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Views of the importance of psychiatric genetic research by potential volunteers from stakeholder groups

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ABSTRACT

Few studies have explored potential volunteers' attitudes toward genetic research. To address this gap in the literature, we developed an empirical project to document views held by individuals who may wish to enroll in genetic studies involving mental disorders. People living with mental illness, family members of people with mental illness, and community comparison volunteers were queried regarding their views on the importance of genetic research generally, in comparison with medical research, and in relation to 12 health conditions categorized in four types. T-tests and univariate and multivariate analysis of variance were used as appropriate. Participants expressed support for the importance of genetic research (mean = 9.43, scale = 1–10) and endorsed genetic research more highly compared with non-genetic medical research (mean = 9.43 vs. 8.69, *P* value = < 0.001). The most highly endorsed genetic research was for cognitive disorders, followed by mental illness disorders, physical illness disorders, and addiction disorders (means = 8.88, 8.26, 8.16 and 7.55, respectively, *P* value = < 0.001). Overall, this study provides evidence of strong endorsement of genetic research over non-genetic research by potential volunteers.

Four hundred and fifty million people live with mental illnesses, placing these conditions among the leading causes of premature death and disability worldwide (World Health Organization, 2001; Horton, 2017). People in every nation, community, and family are affected by the direct and indirect burdens of mental illness (World Health Organization, 2001). Even in economically-established countries, most individuals with mental disorders do not receive sufficient services and are left to cope as best they can on their own (World Health Organization, 2001). Adding to this tragedy, many living with mental disorders are victimized for their conditions and become targets of stigma and discrimination (World Health Organization, 2001).

Although effective treatments exist for mental disorders such as anxiety, depression, and psychosis, the burden of these conditions continues to grow (Whiteford et al., 2013). Innovative research into the origins of mental disorders could lead to new methods of prevention or treatment (Cuijpers et al., 2005; Schoneveld et al., 2017). The Human Genome Project has already been investigating the established genetic contributions to mental disorders (Cowan et al., 2002). Genetic research over the past decade has significantly advanced the identification of associations between candidate genes and a number of disorders. Despite some promising findings with respect to copy number variants and single-gene mutations found in psychosis and autism, psychiatric genetic research has progressed more slowly than anticipated (Fiksinski et al., 2017; Burmeister et al., 2008). Additionally, relatively few resources have been invested into the development of novel therapeutics for psychiatric illnesses in recent decades (Saraceno et al., 2017). For this field to sustain continued advancement in identifying genetic associations and intermediate endophenotypes, deep and sustained engagement with individuals living with mental disorders, individuals at risk for mental disorders (such as close family members), and volunteers who can serve as appropriate comparison subjects in genetic studies is vitally important (Cuijpers et al., 2005).

A large and diverse group of research participants is critical to the study of genetic variation, gene-environmental interaction, and disease expression (Henderson et al., 2008). DeLisi and Bertisch (2005) found that a majority of family members who had other (in some cases multiple) affected family members with schizophrenia would want to be tested if a genetic test were to become available. Since then, some have investigated public interest in predictive genetic testing (Wilde et al., 2010), while many more have examined the concerns, attitudes, and knowledge of health professionals in particular, who are tasked to use genetic information with their patients (Klitzman et al., 2014; Wilde et al., 2014; Salm et al., 2015). Fewer studies have assessed the concerns of at-risk individuals, including vulnerable populations such as youth and pregnant women (Inglis et al., 2018; Laegsgaard et al., 2009), and even fewer have sought to compare potential participants'

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views of the societal importance of genetic research on mental disorders with those of their healthy counterparts (Laegsgaard and Mors, 2008; Roberts and Kim, 2017). Still, little empirical work has investigated the attitudes of potential participants in psychiatric genetics research and the views of those stakeholders who might choose to enroll in genetic studies (Laegsgaard et al., 2009). For example, little research has explored potential participants' views of the societal importance of genetic research on mental disorders (Laegsgaard et al., 2009).

To address these gaps in the literature, we developed an empirical project to document views held by stakeholders in psychiatric genetic research, namely, individuals who might volunteer to enroll in genetic studies or who might benefit, directly or indirectly, from such investigations. We focused on (1) individuals living with mental illness, (2) family members of individuals living with mental illness, and (3) individuals who do not have a personal or family history of mental illness who might serve as appropriate comparison subjects.

