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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.

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Contributors

Dr. Laura Roberts designed the study and wrote the protocol. Dr. Jane Kim managed and undertook the statistical analyses. Dr. Laura Roberts wrote the first draft of the articles, and both authors contributed to and have approved the final article.

Keywords

Informed consent; Genetics; Depression; Attitudes; Research participation

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 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, 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, 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.

METHODS

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

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.

Procedures

Our study procedure is depicted in Figure 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.

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 minutes to complete. Study participants were compensated $20 for their time and effort.

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 supplemental 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).

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 (i.e. willingness to participate now, future willingness to participate in the future, future willingness to participate in genetics study somewhat similar to the read protocol). Because items within each vector outcome were correlated for each individual, we used generalized estimating equations (GEE) with unstructured correlation structures to model associations between repeated outcome measures and covariates. Covariates used for the GEE model were indicators for the item type as well as the covariates listed above.

Missing data—Of the ninety-one individuals who were invited to participate, 12 individuals declined to participate, leaving 79 individuals in the study. Outcomes were missing for 2 out of 79 records. A complete case analysis was performed on 77 observations.

Software—We used R Studio v0.99.892 for all statistical analyses.

RESULTS

Study population characteristics

Our study had 77 adult volunteers. A majority of respondents were women (54%). Mean age was 42.5 years +/− 13.2 years. A majority of respondents were not married (i.e. either single, divorced or widowed, 56%). Ninety-two percent of study participants had at least a high school or GED diploma, and 57% had at least some college or higher graduate degrees. A summary of the study participant characteristics, stratified by past diagnosis (from self-report), is reported in Table 1.

Previous research experience and family history—Most respondents, 87% (n=67), reported a family history of either physical or mental illness. Approximately 42% of study participants reported a family history of both diabetes and depression.

Among all volunteers, only 13% (n=10) of respondents had ever been asked previously to have a genetic test for any reason. Moreover, only 13% of respondents had a family member who had a genetic test in the past. A small proportion of respondents (27%, n=21) had ever participated in any medical research study other than the current study.

Perceived importance of research and likelihood of participation

Overall trends—Respondents on average expressed positive views regarding the importance of genetic research and medical research (means = 8.15 to 8.38 on a 9-point scale, SDs = 1.32). Table 2 reports respondents' average endorsements of the importance of research specific to diagnosis group. Of all respondents in the study, an overwhelming majority, 94% (n=74), endorsed the importance of genetic research and a similarly high proportion (95%, n=75) endorsed the importance of medical research that does not involve genetics.

Respondents on average endorsed the view that people should participate in genetic and medical research (means = 7.24 to 7.68, SDs = 1.70). A greater majority, 86% (n=67), of participants agreed that people should participate in genetic research, and 79% (n=62), agreed that people should participate in medical research. Such trends were consistent across individuals with varied self-reported histories of health.

Influences of participation willingness

Overall trends—Participants rated their influences on their willingness to participate in the genetic study (see Table 2b). Out of the nine given circumstances, participants were most influenced to participate in the genetic study "if the research would help [them] or [their] family in some way" (mean = 8.48, SD = 1.05). Table 2b summarizes the rankings of these influences.

Willingness to participate, willingness to involve family members, and predictors of willingness outcomes

Participation Willingness – overall trends—When asked in simple terms if they would agree or disagree to participate in the described genetic research study, 94% (n=72) of respondents indicated that they would participate. When asked to rate their participation likelihood on a 9-point scale, they expressed on average a moderately high likelihood of participation (mean = 7.32, SD=1.80). Of the people who initially agreed to participate in simple terms, 15% of these study participants rated their likelihood as only "somewhat likely" or below. On the other hand, all individuals who said they would not agree to participate in the initial question held consistent views and subsequently responded that they were either not at all likely to somewhat likely to participate in such a study. A high proportion of study participants expressed willingness to participate in a genetics study in the future (85%).

Exploratory findings related to expressed willingness: Perceived importance of research was associated with higher levels of participation likelihood related to genetic research (β from GEE = 0.57, 95% CI = [0.30, 0.83], p-value = 3*10^−5). For example, a 2-point increase in respondents' average perceived importance of research was associated with a 1-point increase in participation likelihood. Moreover, a strong endorsement of medical and genetic research was associated with an increased likelihood of participation willingness (β from GEE = 0.44, 95% CI = [0.14, 0.74], p-value = 0.004).

Willingness to involve family members in genetic research – overall trends— Irrespective of family history of illness, respondents indicated that they would be moderately willing (mean = 6.6, SD = 2.4) to ask family members to participate in the hypothetical genetic study described in the simulated consent process, and 70% (n=54), reported that they would be likely or very likely to ask family members to participate.

A strong endorsement of the importance of medical and genetic research was associated with a greater likelihood to ask family members to participate in genetic research (β from linear model = 0.49, 95% CI = [0.10, 0.88], p-value = 0.02). Similarly, a perceived importance of medical and genetic research was associated with a higher likelihood of asking family members to participate in genetic research (β from linear model = 0.81, 95% CI = [0.30, 1.32], p-value = 0.003).

