

Preliminary Findings on Public Attitudes Towards Genetic Research



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Genetic Research: Purported Goals

- **Prevention** (Kerr, et al., 1998; Anderson & Nickerson, 2005.)
- **Early detection & intervention**
(Anderson & Nickerson, 2005; National Cancer Institute, 2004; Pastor & Goate, 2004.)
- **Reduction of health disparities**
(NIH, 2001)

Health & Research Participation Racial Disparity

- Blacks have higher rates of chronic & debilitating diseases such as hypertension, diabetes, heart disease & certain types of cancers
- Comparable rates of mental illness, but lower rates of mental health treatment, and poorer treatment outcomes (Kessler, et al., 1994; Shnittker, 2003; US Department of Health, 2001)
- Significantly lower rates of participation in research on mental illness, including genetic research (Friedman & Paradis, 2002; McQuillan, et al., 2003; Neal & Turner, 1991)

Possible Factors Influencing the Research Disparity

- Historical Factors
 - Mistrust
- Attitudes Towards & Beliefs About Mental Illness
 - Stigma
 - More likely to prioritize medical illnesses
 - More likely to be aware of environmental factors that bring about mental distress
 - More likely to endorse spiritual factors

Barriers to Participation

- Structural Factors
 - Overrepresented in institutions (e.g., homeless shelters, prisons, lock-ups, etc.,)that are hard to reach. (Jackson, et al., 2004)
 - No insurance to enroll in hospital-based studies
 - Logistic difficulties in complying with extended research regimens
- Researchers' failure to reach out to minority communities (Wendler, et al, 2006)
 - Fear of being seen as aggressively targeting minorities for research

Study Objective

- To investigate people's attitudes & perceived barriers towards genetic research, as well as their willingness to participate in genetic research of psychiatric disorders.

Attitudes Towards Genetic Research Study – Phase I

- Screening Procedures & Instruments
 - Verbal Consent
 - Focus Group Screener
 - Age
 - Whether ever volunteered to participate in research
 - Race/Ethnicity
 - Education
 - History of mental illness such as depression or anxiety

Screening Procedure & Instruments

- Modified Telephone Screen for Clinical Studies of Anxiety
 - Ever had an emotional problem such as depression or anxiety
 - Ever seen a doctor or received treatment for emotional problem
 - Ever stayed overnight for treatment of emotional problem or substance abuse
 - Psychotic symptoms, e.g., visual/auditory/olfactory hallucinations, delusions, speech that others cannot understand?

Focus Group Instruments

- Written Consent
- Demographic Questionnaire
 - Age
 - Gender
 - Race/Ethnicity
 - Education
 - Parental Education
 - Household Income
 - No. of people in Household

Group Participants

- Married = 3 (11.5%)
- Single = 19 (73.1%)
- Separated/Divorced = 2 (7.7%)
- Unreported = 2 (7.7%)

- ≤ \$9,999 = 7
- \$10,000-\$19,999=6
- \$20,000-\$29,999=5
- \$30,000-\$39,999=0
- \$40,000-\$49,999=2
- \$50,000-\$59,999=2
- \$60,000-\$69,999=1
- \$70,000-\$79,999=1
- \$80,000 and over=1

DEMOGRAPHICS

N = 26

- 8th Grade = 2
- High School = 6
- Tech./Voc. = 2
- Some College = 5
- 2-yr Degree = 1
- 4-yr Degree = 3
- Some Grad. Sch. = 2
- Graduate Degree = 5

- Black = 18 (69.2%)
- White = 8 (30.8%)

- Male = 18
- Female = 8

Group Classification

- Black
 - History of Depression and/or Anxiety; no psychosis
 - No history of psych. disorder/mental health treatment/substance abuse
- Black & White
 - History of depression and/or anxiety; no psychosis
 - No history of psych. Disorder/mental health tx/substance abuse

Participants

		<u>Males</u>	<u>Females</u>
Black	Disorder	10	3
	No Disorder	4	1
White	Disorder	2	0
	No Disorder	2	4

Interview Questions

- Beliefs about causes of mental disorders
- Understanding of genetics & genetic research
- Potential benefits of genetic research
- Potential drawbacks of genetic research
- Personal concerns people have about participating
- Practical incentives to participation
- Practical barriers to participation
- Would be willing to participate (Why/why not?)

