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Concerns about Genetic Testing for Schizophrenia among Young Adults at Clinical High Risk for Psychosis

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Abstract

Background—Genetic tests for schizophrenia may introduce risks and benefits. Among young adults at clinical high-risk for psychosis, little is known about their concerns and how they assess potential risks.

Methods—We conducted semi-structured interviews with 15 young adults at clinical high-risk for psychosis to ask about their concerns.

Results—Participants expressed concerns about test reliability, data interpretation, stigma, psychological harm, family planning, and privacy. Participants' responses showed some departure from the ethics literature insofar as participants were primarily interested in reporting their results to people to whom they felt emotionally close, and expressed little consideration of biological closeness. Additionally, if tests showed an increased genetic risk for schizophrenia, four clinical high-risk persons felt obligated to tell an employer and another three would “maybe” tell an employer, even in the absence of clinical symptoms.

Conclusions—These findings suggest opportunities for clinicians and genetic counselors to intervene with education and support.

Keywords

schizophrenia; genetic testing; prodromal; clinical high-risk for psychosis; young adults; ethics

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INTRODUCTION

Psychiatric, neurological, and behavioral conditions are increasingly recognized to have a genetic component. Schizophrenia has especially high heritability – 81% according to a meta-analysis of twin studies (Sullivan, Kendler, and Neale 2003). While genetic testing for schizophrenia is still in the research and development phase, genetic testing is routinely utilized in other areas of medicine, such as reproductive medicine (Kaback, et al. 1993), pediatrics (Moskowitz et al. 2008) and neurology (Ross and Tabrizi 2011). Existing genetic tests have a variety of uses, each with different ethical implications: predictive testing in asymptomatic persons, predictive or confirmatory testing in symptomatic persons, prediction of treatment response, and genetic selection in reproductive contexts. It is not yet known which of these uses will be most affected by genetic tests for schizophrenia, but as the science advances, it will likely affect each of these domains.

Genetic testing for psychiatric conditions may present both benefits and drawbacks. Evidence from patients, family members, and clinicians suggests genetic information could potentially predict risk, motivate at-risk persons to identify early symptoms and seek help, aid diagnosis, guide treatment decisions, help individuals to make healthy choices and better-informed life decisions, and advance medical research (Austin and Honer 2007; Finn et al. 2005; Meiser et al. 2005; Meiser et al. 2008, Murphy and Thompson 2009; Potokar et al. 2012; Trippitelli et al. 1998; Wilhelm et al. 2009). However, there is also a danger that individuals could misunderstand their test results, especially since genetic testing is likely to indicate only relative risk. Results might negatively affect the person's mood, hope for the future, or vulnerability to discrimination (Meiser et al. 2005; Meiser et al. 2008; Potokar et al. 2012; Wilhelm, et al. 2009; Wilde et al. 2010).

One population that warrants special consideration is young adults at clinical high-risk for psychosis. This is a narrowly defined clinical population with symptoms that may disappear, persist, or worsen into schizophrenia or some other psychotic disorder. The criteria for being considered clinical high-risk for psychosis include: frank psychotic symptoms that are too brief or too intermittent to constitute a fully psychotic syndrome; functional decline (a 30% decline in the Global Assessment of Functioning over 1 year) in the setting of genetic risk factors (a close biological relative with a psychotic disorder or a personal diagnosis of schizotypal personality disorder); or attenuated positive symptoms, such as unusual thought content, suspiciousness, grandiosity, perceptual abnormalities (e.g. experiencing one's name being called when no one else is around); or disorganized communication (Miller et al. 2003). Among persons at clinical high-risk, approximately 35% develop a psychotic disorder within 2.5 years (Cannon et al. 2008).

If researchers develop genetic tests for schizophrenia, clinical high-risk individuals are likely to be affected. They might be helped if genetic testing is able to clarify which persons are at greatest risk of converting to psychosis or identify which treatment options are optimal for different persons. However, clinical high-risk persons might be especially vulnerable to harm if their symptoms – such as odd beliefs or disordered thoughts - make it difficult to learn about, consider fully, and discuss appropriately the risks and benefits of genetic testing.

