbara McKown ⁷

Donna Bush ⁸

Donald Reed ⁹

Meagan E. Stabler, PhD, CHES ¹⁰

Jianjun Zhang ¹¹

Geri Dino, PhD ¹²

Taura L. Barr, PhD, RN ¹³

¹ Assistant Professor, WVU School of Nursing; Robert Wood Johnson Foundation Nurse Faculty Scholar, WV Clinical & Translational Institute Scholar Alumni, jamallow@hsc.wvu.edu

² Associate Professor, WVU School of Nursing; Clinical Associate Professor, WVU School of Medicine, Robert Wood Johnson Nurse Faculty Scholar Alumni, American Nurses Foundation Scholar, ltheeke@hsc.wvu.edu

³ Co-Chair , WV Prevention Research Center Community Partnership Board; Director of Rural Outreach, West Virginia School of Osteopathic Medicine pcrawford@osteo.wvsom.edu

⁴ West Virginia University Prevention Research Center

eprendergast@hsc.wvu.edu

⁵ WV Prevention Research Center Community Partnership Board, chuckrayconner@yahoo.com

⁶ WV Prevention Research Center Community Partnership Board, gparichards@gmail.com

⁷ WV Prevention Research Center Community Partnership Board, bmckown@mhcc.com

⁸ WV Prevention Research Center Community Partnership Board; Rural Coordinator, Institute for Community and Rural Health , djbush@hsc.wvu.edu

⁹ WV Prevention Research Center Community Partnership Board, tobaccospecialist@strongcommunities.org

¹⁰ West Virginia University, School of Public Health, Department of Epidemiology, mstabler@hsc.wvu.edu

¹¹ West Virginia University Prevention Research Center, jzhang@hsc.wvu.edu

¹² West Virginia University Public Health, West Virginia University Prevention Research Center, gdino@hsc.wvu.edu

¹³ Chief Scientific Officer CereDx, Robert Wood Johnson Foundation Nurse Faculty Scholar Alumni, taurabarr@gmail.com

Abstract

Purpose: Rural communities have limited knowledge about genetics and genomics and are also underrepresented in genomic education initiatives. The purpose of this project was to assess genomic and epigenetic knowledge and beliefs in rural West Virginia.

Sample: A total of 93 participants from three communities participated in focus groups and 68 participants completed a demographic survey. The age of the respondents ranged from 21 to 81

years. Most respondents had a household income of less than \$40,000, were female and most were married, completed at least a HS/GED or some college education working either part-time or full-time.

Method: A Community Based Participatory Research process with focus groups and demographic questionnaires was used.

Findings: Most participants had a basic understanding of genetics and epigenetics, but not genomics. Participants reported not knowing much of their family history and that their elders did not discuss such information. If the conversations occurred, it was only during times of crisis or an illness event. Mental health and substance abuse are topics that are not discussed with family in this rural population.

Conclusions: Most of the efforts surrounding genetic/genomic understanding have focused on urban populations. This project is the first of its kind in West Virginia and has begun to lay the much needed infrastructure for developing educational initiatives and extending genomic research projects into our rural Appalachian communities. By empowering the public with education, regarding the influential role genetics, genomics, and epigenetics have on their health, we can begin to tackle the complex task of initiating behavior changes that will promote the health and well-being of individuals, families and communities.

Keywords: Rural, Genetics, Genomics, Focus groups, Community Based Participatory Research

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Genetics is the study of heredity; genomics is the study of the interaction between the genes in the genome; and epigenetics is the study of the interaction between the genes in our genome and the environment (Anderson & Monsen, 2014). Increasingly, individuals and families have to make decisions that involve both genetics and genomics in the areas of health promotion, disease prevention, screening, diagnosis, selection of treatment, and evaluating treatment effectiveness. Hence, our understanding of the link between genetics, genomics, and epigenetics is rapidly changing the way nurses and other healthcare professionals approach the health and disease of individuals, families, and communities. These advances and their application to common chronic illnesses have generated a need to translate knowledge into interventions and provide education to communities (Calzone, Jenkins, Bakos, et al., 2013).

