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Receptiveness to participation in genetic research: A pilot study comparing views of people with depression, diabetes, or no illness

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ABSTRACT

Background: Genetic research in human health relies on the participation of individuals with or at-risk for different types of diseases, including health conditions that may be stigmatized, such as mental illnesses. This preliminary study examines the differences in attitudes toward participation in genetic research among individuals with a psychiatric disorder, individuals with a physical disorder, and individuals with no known illness.

Methods: Seventy-nine individuals with a history of diabetes or depression, or no known illness, underwent a simulated consent process for a hypothetical genetic research study. They were then surveyed about their willingness to participate in the hypothetical study and their attitudes about future and family participation in genetic research.

Results: Participants with and without a history of depression ranked participating in genetic and medical research as very important and indicated that they were likely to participate in the hypothetical genetics study. Expressed willingness to participate was generally stable and consistent with future willingness. Individuals less strongly endorsed willingness to ask family members to participate in genetic research.

Conclusion: Individuals with and without a history of mental illness viewed genetic and medical research favorably and expressed willingness to participate in real-time and in the future. Informed consent processes ideally include an exploration of influences upon volunteers' enrollment decisions. Additional empirical study of influences upon genetic research participation is important to ensure that volunteers' rights are respected and that conditions that greatly affect the health of the public are not neglected scientifically.

Genetic research is leading to a greater understanding of many diseases and has accelerated the process of identifying novel interventions to prevent and treat diverse physical and mental disorders (Jordan and Tsai, 2010; Lau and Eley, 2010). Analysis of large-scale genomic data has helped to discern valuable biomarkers, providing insights into the genetic correlates and contributions to disease and, in some cases, predicted responsiveness to pharmacological agents (Bloss et al., 2010; Hirschhorn, 2009; Jordan and Tsai, 2010; McCarty et al., 2007). In the context of neuropsychiatric conditions, genetic research may yield new strategies for earlier and more accurate diagnoses for mental disorders, improved treatments, and more positive perceptions of these illnesses in society (Braff and Freedman, 2008; Erickson and Cho, 2011; Hoop et al., 2010; Spriggs et al., 2008; Wright and Kroese, 2010).

Advances in psychiatric genetics have lagged, however, in part because of scientific challenges that accompany the fact that mental illnesses are typically complex disorders influenced by many interdependent genetic and environmental factors (LaPorte et al., 2008). Psychiatric genetics research also has intrinsic challenges because of the many issues associated with human research involving ill and potentially vulnerable volunteers (Coors and Raymond, 2009; Ryan et al., 2015). While all genetic inquiry raises certain ethical, legal, and social issues, psychiatric genetic investigation presents additional concerns (Laegsgaard and Mors, 2008). For instance, mental illness involves capacities relevant to a person's identity to a larger extent than somatic illness (Laegsgaard and Mors, 2008). Moreover, it is unclear how the "geneticization" of mental illness will affect the stigma and guilt often associated with these disorders (Hoop, 2008). Although some

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theories claim that evidence of a genetic component for mood disorders would shift responsibility away from the self and to one's biology, opposing perspectives claim that a genetic model for mood disorders may increase the perceived gravity and unchangeable nature of these illnesses, thus labeling people prior to the emergence of illness symptoms and increasing their potential stigma (Erickson and Cho, 2011; Laegsgaard and Mors, 2008; Meiser et al., 2007; Spriggs et al., 2008; Wilde et al., 2010). Empirical studies suggest that when the role of genetics is explained to individuals with psychiatric disorders and their families in the context of the role of the environment (i.e. genetic counselling), outcomes are positive (Austin and Honer, 2008), internalized stigma can decrease (Costain et al., 2014a, 2014b; Hippman et al., 2016), and empowerment increases (Inglis et al., 2015).