Research is limited in this area. In a prior literature review, we identified 18 quantitative studies and 6 qualitative studies of beliefs about genetic testing in psychiatry (Lawrence and Appelbaum 2011), but only 2 studies included persons with psychotic disorders (Laegsgaard and Mors 2008, Laegsgaard, Kristensen, and Mors 2009). Both investigations were conducted by a single research group in Denmark, and neither focused on schizophrenia. An updated search, using the terms “psychiatry,” “genetic testing,” and “schizophrenia” in December 2014, yielded only two additional studies with original data, which assessed views among psychiatrists (Klitzman et al. 2014) and pedestrians walking past a pharmacy (Salkovskis et al. 2010), rather than among psychiatric populations or clinical high-risk individuals specifically. While there is much discussion among ethicists of hypothetical benefits and drawbacks of genetic risk information, there is little study of how actual patients facing the prospect of schizophrenia think about these benefits and drawbacks.

For the current study we interviewed young adults at clinical high-risk for psychosis, inquiring about their beliefs regarding genetic testing for schizophrenia. The full interview assessed participants’ familiarity with genetic testing, hopes and perceived benefits, and potential concerns. The results described in this paper focus on participants’ concerns: whether they perceived any drawbacks to genetic testing, how they would feel if they had an increased genetic risk for schizophrenia, and to whom they would reveal the results of genetic testing.

METHODS

Participants

Participants were recruited from the Center of Prevention and Evaluation (COPE). This is a research clinic for young people, ages 14–30 years, considered to be at clinical high-risk for psychosis. It is located at the New York State Psychiatric Institute at Columbia University Medical Center in New York City. Patients at the clinic are referred from private and hospital-based mental health professionals, academic counseling centers, or self-referral through COPE’s website. All patients at the clinic meet criteria for one or more psychosis-risk syndromes, as defined by the Structured Interview for Psychosis-Risk Syndromes (SIPS) (Miller et al. 2003). The clinic has been enrolling patients since 2004, and patients are followed for up to 2.5 years. At any given time, there are approximately 25–30 active patients in the clinic.

Exclusion criteria for the clinic included past or current frank psychosis, significant risk of harm to self or others which was deemed inappropriate for outpatient care, any major medical or neurological disorder known to affect the brain, and $IQ < 70$. Individuals were also excluded if attenuated positive symptoms occurred only in the context of substance use or were clearly accounted for by another psychiatric disorder.

Participants provided written informed consent. The study was approved by the Institutional Review Board (IRB) at the New York State Psychiatric Institute at Columbia University.

Recruitment

All participants were English-speaking young adults between the ages of 18 and 30 years old (we excluded minors from this sample).

Throughout 2014, research staff identified clinic patients who might participate in this interview study. Invitations were limited to persons who were English-speaking, ages 18 to 30 (we excluded minors), in communication with staff and reachable by phone, and who resided close enough to allow in-person interviews. Additionally, because early phases of the cohort study involve a series of clinical evaluations, questionnaires, and biological measurements (including neuroimaging), we only interviewed participants who were finished with data collection for these core elements of the study in order to minimize participant burnout.

Participants

Seventeen persons were invited to participate; fifteen scheduled and attended interviews.

Interviews

One author (RL) conducted in-person interviews at the New York State Psychiatric Institute, each lasting approximately 30 minutes. A semi-structured questionnaire assessed perceived drawbacks to genetic testing, anticipated emotional reactions to discovering an increased genetic risk, and privacy concerns (see Results section for the specific language used in each question). RL audio recorded and transcribed each interview. Participants received \$30 cash.

After 15 interviews, participants were noted to be repeating themes mentioned in previous interviews, suggesting that theme saturation had occurred and that additional interviews would not yield new themes. Recruitment was ended at that point.

Analysis

Two authors (RL and PF) read the transcripts multiple times, independently listing the answers to each interview question. Answers were grouped together thematically. RL and PF generated a codebook to describe the range of answers, and independently labelled each answer using the codebook. Coding discrepancies were discussed until consensus was reached. RL drafted the results, summarizing the range of answers for each question, which was reviewed by PF.

RESULTS

Demographic characteristics for participants are shown in Table 1.

Drawbacks to Genetic Testing

We asked participants: *Can you think of any drawbacks to getting tested? Are there any reasons you would not want to know your genetic risk for developing schizophrenia?*

Participants said genetic testing would trigger many fears: fear that testing would confirm high-risk status (Participant #1), “the idea that something that terrible could happen to you”

(Participant #1), “fear of knowing that I could possibly have this disease” (Participant #2), fear of learning “something that negative” (Participant #5), and fear of one’s children developing schizophrenia (Participant #6):

I would have a substantial amount of fear... I’m dealing with the problem right now, and that’s fine with me, but if I want to raise a family, how will I know? I’ll know, but I’d rather much have no problems genetically with my children than having those problems with my children. (Participant #9)

Many were also concerned that people might worry too much:

...if I were at risk, but looking forward in my life if I were never to develop schizophrenia, I would live my whole life being terribly afraid of it, and that’s an unnecessary emotion to feel. (Participant #6)

There was concern that genetic testing might negatively affect mental health. People might get depressed (Participant #8) or become suicidal (Participant #6). One participant suspected that learning of a 25% genetic risk for schizophrenia might “give me an excuse not to fight it as much... [in] therapy” (Participant #1).