The evidence base on epigenetics and genomic literacy (as defined above) is developing (Badzek, Henaghan, Turner, & Monsen, 2013; Calzone, Jenkins, Nicol, et al., 2013; Conley et al., 2013; Roberts, Dolinoy, & Tarini, 2014). Ensuring the public has access to the knowledge and skills needed to keep up with the technical intricacies of “genetic and genomic information” has been a focus of The American Public Health Association, Health People 2020, and the Institute of Medicine. However, members of rural communities are underrepresented in genomic education initiatives. In addition, little is known about rural populations’ knowledge, literacy, and desire to integrate this knowledge into their lives. Recently, a blueprint for genomic nursing science was developed, and emphasized that the focus for nursing should include all care settings, be addressed with varied populations, be centered on the person, family, and community, and incorporate cultural contexts (Calzone, Jenkins, Bakos, et al., 2013). Nurses and

other healthcare providers must include key stakeholder groups from rural populations as we progress in developing interventions that affect these communities.

Using qualitative research to contribute to the development of community-based interventions, and providing ongoing assessments in real world situations allows for the development of true patient and community centered interventions (Jansen, Foets, & de Bont, 2010). The Medical Research Council (MRC) guidance on developing and evaluating complex interventions (Craig et al., 2008) and a process for Community Based Participatory Research (CBPR) (Minkler & Wallerstein, 2011) are being used to guide the development of a series of community engagement projects in rural Appalachia. The first step of the MRC Framework requires identifying evidence and acquiring knowledge of the phenomenon (Craig et al., 2008). The process of CBPR involves a great deal of time and a high level of community involvement. Developing such a partnership is likely to address the health concerns of highest concern to native communities and thus, increase the probability for success (Minkler, Blackwell, Thompson, & Tamir, 2003).

The first step of this series of community engagement projects involves the assessment of rural communities' knowledge, beliefs, and desires about genetics/genomics. Assessing knowledge and beliefs can be done through questionnaires. However, eliciting rich responses related to a communities' desires and concerns may be best accomplished through community lead focus groups discussions (Kitzinger, 1995). To begin the process, town hall focus group discussions in three rural WV communities were completed. Information was collected via open discussions regarding family health history. Information was gathered about: 1) knowledge surrounding genetics, genomics, and epigenetics, 2) how participants talked to their families, friends, and health care providers about genetic and genomic information and 3) perceptions of

risks and benefits surrounding genetics and genomics. In addition, surveys of demographic information were collected. The primary purpose of this project was to assess genetic and genomic knowledge of persons living in rural WV communities.

Methods

The research team included the WV Prevention Research Center (PRC), a Community Partnership Board (CPB), an inter-professional academic research team, and identified lay leaders in three rural WV communities. The communities were selected due to their respective leadership requesting collaborative activities and involvement with the University. Together, this team developed the research questions, study methodology, identified target communities, recruited participants, collected the data, interpreted the findings, and disseminated results, which included generating future research recommendations.

The use of a CBPR approach safeguarded the voices of our rural Appalachian communities and enhanced relevance for rural populations. Prior to implementation, we followed a 7 step CBPR process which included: 1) Identifying CPB members to lead the initiative in their respective communities and by helping to integrate concepts and priorities for all three communities. 2) Utilizing the CPB partners to engage community leaders in their respective communities. 3) Facilitating a community-academic dialogue meeting to solidify a shared agenda and discuss the CBPR process. 3) Collectively determining the most effective ways to assess knowledge, attitudes, and beliefs about genomics in their communities. 4) Developing focus group talking points and survey questions. 5) Developing methods and procedures for incorporation of the broader community. 6) Seeking approval by the WVU Institutional Review Board. (This study was approved by the WVU Institutional Review Board: Protocol Id - 1301011317.) 7) Completing community focus groups.

Focus group sampling.

A focus group is an interview method that uses members of a specific group who share similar characteristics, and have information to share about a pre-determined topic (Kitzinger, 1995). While one-on one interviews may illicit responses, the type and range of information generated through the interaction of the group are often deeper and richer (Krueger, 2009). The recruitment for each forum was directed by the CPB and the research team. Approximately 100 personal invitations per community were sent to community leaders and lay persons 1-3 weeks in advance. In addition, flyers were hung in local areas (places of worship, grocery stores, community centers, etc.). CPB members suggested that the invitations and flyers not include the words “genetic” or “genomic”, but rather “genes” and “a discussion of family health history.” All participants that came to the forum were welcomed, no participant was turned away, and informed consent was not required for participants to listen or speak.