Causes of Mental Disorders

1. Stress (e.g. job, relationships, money)
2. Family upbringing and circumstances
3. Genes you get from parents
4. Societal stress (e.g. Hurricane Katrina)
5. Drugs & Alcohol

Genes and/or Environment?

- MAN: “I think that the environment – like he was saying, the environment is because everything in my environment was learned. I mean I learned how to do drugs, and I thought that was the norm. And then here comes someone – it’s wrong. What do you mean it’s wrong? I saw how to do that. And so I just think that the environment – ‘cause everything is like learned behavior.”
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- MAN: “I think it’s the environment and the people as well. And our families and stuff. And then it plays on a part of when we were young also. We watch and imitate what our fathers and mothers do. Like if they’re abusive, we saw it, and then maybe when we get older we might wind up doing the same thing. You might play the same part that they played. Okay, like say our mothers and our fathers used to fight and argue, so when we get married or when we get into a relationship we might do what we saw that they did. Like that.”

Understanding of Genetics

- What is passed down from family members
- DNA
- Chromosomes
- Ancestry
- Blood lines
- Don’t know much

Understanding of Genetics

- MAN: “I heard a little bit... I just started getting to know really what it really means. It’s got to do with, you know, I think as a family – genetic research with your family. You know, you and your brother got the same type of attitude or you know, your mom is – to me it’s like the environment of your family. If all of ya’ll got the same – how do I put it? – the same... I can’t explain it right. I know it’s got to do with the family environment, that’s what I know about it. The genetics in your body, in your family. Me and my brother have the same type of blood or whatever.”
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- WOMAN: “It has to do with your ancestral line, right? And the fact that, say, seven generations down we could be inheriting something that our genealogical line had way back then – if that’s the case. But as to the research I really don’t know how that goes. But I know that it might have something do with genetics.”

Understanding of Genetic Research

- Trying to find out whether a disease/disorder runs in the family
- Testing for specific genes for certain diseases (e.g., cancer, Alzheimer’s Disease)
- Genetic Engineering

Understanding of Genetic Research

- MAN: “I don’t think people know enough about it. Minorities anyway. It’s not something that we’re really focused or really concerned about, to be honest. It’s not an issue in our community – genetics. It’s really not a big issue. I mean it might be a general issue where we know general things about DNA, RNA – that my child has my genes. In general, we all know that. But when we get into – like you’re talking mental illness, genetics can cause mental illness. Well, it can come from genetics. I wouldn’t know anything about it if I didn’t read or watch television the way I do.”

- WOMAN: “Well, I think people know about what gets a lot of media attention, like – or advertising. So people know about Dolly the sheep and like people are outraged about it because it’s hype. Or I feel that people know about drugs that are advertised on TV. But other kinds of research I don’t think very many people know really. I’d love to be wrong.”

Potential Benefits of Genetic Research

- Finding out about causes of diseases/disorders
- Finding better treatments for diseases/disorders
- Learning more about oneself and family
- Taking the blame away from parents

Potential Drawbacks of Genetic Research

- Labeling and overgeneralizing
- Altering things that should not be tampered with
- Doing more harm than good from exploration

Drawbacks of Genetic Research

- MAN: "...But if you're talking about doing genetic engineering, most people have problems with it – in developing the perfect human. That's where a lot of the problems come in. It's ethics issues that come into play when you're talking about genetic engineering of human beings. 'Cause then what you're saying is this is the perfect race, you are perfect, and you'll be going through Logan's Run – remember that Logan's Run type thing – the (im)perfect people you get rid of [SIC] and you just keep the perfect people. So that could definitely create problems down the road."

- WOMAN: "Genetic research – I'm a little like leery with that word research. You know, after reading about certain things – they use people for research and they're like really messed up. I know that somebody has to step up, you know, so you get testings or see how things are going to work. Genetics – I think it has to do with the DNA or your genes or something like that. As far as like splicing animals with different animals and stuff like that, I think that's kind of like playing with fire, you know."

Potential Drawbacks of Genetic Research

- MAN: “Now I’ve got to go back to my dark world. [CHUCKLES] This is very hypothetical, but my only problem would be, like I said, if someone has been convicted of violent [UNINTEL] or is prone to violence, sexual aggression or whatever, it would give you a chance to look for that in an offspring or the next generation of violent behavior. It would give you a warning sign, something to look for.”
- MODERATOR: “So that would be – you would consider that a drawback?”
- MAN: “Well, not that. The drawback would be – here we go again. This is all hypothetical. If my father was a violent felon who was [UNINTEL] for murder, and if they did the research that would be necessary to find that if I carried this, quote-unquote, “violent gene” – all right, even if I didn’t I could be ostracized the rest of my life. So that’s one of the drawbacks .”

