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"I don't believe it." Acceptance and skepticism of genetic health information among African-American and White smokers

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ABSTRACT

Rationale: Effective translation of genomics research into practice depends on public acceptance of genomics-related health information.
Objective: To explore how smokers come to accept or reject information about the relationship between genetics and nicotine addiction.
Methods: Thirteen focus groups ($N = 84$) were stratified by education (seven < Bachelor's degree, six ≥ Bachelor's degree) and race (eight black, five white). Participants viewed a 1-min video describing the discovery of a genetic variant associated with increased risk of nicotine addiction and lung cancer. Next, they provided their opinions about the information. Two coders analyzed the data using grounded theory.
Results: Pre-video knowledge about why people smoke cigarettes and what *genetic risk* means informed beliefs about the relationship between genes and addiction. These beliefs were not always consistent with biomedical explanations, but formed the context through which participants processed the video's information. This, in turn, led to information acceptance or skepticism. Participants explained their reactions in terms of the scientific merits of the research and used their existing knowledge and beliefs to explain their acceptance of or skepticism about the information.
Conclusion: Laypeople hold complex understandings of genetics and addiction. However, when lay and biomedical explanations diverge, genetics-related health information may be rejected.

Advances in genomics research hold promise for improving clinical outcomes and population health (Green et al., 2015), although this promise depends on the translation of results into clinical and public health practice. This translation effort requires helping the public understand that health problems tend to be multifactorial—that is, they are caused by a combination of genetic, environmental, and behavioral risk factors (McBride et al., 2015). For example, certain genetic variants on the nicotinic cholinergic receptor are associated with an increased risk of severe nicotine dependence and an increased risk of lung cancer independent from the risk conferred from severe nicotine dependence (Bierut, 2010). Yet, the high-risk allele cannot be expressed unless the person with the variant uses tobacco.

Two possible strategies for promoting public health by providing information about the multifactorial nature of nicotine addiction and lung cancer are attempting to motivate smokers to quit by informing them that they have a high-risk genotype (Hartz et al., 2015; Smerecnik et al., 2012) and tailoring smoking cessation therapies to genotypes (Marteau et al., 2012). Informing individuals that they have a high-risk variant can increase their lung cancer risk perceptions (Lipkus et al., 2015; Sanderson et al., 2014; Shepperd et al., 2013), worry (Shepperd et al., 2013), and 30-day cessation (Lipkus et al., 2015). However, systematic reviews, a meta-analysis, and a randomized controlled trial have each questioned the efficacy of using personalized genetic testing to motivate smoking cessation and other health behavior changes (Godino et al., 2016; Hollands et al., 2016; Marteau et al., 2010).

Another consideration is that individuals with limited access to healthcare may lack affordable or convenient access to genomic technologies, thus limiting their exposure to genomic information to mass media news reports and social networks. Because medically underserved populations have lower cessation rates (US Department of Health and Human Services, 2014)), translating genomics research findings without considering healthcare access

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could inadvertently exacerbate health disparities. Relatedly, most genomics research is conducted with samples that are primarily white, highly educated, and motivated to engage in healthy behaviors (McBride et al., 2015). The reach of genomics-related health advances and their consequent health benefits will be limited if we fail to consider the perspectives of socio-demographically diverse groups.

To understand how people understand and act on information about the combined effect of genetic and behavioral risk factors while being cognizant of the likely inaccessibility of genomic testing for medically underserved populations, the present study initially sought to identify gaps in the understanding of genomics research conveyed via the mass media among socio-demographically diverse smokers. One area of concern was that the news media might inadvertently discourage engaging in healthy behaviors because it does not always communicate genetics research findings effectively (Condit, 2007; Donelle et al., 2004; Petersen, 2001). Our conceptual framework asserted that information about the genetic basis of nicotine addiction and lung cancer might produce unfavorable changes in health beliefs and attitudes that can lead to smoking cessation, such as lower perceived harm from smoking and lower quitting self-efficacy (Jeong, 2007; Sanderson et al., 2009; Smerecnik et al., 2009). However, it also allowed for the possibility that participants' interpretations of the information might be influenced by their current beliefs about genes and genetics, by the extent to which they held multifactorial causal beliefs about nicotine addiction and lung cancer, by the extent to which they understood the mechanisms that linked genes to addiction, and by the extent to which genes do or do not determine one's fate (Bates et al., 2003; Cameron et al., 2012; Condit, 2010, 2011; Condit and Shen, 2011; Wang and Coups, 2010). The results were intended to be used to develop health communications that conveyed these complex concepts in a way that was accurate, clear, meaningful, and useful.