Questionnaire.

Informed consent was obtained prior to completion of demographic surveys and all participants who completed a survey received a \$20 gift card. The survey contained basic demographic information as well as qualitative and quantitative questions. The first step in questionnaire development was to provide the CPB team with some background information including: the National Human Genome Research Institute (NHGRI) vision for genomic medicine (Collins, Morgan, & Patrinos, 2003), questions and themes derived from a national GenoCommunity think tank sponsored by The Office for Public Health Genomics, in the Centers for Disease Control and Prevention ("GenoCommunity Think Tank Knowledge modules," 2011), and the topics of interest to the researchers and CPB team. All team members developed a series of questions for the survey. These questions were compiled into one document for discussion.

Multiple meetings were held to discuss the inclusion and exclusion of compiled questions. Once the survey questions were unanimously agreed upon, a letter of exemption was applied for and received from the West Virginia University Institutional Review Board.

Community forum implementation.

An important part of each forum was having a community person begin the evening with a discussion of a personal family health story. This was a way to engage the community through story-telling and gain trust by using a respected community leader. Our CPB leaders identified these key informants at all sites. The family health stories took about 15-20 minutes. Following the stories, pre-developed questions to stimulate discussion were used. In all instances, the focus group facilitator let the community lead the discussion and only talked when the conversation needed propagation or re-direction. The conversations lasted from 1 ½ to 2 hours. During each community discussion, members of the investigative team took field notes. Immediately following the conversation, participants completed the demographic surveys. Community leaders and PRC members were available to assist participants who could not read or write.

Data analysis.

The field notes were entered into a Microsoft Access database with the demographic information and responses to specific questions to identify key concepts related to family health history, genetic/ genomic literacy and the interaction between genes and the environment. Several procedures were employed to maximize the transcription quality, and to ensure that quality standards were maintained (Poland, 2003). Verification of the accuracy of the field notes was achieved by randomly cross-checking the field notes by research team members present during the focus group. An analysis team of researchers and the CPB members was formed. “An

analysis was conducted by each member of the team in order to discover the key concepts of each of the three focus groups. Each team member made a list of key results identified from being present at the focus groups and reading the transcribed field notes. Each team member then presented their personal analysis to the team. A group vote was held and consensus was considered to be achieved by a simple majority.” The results of each focus group were then summarized and are presented in the results below.

Results

Sample demographics.

A total of 93 people from three communities participated in 3 different focus group discussions (Group 1 N = 28, Group 2 N = 31, Group 3 N = 34) and 68 (73%) completed a survey. The age of the respondents ranged from under 21 to 81 years with the majority of respondents between the ages of 52 and 69 years (52%). Over half of the respondents had an annual household income of less than \$40,000. There majority were female (65%) and most were married living with their spouse (58%). Approximately 81% of the population was Caucasian and 10% African American; the percent of African Americans was higher than that in West Virginia (3%). Over 42% identified themselves as a parent and a grandparent, 48% completed at least a HS/GED or some college education, and 60% were working either part-time or full-time.

Questionnaire results.

Most participants (84%) felt that knowing family health history is “very helpful” for understanding their health and the health of their children. About 89% had at least one family member who has died of heart disease, diabetes or cancer. About half of the participants said

they would participate in genetic studies of family health history (52%), chemicals and the environment (44%), obesity and diet (47%), and inherited risk for diseases (49%).

Younger participants (<58 years) ranked the importance of knowing family health history higher on average in comparison to older participants (97.73% vs 83.33%, $p = .03$). Most respondents, believed that healthy lifestyle behaviors such as not smoking, healthy eating habits, and physical activity could prevent disease (i.e., heart attack) even when a positive family history of that disease is present. However, older participants [younger than 58 (97.37%) vs. 58 and older (77.27%), $p .01$] and females of all ages [male (100%) vs females (83.78%), $p = .05$] were less likely to believe that health promotion could mediate disease risk in the presence of a family history.

Knowledge and beliefs surrounding genetics/genomics, epigenetics.

Most participants had heard of genetics and had some basic understanding of its meaning, associating it with something that would pertain to family. The comments related to genetics focused on inheriting illness and disease, not the converse of health or hardiness. A few participants described genetics in reference to research and as “science fiction.” There was very little understanding of the interaction between our genes and genomics.