1. Methods

1.1. Study design

For this NIH-funded, IRB-approved project, key stakeholders were surveyed via face-to-face interview to assess their: (a) understanding and attitudes toward ethical issues in psychiatric genetic research, (b) perceptions of participant-oriented safeguards, and (c) knowledge and intentions regarding use of genetic information in making significant decisions. Three groups of people who are potential psychiatric genetics research participants were surveyed and their responses compared: (1) people with mental illness, (2) first-degree family members of people with mental illness, and (3) community comparison volunteers with no personal or close family history of mental illness. These groups were identified as key stakeholders for psychiatric genetic research because such investigation has direct relevance for people with mental illness and their relatives and healthy people are indirect future and current societal beneficiaries.

1.2. Study population and procedures

One hundred and eighty two volunteers from the communities surrounding Milwaukee, WI, and Albuquerque, NM were surveyed. Participants learned of the study through advertisements on clinical research websites and postings at clinics. Participants provided written informed consent after a thorough discussion of the study and were compensated with a $50 gift card. The interviews were approximately 2 h long and included 344 survey questions and open-ended items on ethical, legal, and social issues regarding psychiatric genetic research.

1.3. Survey

A novel survey instrument was developed for this project based on published scientific and ethics literature related to psychiatric genetic research, as well as findings from 12 focus groups. A total of 48 individuals participated in the focus groups, including members of each stakeholder group. In addition, several published instruments were considered for possible use in the survey/interview phase of the project. The Brief Symptom Inventory and SF-12 and REAL-G were included, along with new questions (e.g., knowledge of genetics, attitude measures). The survey was pre-piloted, revised, and piloted. The survey ultimately contained 344 items and was designed to assess 13 different aspects of ethical, legal, and social issues related to psychiatric genetic research.

For this analysis, perceptions of the importance of genetic research were assessed and compared with responses regarding the importance of medical research more broadly. The importance of genetic research was queried in relation to 12 health conditions: alcoholism, Alzheimer's disease, anxiety disorder, asthma, autism, bipolar disorder, colon cancer, drug addiction, heart disease, major depression, schizophrenia, and type 2 diabetes. In addition to being evaluated individually, the 12 health conditions were combined into 4 disorder types:

1. Cognitive disorder: Alzheimer's disease
2. Mental illness disorders: anxiety disorder, autism, bipolar disorder, major depression, and schizophrenia
3. Physical illness disorders: asthma, colon cancer, heart disease, and type 2 diabetes
4. Addiction disorders: alcoholism and drug addiction

Question responses were rated on a scale from 0 to 10 (0 = Not important at all, 5 = Somewhat important, 10 = Extremely important).

1.4. Ethics safeguards

The study protocol was approved by the IRBs at the Medical College of Wisconsin and University of New Mexico. As part of the survey procedure, all participants were provided with background information about the study along with a printed hard-copy consent form. Collected data were encoded with numbers and analyzed with identifiers removed.

1.5. Data analysis

The main covariates were gender (male or female) and race/ethnicity (white or other). Categories of full-time and part-time employed were pooled into one employed category. Categories of full-time and part-time student were pooled into one student category. Race/Ethnicity was pooled into two categories, White and Other (Other = American Indian or Alaska Native, Asian or Asian American, Black or African American, Hispanic, Latino or Spanish origin, Native Hawaiian or Pacific islander), to have a balanced group.

The importance of genetic research was analyzed using analysis of variance (ANOVA) tests, paired t-tests and multivariate analysis of variance (MANOVA) tests. The importance of genetic research for disorder types was analyzed using analysis of variance (ANOVA) tests, repeated measures ANOVA tests, multivariate analysis of variance (MANOVA) tests and independent t-tests. Multivariate linear regression analysis was performed to assess the association between the primary outcome controlling for potential confounders. We used generalized estimating equations (GEE), a method suitable for correlated data that are observed in clusters. We included the background characteristics listed in Table 1 as potential confounders.

1.6. Software

We used SPSS Statistics (version 24) for all statistical analyses and R software (R version 3.0.0, GNU project).

2. Results

2.1. Background characteristics of community members

Volunteers for this study included adults with a self-reported serious mental illness (n = 71); adults with a self-reported first or second-degree family member with serious mental illness (n = 54); and individuals with no diagnosed mental illness and no known first or second-degree relatives with mental illness (i.e., community comparison volunteers; n = 57).

Overall, the majority of respondents were female (57.1%), white (62.6%), not married or with a long-term partner (56.6%, statistically significant difference between the community groups – P value = 0.045), with a college degree (51.6%), and employed (47.7%, statistically significant difference between the community groups – P value = 0.042). The average age of participants was 42.3 years.