The study methodology was based on the constructivist paradigm, which asserts that a person or group's reality is based on specific social and individual experiences (Guba and Lincoln, 1994). Critically, these realities are not static and can be refined. This paradigm is consistent with the study's focus on explicating how individuals understand the relationship between genes and nicotine addiction (Charmaz, 2006), with the study's goal of improving genetic communication (i.e., “refining realities”), and with the overarching conceptual framework that was used to guide the focus groups.

Halfway through data collection, it became apparent that participants were very skeptical about the validity of the genetics research findings being presented to them. This skepticism was unexpected, and by the end of data collection (using the same interview guide throughout), the research team noted that such widespread skepticism seemed to reduce participants' receptivity to genetics-related health information. Recognizing that such skepticism might reduce the effectiveness of communication in actual public health and clinical settings, our planned analyses shifted course from identifying better communication strategies to exploring the process by which smokers come to accept or reject information about a genetic basis for nicotine addiction.

1. Method

1.1. Study overview

Thirteen focus groups ($N = 84$) were conducted in the St. Louis metropolitan area from April to August 2012. Participants stratified by race (African American, White) and educational attainment (<Bachelor's degree, ≥Bachelor's degree). Four groups fell within the higher education/African American and lower education/African American strata, two groups within the higher education/White stratum, and three groups in the lower education/White stratum. Assuming six to eight participants per group, we estimated reaching thematic saturation after two to three groups per stratum. We allowed for the possibility that additional groups might be needed. Mean attendance was six participants per group (range three to ten).

1.2. Participants

All study materials and procedures were approved by the Washington University in St. Louis Human Research Protection Office. Recruitment occurred in the local community using several methods, including distributing and posting flyers, word of mouth, and a volunteer research participant registry. Individuals were eligible for participation if they were 18 years or older, had smoked at least 100 cigarettes during their lifetimes, currently smoked every or some days of the week, self-identified as African American or White, and attended to the news at least once in the previous week. Participants could not consider themselves a genetics expert but needed to have basic knowledge of the terms “gene” or “genetic” (e.g., “passed down”, “where you get your traits from”). This requirement was because the initial study goal of examining how smokers conceptualize the idea that there is a genetic basis for nicotine addiction was predicated on participants having at least some idea of what the word “gene” meant. We were also concerned that including individuals with no knowledge of genetics would marginalize them relative to other participants and would limit the extent to which they could participate meaningfully in a discussion about genetics.

1.3. Procedure

Participants provided written informed consent and verified their demographic and tobacco history information. After introductions, the facilitators asked participants why they thought people smoke and what they thought the terms *genes* and *genetics* meant. Then, the terms *genes* and *genetics* were briefly explained in lay terms to so the conversation could proceed with all participants having a minimum level of common understanding. Participants were asked to convey their beliefs about the role of genetics in the etiology of chronic health conditions and in cigarette smoking. Next, they viewed a 1 min Associated Press video clip that described the discovery of a genetic variant associated with severe nicotine addiction and an increased risk of lung cancer (http://youtu.be/sO3X8xBr8YQ). The video cited a geneticist who described the variant as a “double-whammy gene” because it has dual negative effects (i.e., a “whammy”): one effect maintains addiction and one effect increases lung cancer risk. Last, participants were asked to provide their thoughts about the believability and potential utility of the information presented in the video. Groups lasted 60–90 min and were audio-recorded. Each participant received a $40 gift card.

Each focus group was led by a facilitator who conducted the group according to an interview guide composed of open ended questions (Appendix 1) and a note-taker, both of whom were race-matched to the group. The questions were crafted to be flexible enough to elicit beliefs related to the concepts identified in prior research that examined genetics beliefs (e.g., Condit, 2010), while allowing the group to convey novel ideas (Charmaz, 2006). If group members did not spontaneously mention a construct of interest, moderators probed for it. To reduce the risk of bias, the questions and probes targeted the concepts indirectly. For example, to elicit concerns about discrimination, participants were asked whether