The ability of patients, society, and the scientific community to reap the potential benefits of genetic research will depend on the ethical inclusion of volunteers with psychiatric disorders such as depression, which are stigmatized conditions with genetic underpinnings that are complex and incompletely understood. At this time, there is limited research regarding individuals' willingness and attitudes toward participation in genetic research (Bui et al., 2014; Erickson and Cho, 2013; Lawrence and Appelbaum, 2011; Lemke et al., 2010). To this end, the authors conducted a project involving a simulated consent process for a hypothetical genetics research study. We sought to understand the attitudes of individuals who would likely be eligible for genetic research enrollment in order to learn the views regarding their willingness to participate in the proposed hypothetical genetic research study, to participate in genetics research in the future, and to ask family members to participate in research described in the simulated consent procedure. We compared whether views of people with a history of mental illness (i.e., in this case, depression) or a physical illness (i.e., in this case, diabetes) differ and whether these views differ from the views of people without a history of illness. We explored associations between expressed willingness, personal characteristics, and other attitudes related to genetics research.

1. Methods

The Human Research Review Committee (IRB) of the University of New Mexico (UNM) provided prospective approval of this minimal risk study.

1.1. Study population

Adult participants were recruited through flyers posted in outpatient clinic settings at a university-based medical school for participation in the simulated consent process for a hypothetical genetics research project. Individuals who reported having depression or diabetes, or no known illness were invited to volunteer. All volunteers provided written informed consent.

1.2. Procedures

Our study procedure is depicted in Fig. 1. Volunteers who self-reported a past diagnosis of depression were assigned to a depression simulated consent process; volunteers who reported no prior depression experience but had history of diabetes were assigned to a diabetes simulated consent process; and those with no illness experience were randomly assigned to either the depression simulated consent process or to the diabetes simulated consent process. Our project was not a deception study, i.e., potential participants were informed that they would not be enrolled in an actual genetic research protocol and that we were trying to learn about their views by engaging in a simulated consent process.

Participants underwent a simulated informed consent process resembling those used in other genetic studies. A trained interviewer explained the hypothetical protocol and explained to participants that they would be asked to fill out questionnaires about their physical (or mental) health and family history of health and give a blood sample, which will be stored indefinitely and used by future studies. Risks and benefits, information about confidentiality information, policies regarding research-related injuries, and payments concerning the hypothetical study were also explained. Participants read their respective simulated consent form and discussed it with the interviewer. This interaction was intended to resemble the consent interaction at the beginning of an actual research study.

1.3. Measurement of outcomes

Upon completion of the simulated consent process, a survey was administered to study participants to assess their attitudes regarding the consent process and their willingness to participate in genetics research resembling the hypothetical study. This survey included 31 scaled or open-ended questions concerning the simulated consent experience and attitudes toward research participation, 11 demographic questions, and 7 additional items related to the interaction with the interviewer during the simulated consent experience. The survey took approximately 30 min to complete. Study participants were compensated $20 for their time and effort.

1.4. Main outcome measures

Main outcome measures were attitudes regarding respondents' willingness to (1) participate in the proposed hypothetical genetic research study, (2) participate in genetics research in the future, and (3) ask family members to participate in a trial like the one described in the simulated consent procedure. The first outcome was addressed in two questions. Participants were first asked if they would agree or not agree to participate in the described hypothetical genetic study (see Supplementary Material). Measures included respondents' willingness to participate in the genetic research study (rated on a 9-point scale; yes or no). "Endorsements" of beliefs and "strong agreement" were defined by dichotomizing 9-point Likert items as 6 and greater, or 5 or less.

Secondary outcome measures included respondents' willingness to participate in the genetic research study on a 9-point scale, under various influences (see Supplementary Material and Table 2b), including: a) if one had the illness being studied in the genetic study, b) if the study concerned a disease that a family member had, c) if the study in question would yield personal or family benefit, d) if the study in question would yield societal benefit (but no personal benefit), and e) if the study would yield scientific understanding (but no immediate personal or societal benefit).

1.5. Statistical analysis

We summarized overall trends of respondents' perspectives on endorsements of research and their influences on participation willingness using descriptive statistics such as T-tests and chi-squared tests as appropriate. As a secondary aim, we assessed the association between participation willingness and covariates.

Covariates. Covariates in this study were respondent age, gender, race, self-reported history of illness, prior experience with a genetic test, endorsements of the importance of medical and genetic research, and family history of illness. Illness histories were not based on medical records but on self-report.

Tools. We took responses of multiple items as a vector outcome