Self-reported family history of illness was found to be associated with a positive willingness to participate in such a genetic study. Individuals with family history of illness endorsed participation likelihood compared to individuals without or unsure of family history of illness. Of respondents who reported a family history of illness, 97% (n=67) of individuals responded with a positive willingness to participate in a genetic research study, compared to 70% of individuals who reported no family history of diabetes or depression (n=10) (p-value from pearson chi-squared test of association = 0.013).

DISCUSSION

This is the first published study, to our knowledge, to examine genetic research participation willingness in the context of a carefully constructed simulated informed consent process, comparing individuals with a mental illness (depression), physical illness (diabetes), or no such history of illness, and to assess influences on the expressions of willingness or unwillingness by these potential volunteers. For our study, we engaged with individuals in the locale of an academic medical center using recruitment techniques routinely used in health research. These individuals were certainly, on some level, receptive to research participation, as evidenced by their willingness to engage in our project and, not unexpectedly, we found that these individuals view genetic and medical research as very important. Most but not all of those in our study indicated that they would likely participate in the genetic research project described in the simulated consent process, now and even more so in the future. The overall pattern of willingness to participate was no different by history of illness (i.e., mental illness, physical illness, or neither) and appeared to be greatly shaped by individuals' hopes that their participation might help to serve others, science or medicine, or their own health. Self-reported family history of depression or diabetes appeared to positively influence expressed willingness to participate in the proposed genetic research project. Interestingly, among the small minority who consistently expressed unwillingness to participate in the genetic research project, there was some openness to future participation. Most individuals in our project indicated that they would be willing to involve family members in a genetic research study, but this this was endorsed less strongly than personal willingness.

Whether individuals with mental illness should have special and additional protections in the context of human research has been debated for many years without resolution. Our findings suggest that there is no clear case that individuals with depression who are considering participation in genetic research require an "exception" to usual approaches or rules in human research. In our study, individuals with self-reported depression expressed views that were similar overall to those of individuals with a chronic physical illness, namely diabetes, and to individuals with no past experience of depression or diabetes. Individuals with depression affirmed the importance of self-benefit and altruism in genetic research, consistent with our and others' prior findings (Lemke et al., 2012; Roberts et al., 2005). Recognition of the strengths of people with mental illness is important so that they are not inappropriately excluded from opportunities to participate in research, which may diminish the rights and respect owed to those with mental illness and inadvertently perpetuate scientific neglect of neuropsychiatric disorders (Humphreys et al., 2015; Roberts and Kim, 2014).

In this study, individuals with mental illness expressed interest in participating in genetic research. It is well documented that there is a strong interest in genetic testing for the risk of mental illness in clinical settings (Laegsgaard and Mors, 2008; Laegsgaard et al., 2009; Meiser et al., 2008; Smith et al., 1996; Trippitelli et al., 1998). Much remains unknown about the causes and care of mental illness, thus there is much need to advance genetic inquiry for neuropsychiatric and other brain-based conditions (Cichon et al., 2009; Lake and Baumer, 2010; Lau and Eley, 2010; Merikangas, 2007). Finding ways to accelerate such

research is important to the health of the public, given the prevalence and significant suffering and social and economic effects associated with these disorders (Fung et al., 2015; Kassenbaum et al., 2016; Mechanic et al., 1994).

This novel study has the limitations inherent in a preliminary study using a self-report survey method. Moreover, the survey was created *de novo* for this project and has yet to be fully tested for its psychometric strengths or weaknesses. Another limitation derives from the fact that stated interest in hypothetical genetic research may or may not be a robust predictor of actual research enrollment or genetic testing "uptake" (e.g., Lerman et al., 2002); therefore the high numbers of individuals expressing intention to participate in this study may not reflect the true proportion of individuals who would actually choose to enroll. Finally, these findings may or may not be generalizable to other mental health populations or generalizable beyond the single site recruitment population. For these reasons, the study should be repeated with a larger, more diverse sample.

Nevertheless, our findings indicate that individuals across the groups assessed are inclined to participate in genetic research, as has been found in prior empirical work with other populations (Hoeyer et al. 2004; Wang et al., 2001). Individuals in our study were, overall, willing to engage with their families around genetic research and endorsed relevant and logical influences on their intentions to participate in genetic research. Clarifying motivations and influences upon research enrollment decision-making may be of value in the informed consent process, especially in the context of novel genetic research, if only to affirm the strengths of individuals who generously volunteer to enroll in human studies. In particular, our findings underscore the importance of assessing the understanding of participants, making certain that they are aware that research results, as with all human investigations, may not bring personal benefit. Moreover, genetic research may result in increased biopsychosocial risks, such as social stigma and negative health implications for genetic family members, particularly if the research volunteer has other sources of vulnerability in the research context (Biesecker and Peay, 2003; Bortolotti and Widdows, 2011; Coors and Raymond, 2009; Nwulia et al., 2011). Efforts to ensure a robust informed consent process may serve to reassure investigators that they have engaged with their volunteers in a careful manner that supports authentic decision-making, ensures that decisions are grounded in accurate information, and diminishes the chance of exploiting volunteers who may be potentially vulnerable by virtue of their illness experience (DeLisi and Bertisch, 2006; Roberts et al., 2005).