While participants did not use the word epigenetics, most participants discussed that the environment can influence health. Participant discussions identified the influence of the physical environment, such as air and water quality, pollutants, and the land (soil). Conversations centered on beliefs that the environment can affect “breathing problems” such as “coal dust in mining towns and cancer from high wires with electricity.” In addition, living where there is less pollution, opposed to areas surrounded by factories, was believed to be healthier. Mining and coal dust were topics brought up in all conversations and participants saw them as negatively

impacting their health. Lastly, cigarette smoking was viewed as a harmful behavior that can adversely influence health. In addition, some respondents perceived their current state of health as worse than those of our ancestors and attributed this to the environment.

Few participants viewed psychological stress, or how they reacted behaviorally or emotionally to a situation, as a part of their environment. When asked whether stress can play a part in disease, participants agreed that it is important, but they did not view it as a part of their environment or as a risk factor for poor health. Participants did report healthy and/or unhealthy behaviors as part of their environment and agreed that behaviors can be inherited just as genes are inherited. Participants discussed the need to “eliminate stressors” but noted that there are some psychological stressors that they could not change. Managing stress was discussed as an activity that needed to be done in reaction to a particular stressful situation, not as something to be prevented.

How participants talked to their families about genetic/genomic information.

Most participants reported that they would “just ask” if they wanted to discuss family health history with relatives. However, this discussion would normally follow a crisis or event. Participants did not discuss family health history as a prevention tool. In fact, the discussions were presented in the future tense, as “I would” do this or “I would” do that when I had the discussion. The future tense used implies that these discussions have not yet happened. Participants reported not knowing much of their family history. Many talked about looking up their personal family history prior to the focus group in preparation for the event. In some cases, participants were involved in the care of their parents, thus they were privy to the information without asking. In addition, a few participants responded that the family “would not share” this

information. These participants thought older generations were less open to sharing their personal diagnoses and issues surrounding their health.

Even though the majority of participants had no problem discussing family health history, there was agreement that mental health and substance abuse were not generally discussed within families. There were various reasons for not discussing these topics; ranging from “not wanting to upset or scare my children” to concerns about the social “stigma” attached to mental health disorders and substance abuse. Some participants did agree that it was easier to discuss these issues when family support was available, but most remarked it “would create family problems”.

Perceptions of risks and benefits surrounding genetics and genomics.

Participants were divided between those who felt there were no risks associated with genetics (e.g., “They could help you get a better understanding of your health and family health”) and those who had a fear of the unknown. There were many participants who expressed concerns that the information given to them by health care providers may not be accurate. Others had a concern about discrimination or being segregated. One example would be discussions about health insurance agencies gaining access to personal information that could subsequently lead to difficulty obtaining coverage. Some participants expressed a sense of futility over gaining information about risk of disease without the ability or knowledge to prevent occurrence. Respondents also expressed fear of learning about undisclosed adoptions through genetic testing.

Overwhelmingly, respondents wanted to participate in the study to gain knowledge. This knowledge seeking was expressed in all discussions. Community members wanted to know about diseases, signs and symptoms. In addition they questioned ways to prevent or decrease their risks, and how to teach their children.

Discussion

Genetic and genomic knowledge.

These rural communities understand that genetics, lifestyle choices, and the environment can influence health and disease. However, many people believed that our genes are our destiny – they are fixed and ultimately set the limits of the diseases we get and how we will respond to them. Scientific advancements have shown that lifestyle choices and environmental factors can change the way genes are expressed and that these changes can be passed on to the next generation, affecting disease risk and outcomes (Gapp, von Ziegler, Tweedie Cullen, & Mansuy, 2014). Helping patients and communities understand the concepts of epigenetics may serve as a powerful strategy to promote healthy lifestyle changes. It has been suggested that a broader understanding of how genomics relates to chronic conditions could help clinicians better assess risk and plan management of patients (Taylor et al., 2013). Conversely, it is obligatory that providers understand the community knowledge so that care can be comprehensive and culturally sensitive (Badzek et al., 2013).

The National Health and Genomics Research Institute has supported community conversations on genetics and genomics in primarily urban settings (Collins et al., 2003). The current study is one of the first to conduct these conversations in a rural setting. The information we have gathered provides direction for future genetic education targeting rural communities, such as those in the Appalachian region.