Personal Concerns People Might Have about Genetic Research

- Stigma (particularly with mental disorders)
- Confidentiality/Insurance issues
- Finding out you have a disorder that cannot be treated – “being under the executioner’s axe”

Personal Concerns About Genetic Research

- MAN: “I have no medical illnesses I’m ashamed of. But when it comes to my mental health issues, what I share with my doctor and those professionals is my own personal – and I mean very personal information. And for a person like me, and I don’t want to make anybody nervous – but if I found my information on a website or something I’d approach my doctor and it wouldn’t be nice. So I think confidentiality is probably one of the foremost important things.”

WOMAN: “Very interesting. I think there’s a stigma attached to psychiatric disorders, especially in my family – it’s all hush-hush. I don’t want to generalize, but let’s say my family – I think some of them might be more willing to come and have a blood test to see if certain people are predisposed to cancer or something other than this mental illness stuff. That’s just my impression.”

Things that Encourage People to Participate

- MONEY
 - Cash
 - Train fare
 - Food, coffee, snacks, etc.
- Detailed information about procedures and consent to participate
- Follow-up
- The simple desire to do good

Things that Encourage People to Participate

- WOMAN: “Yeah, I agree with that. I think that an awful lot of these market research focus groups and studies and stuff, they don’t keep track of you and they don’t tell you what happened later. I think if people found out more information, if there was a follow-up... They know they’re participating in this but – you know, then you got an email six months later or a year later, they’re having another group and they came up with this theory, this research – something which makes your participation have more significance in some sort of a context.”

Barriers to Participation

- Fear (invasive procedures, such as needles, ingesting pills or other substances)
- Distance (time, transportation, etc)
- Researchers who are aggressive, insensitive and/or condescending
- Lack of Money
- Hassle

Barriers to Participation

- MAN: Going back to drawbacks again for a second – this is not only about genetic research of psychiatric disorders, but all research – it applies here as well. I think it could be upsetting to the person themselves, going discussing it could be very upsetting. I was surprised – I was involved in a study recently with depression – I was surprised at how upsetting I found it. You know? And I think sometimes that's not realized. And I think the staff needs to be sensitive to that. I think also a person may be concerned that the staff looks down at them. You kind of feel shame coming in there and divulging that you have this disorder and thinking that they may think you're kind of scum, you know? So just those kinds of issues need to be – you need to be sensitive.

Barriers to Participation

- WOMAN: “Being afraid. Being afraid to do it. You know, being afraid to do it ‘cause of things that happened to other people participating in... I actually did take a drug at ___ before I started getting on like medication for whatever. And I mean it didn't even have a name, it had a number. I had to take six pills like three times a day, and these pills were like this long. You know? And I've never been more scared. I wanted to do it, and I wasn't even getting paid for doing this. And I said, yeah, I'm helping with research, yeah, I might be the breakthrough. And after I took my first couple of pills I was like, man, you know what could happen to you? I started getting all paranoid and I didn't take any more of them. You had to refrigerate them. And it was just – I don't know. I started having these dreams – I was like, oh, man.”

Race-Based Differences in Attitudes

- No major differences found in attitudes towards genetic research; Blacks and Whites appeared equally willing to participate in ongoing studies.
- Blacks & Whites did not differ substantially on the concerns and reservations they had about genetic research

Differences in Attitudes Based on History of Psychiatric Disorder

- Blacks who had a history of psych disorder were more likely to believe that drugs and/or alcohol played a role compared to Blacks without a history of psych disorder and compared to Whites.

Summary

- Participants do not have an “all-or-nothing” approach to genetic research. They are able to think about benefits and drawbacks.
- Although they voiced concerns about potential drawbacks, they were generally positive in their views
- All participants expressed a willingness to participate as long as they were informed of the procedures and risks
- Monetary compensation is a primary motivating factor towards participation in research

Limitations/Concerns

- Partially selecting on variable tested
- Participants may have unconsciously felt pressured to participate or to say that they would participate
- Focus group design limits generalization

Next Steps

- Attitudes Towards Genetic Research
 - Phase II: Questionnaire Development
 - Reliability Coding of Qualitative Interviews
 - Formulation of Questionnaire Items
 - Pilot Testing
 - Factor Analyses

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