Participants were concerned they would be treated differently. They mentioned that mental illness carries a stigma (Participants #1, 7, 15). One was fearful that psychiatrists or other doctors might pay “too much attention” to the test results, “when they could be paying more attention to something I was saying” (Participant #3). The same person feared the government could test everybody and discriminate against specific people (Participant #3). Understandably then, information security and privacy were important concerns (Participants #1, 3, 15).

Occasionally there were concerns about the test itself: cost, accuracy (Participant #2), validity (Participant #2), whether it generates “the right number” (Participant #10), or whether the sampling is “done right” (Participant #10). One suggested unavoidable uncertainty:

...the way um inductive reasoning works is that you cannot ever be certain that uh, that the conclusion drawn is ever correct, because that’s not how it works. (Participant #10)

Genetic testing might give people information they cannot use effectively. People might not feel they have enough information to make decisions (“all it tells me is a percentage” [Participant #10]). Genetic testing might create a self-fulfilling prophecy (Participants #1, 7):

You don’t want to end up having it be a self-fulfilling prophecy, you know, take on the sick role, [when] you don’t necessarily have to, because [you] assume you’re definitely going to get sick because you have this likelihood of it. (Participant #1)

Some worried that people who would not want medical treatment, even if they were to develop schizophrenia, might feel pressured by genetic test results (Participants #1, 10).

Emotional Reactions to Increased Genetic Risk

We asked: *If a test showed you have a 25% risk of developing schizophrenia, how would that make you feel? How would it affect your mood? How would it affect your self-esteem?*

Positive reactions included happiness (Participant #8), “joy that now I know” (Participant #15), and improved self-esteem (Participants #3, 5, 6):

I think it would actually improve my self-esteem. Because I think that I would consider myself to have low self-esteem because I have a lot of uncertainties... so knowing you are at 25% risk, then I would be able to interpret things that I felt or thoughts that I had and it would decrease the uncertainty of whether or not they're normal... (Participant #6)

Several said they would feel relieved (Participants #1, 3, 6, 8, 13) because the test provided concrete information (“When I understand something I feel more comfortable with it” [Participant #13]), or because a 25% risk was lower than they expected (Participants #1, 6). Sometimes the relief came from feeling like the test provided an explanation:

...it would be like an excuse and an explanation for a lot of things in my life already, like certain, the way I feel, and like, it's a lot harder to like feel insane and then everyone tells you that there's nothing wrong with you. It's almost better to be told that like “It's OK, you know, you have this whatever.” (Participant #3)

Occasionally, genetic information was considered empowering:

The positive would be, as long as I take care of it, and I keep up with it, and I watch these signs and make sure I don't have them, and educate myself about schizophrenia more, um then possibly I, you know, I could prevent me from becoming, you know, the individual that you hear on the news, or that you see on the train; from hurting somebody or, you know, going all out and losing your mind. (Participant #5)

Many expressed concerns about negative reactions, such as lower self-esteem (Participants #2, 3, 14, 15), anxiety (Participant #2), worry (Participant #3), fear (Participants #2, 5, 6, 9, 14), helplessness (Participant #6), hopelessness (Participant #6), feeling small (Participant #6), feeling sad (Participants #2, 6, 9, 15), or feeling disappointed and “down” (Participant #12).

I don't want to uh be diagnosed with something like that. I already have enough problems. So I would feel crappy if I knew I had it. (Participant #14)

One suspected that it would increase the “amplitude” of happy or sad mood states.