The information learned in this project could be used to identify target areas of focus for culturally competent nursing interventions that give knowledge and address the fear that people experience related to potential heritability of illness. The identification of fear as an emotion experienced by these participants is new and may require intervention. Fear is a known

psychosocial stressor that is linked to negative health outcomes such as depression, making this finding significant (Krishnan, 2014). Based on these themes we would approach genomic education interventions by addressing the concurrent fear that members of these rural communities have expressed.

Genetic literacy affects family conversation.

The general public's genetic literacy is modest and for rural communities with high health disparities and low socioeconomic status (SES), genetic literacy is estimated to be even lower (Lea, Kaphingst, Bowen, Lipkus, & Hadley, 2011). Therefore, educational efforts to address health literacy, combined with genetic education, should be implemented (Kutner, Greenburg, Jin, & Paulsen, 2006). These findings confirm the importance of oral reporting and the use of the narrative to engage individuals with limited health literacy. Recent evidence within a Latino population supports the importance of alternative methods like using lay health advisors who understand the community to engage health illiterate people (Kaphingst, Lachance, Gepp, D'Anna, & Rios-Ellis, 2011). The challenge for genomic medicine is to provide individual risk estimates in a manner that motivates individuals to reduce risky behaviors and embrace positive health behaviors.

Developing understandable and usable information about genomics and how it applies to health will be critical for implementing community-based health promotion initiatives. Engaging community leaders will be critical in teasing out the best approach to providing individualized risk plans within the context of culture and community history. Similar to the literature, these findings suggest open family dialog, including children and grandchildren to begin this process. Genetic knowledge is lower in older individuals and these individuals are also more likely to attribute disease to genetics, rather than behavior (Ashida et al., 2011). Intergenerational

educational efforts may help to alleviate these age disparities. All of our participants were knowledge seeking, which is consistent with recent studies in other rural populations (Kelly, Andrews, Case, Allard, & Johnson, 2007). They understood their limitations in understanding how to use family health history and were eager to learn.

Perceptions of risks and benefits.

Our conversations did reveal that fatalistic views of health and disease still exist in rural Appalachia. Lifestyle choices are complex and mediated by cultural beliefs (denial, fatalism, and resistance to change), economic stability, and attitude. The perceived role of genetics and heredity (i.e., family health history) varies and is mediated by a personal history of disease; those who have a positive family history for a disease are much more likely than those with a negative history to attribute the disease to genetics (Lea et al., 2011). Perceived risk of developing a disease and fatalism will affect how individuals respond to genomic information and motivate behavior change (Drew & Schoenberg, 2011). In addition, we understand that people who experience identified social determinants of health like poverty and poor access to fresh foods and those not currently having symptoms of a disease may be less likely to adopt health promoting behaviors (Koh, Piotrowski, Kumanyika, & Fielding, 2011).

Evidence suggests that significant access barriers exist for genetics services in rural areas (Hawkins & Hayden, 2011; Kelly et al., 2009). Most populations deemed “fatalistic” are also low resource communities who lack health insurance or who have low access to health care and have less education. Contrary to popular belief, Appalachian fatalism is not a cultural tradition, rather the result of poverty and isolation (Theroit, 2001). Fatalism can be addressed by using community engaged research approaches to gain the trust and respect necessary to implement educational initiatives. In addition, identifying individuals who changed behavior and thus

avoided diseases even with a positive family history of disease will be important to provide concrete, relevant examples.

Conclusion

This project is the first of its kind in West Virginia and is foundational to future infrastructure development for serving these communities. Future initiatives that extend genomic projects into our rural Appalachian communities are needed. This success of this project is owed to the strong partnership with our Community Partnership Board (CPB) who identified and facilitated interaction with our target communities. Advancing the epigenetic knowledge of rural communities requires ongoing dialogue with rural residents, respected community leaders, and community health professionals. By empowering the public with education regarding the influential role genetics, genomics, and epigenetics has on health, communities can begin to tackle the complex task of initiating behavior changes that could lead to enhanced health and well-being of individuals, families and communities. Involvement of the community at all stages of development will enhance acceptability and increase the likelihood of community self-sustained positive culture of health.

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