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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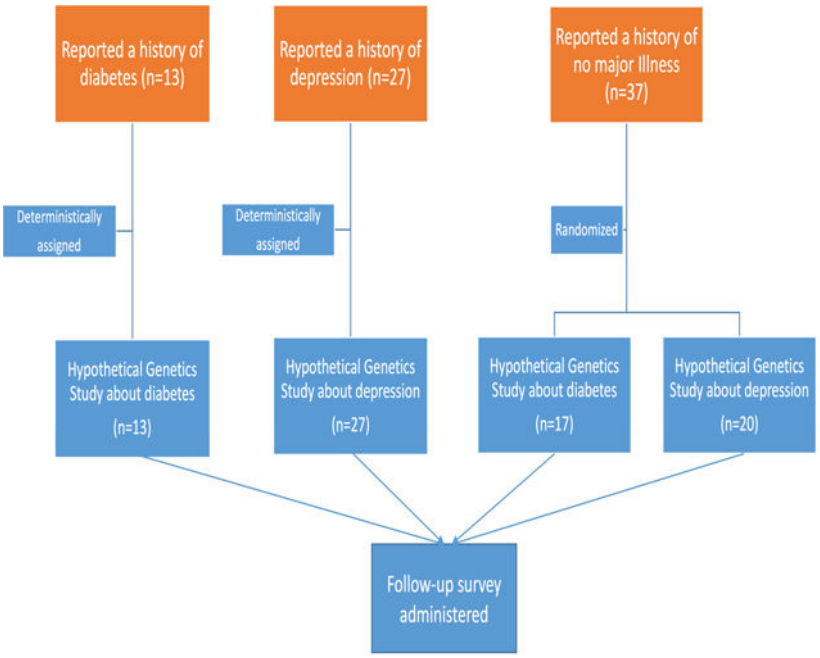

Figure 1.
Study design

Table 1

Characteristics of study participants by illness group

	Depression *N* = 27	Diabetes *N* = 13	Healthy *N* = 37
Gender			
Women	59% (16)	69% (9)	49% (18)
Men	41% (11)	31% (4)	51% (19)
Median age	37 45 51	38 41 59	30 38 48
Education			
Less than HS	4% (1)	8% (1)	11% (4)
HS or GED	30% (8)	15% (2)	41% (15)
Some college or 2-year degree	41% (11)	46% (6)	35% (13)
College	4% (1)	23% (3)	8% (3)
Graduate degree	22% (6)	8% (1)	5% (2)
Marital Status			
Single	44% (12)	8% (1)	35% (13)
Divorced or widowed	22% (6)	23% (3)	22% (8)
Married/Partner	33% (9)	69% (9)	43& (16)
Race/Ethnicity *			
Hispanic	24% (6)	54% (7)	38% (12)
Native American	4% (1)	38% (5)	31% (10)
White	72% (18)	8% (1)	31% (10)
Protocol Assignment			
Hypothetical Depression Study	93% (27)	0% (0)	54% (20)
Hypothetical Diabetes Study	0% (0)	100% (13)	46% (17)
Family history of illness			
Yes	93% (25)	85% (11)	84% (31)
None or unknown	7% (2)	15% (2)	13% (6)
Prior exposure to genetic study			
Yes	22% (6)	15% (2)	19% (7)
No	78% (23)	85% (13)	81% (29)

a b c represent the lower quartile *a*, the median *b*, and the upper quartile *c* for continuous variables. Numbers after percents are frequencies.

* 6 missing values.

Table 2a

Outcomes: participation willingness by self-reported history of illness

	Depression (N=29)		Diabetes (N=13)		Healthy /(N=37)		
	mean	**sd**	**mean**	**sd**	**mean**	**sd**	**p-value**
Likelihood of participation in the genetic study*							
If asked to participate now	7.77	1.34	7.46	1.56	6.95	2.13	0.20
If asked to participate in the future	7.85	1.43	7.92	1.19	7.35	1.93	0.39
Willingness to approach family members*							
If asked to approach for the genetic study	6.11	2.87	7.85	1.34	6.43	2.09	0.08

Table 2b

Influences on participation willingness overall and amongst the most highly willing to volunteer

	Overall		Participants "highly" willing
	mean	sd	%
If the research would help you or your family in some way	8.40	1.13	92
If the study concerned a disease that one of your family members had	8.14	1.34	88
If your family doctor recommended that you participate	7.78	1.75	82
If the research would help other people in some way, but not you or your family	7.73	1.59	83
If the research would increase scientific understanding, but not help people right away	7.68	1.63	82
If you were given more time to think about participating	7.62	1.72	79
If your family members encouraged you to participate	7.51	2.08	74