I think that it could become like a big depressant for me potentially, um but it would be very dependent on like the decision I made of how to interpret it, um, which would be a difficult decision to make, but uh I think that it would make my mood – whether it be on either side of the spectrum – be of a much greater amplitude. So I think that it would sort of create an extreme in a mood, whether it be um like trying to create myself to be really happy, to like compensate for this, or like let it take me away and like flood me with terrible feelings. (Participant #6)

Occasionally participants expected their reactions would be emotionally neutral. One person would “feel, like, curious about it” (Participant #2). Others expected no change in their mood (Participants #4, 5, 10, 11, 12, 13, 14, 15) or self-esteem (Participants #8, 9, 10, 11, 12, 15):

Um, it wouldn't actually affect my self-esteem whatsoever. I feel pretty good about myself, and if I do, let's say I do have schizophrenia, it's just something I need to handle in a certain way. I know my friends who I'm really close to, my real friends that I hang out with will accept me for me being me no matter what I have.
(Participant #13)

Privacy Concerns

We asked: *If you discovered you have an increased genetic risk of developing schizophrenia, who would you want to know? Who would you NOT want knowing your genetic test result? Would you feel an obligation to warn family members? A significant other? An employer?*

Participants generated a list of persons they would or would not tell about their genetic risk for schizophrenia (Table 2).

When asked how they selected persons to tell, many reported that they would tell those with whom they felt comfortable (Participant #1) or emotionally close (Participants #1, 2, 5, 6, 13):

I'd probably tell people I was very close to. Like I have, I talk to my best friend about most [things], and we've been best friends since we were 6 years old. She's seen me go through all of my illness... Or people I felt like I could relate to. Like I have a few other friends who have mental illness, and I usually feel more comfortable talking to them about things related to mental health and treatment... You feel more comfortable talking to people that you know have had shared experience. (Participant #1)

Similarly, there was an interest in telling only “the people I trust the most; the people who I know wouldn't judge me or treat me any differently” (Participants #8, 9).

Several would tell close friends and family in order to build a “safety net” (Participants #5, 6, 9):

I would want my brothers to know... those are the people who, you know I live with and keep me grounded, so they'll be able to watch and say [name] you're doing something a little off, you know, so that's pretty much why I would want them to know. (Participant #5)

There were a few additional need-to-know scenarios: “doctors who needed this information to treat me” (Participant #1), school administrators who “could kind of help you around it” (Participant #15), and family members after an argument (“If we go through a fight, then I would have to tell them what I'm going through” [Participant #14]).

Two persons would tell family members because family members might carry the same gene (Participants #3, 5):

Oh, because of my, because that might affect if they had a kid? If I had it, then they might probably be more likely to have a kid with it?

There were a number of reasons for not disclosing genetic risk: results might be misunderstood or misinterpreted (Participants #10, 12), rumors could start (Participants #7, 8, 15), relationships could be harmed (“people might treat me with more caution” [Participants #6, 8]), critical judgments could form (Participants #5, 8), family members are too young (Participant #2) or too sensitive (Participant #14), and many people have no need to know (Participants #1, 2). Sometimes infrequent contact was the reason (Participants #2, #8):

I’m not in contact with them as much. So I wouldn’t want to, like, put the effort into calling, because I don’t call them anyways.

We asked if persons with an increased genetic risk of schizophrenia were obligated to warn their employers. Answers included yes (Participants #6, 9, 13, 14), maybe (Participants #2, 3, 12), and no (Participants #1, 4, 5, 8, 10, 11, 15).

Participant (#9): An employer? Uh, I think that’s, that’s kind of a given. I think you have to. I think they need to be aware that you have some kind of medical problem that could just burst out at any moment. And they have to be prepared for that. I mean you can’t just like keep that secret from your boss.”

Interviewer: When you say “have to,” do you mean it’s like the law? Or do you mean it’s like a moral obligation?

Participant (#9): It’s a moral obligation.

Interviewer: OK. And this is, you’d want to tell him you have the risk, even if you’re not having any symptoms.

Participant (#9): Yeah, I think that’s, that’s called for as well.

Specific reasons for telling the employer include: safety (“I hold people’s lives in my hand” [Participant #6]), accountability (Participant #6), “they would want to know” (Participant #6), and “just in case [something happens at work] they understand that it’s because of this, not because, I’m not incompetent or something” (Participant #13). One person explained:

Participant (#14): ...what if I’m going through problems at work, and um the employer would need to know that I’m not just doing it on purpose, that there’s something wrong with me. I have a defect in me. And hopefully the employer would understand, you know, that I’ve done a good job for some, for a long time, you know, I’ve been steady for the first few months, for the first year or whatever, and then something happens and then, and then the employer would need to know. They would have to have a better understanding of me and my private life.”

Interviewer: This is, we’re just talking about the risk. Even without any symptoms.

Participant (#14): Um, when it comes to a risk, uh, as I said, uh, if something happens at work then I would tell them. I would only tell them on a need to know basis.

Some would “maybe” tell the employer “if I have a close relationship with my manager or my boss, then I will tell them maybe... it all depends on my relationship with them” (Participant #2, also 3), or “I would tell an employer if, um, I knew they understand, they understood exactly what it meant, that it’s just a genetic risk for it...” (Participant #12).

Several would not share their genetic information due to concerns about not being hired (Participant #4), being fired (Participant #15), employers having misconceptions (Participant #1), employers assuming the person can no longer “handle this job anymore” (Participant #2), and concerns about employers “labeling me... and filtering everything I say” (Participant #3). One person said genetic tests are irrelevant to workplace productivity:

I feel like that’s a personal thing. If I can do the job properly, if it’s not changing my way of doing the job, there’s no reason for them to know that. (Participant #5)

DISCUSSION

In this study we interviewed young adults at clinical high-risk for psychosis, asking about their concerns regarding genetic testing for schizophrenia. On the whole, participants described concerns that were reasonable and consistent with concerns shared by ethicists, such as: whether tests are reliable, whether clients and clinicians interpret results correctly, whether results increase stigma or discrimination, whether results cause psychological harm, whether results complicate family planning, and whether privacy can be maintained (Caplan 2010; DeLisi 2014; Gershon and Alliey-Rodriguez 2013).

Importantly, participants’ comments occasionally varied from the ethics literature. Ethicists debate whether family members have a right to access genetic test results (DeLisi 2014; Gershon and Alliey-Rodriguez 2013). In our sample, participants were primarily interested in telling people to whom they felt emotionally close, and expressed little consideration of biological closeness. Additionally, ethicists frequently discuss the risk of workplace discrimination due to genetic test results (Caplan 2010; Wilde et al. 2010); however, in our sample, four clinical high-risk persons felt obligated to tell an employer and another three would “maybe” tell an employer their genetic test results.

This openness to disclosing high-risk status to an employer is particularly interesting since privacy was a major concern in previous studies (Wilde et al. 2010), and a major impetus behind the Genetic Information Nondiscrimination Act (GINA) that prohibits US employers from discriminating on the basis of genetic information (U.S. Equal Employment Opportunity Commission). Perhaps this openness stemmed from the fact that all participants were young adults, and many were still in school or relatively new to the workforce, and had not yet seen or experienced workplace discrimination. Additionally, participants routinely conflated genetic risk with having a medical disorder, and maybe thought an employer would notice symptoms. Notably, workplace disclosure of genetic risk information has been studied elsewhere. A French prospective study of BRCA1/2 carriers found that 32.2% had disclosed their status to employers within 2 years (median time to disclosure was 6 months) and also found that less education predicted higher rates of disclosure (Eisinger et al. 2012). An important implication is that young adults may need to be educated about the distinction

between carrying a genetic risk and having the disorder, and the unfortunate discrimination they could face if they tell their employer about risks that may never materialize.

These findings validate the important role of genetic counselors, who are well positioned to help persons understand the risks and benefits of getting tested, understand their test results, and decide whom to tell. Importantly for ethicists, these findings invite additional discussion about the pros and cons of direct-to-consumer genetic testing and about how genetic information is catalogued and stored.

This study has strengths and limitations. Strengths include an ethnically diverse sample, a focused clinical sample, and structured assessment during initial enrollment. The relatively small sample size (n=15) allowed researchers to pay careful attention to each participant's perspective; however the possibility that additional perspectives exist cannot be definitively excluded. We cannot comment on the frequency of expressed views. The relatively low number of females (n=4) is consistent with the clinic population (26% female), but serves as a reminder that additional viewpoints may exist.

Responses must be considered hypothetical, since none of the participants has actually been exposed to genetic testing. Prior research literature has estimated that approximately 35% of persons at clinical high risk for psychosis develop a psychotic disorder within 2.5 years (Cannon et al. 2008), and it is unknown whether participants were aware of this risk estimate, or whether this factored into their comments about how they would respond if a genetic test showed a 25% risk. We asked participants to consider a genetic test that revealed a 25% risk in order to draw out the distinction between having a genetic risk and having the clinical disorder; however, psychotic disorders have a multifactorial etiology, and it is unknown how much risk a genetic test will be able to quantify.

Because this is a cohort study, there was no comparison arm assessing the views of other populations. Participants were operating within a structured clinical setting, and it is unknown whether their beliefs differ from patients treated by private office-based psychiatrists or patients in general outpatient settings. As a single-site study, involving a specific population, caution must be used if the results are generalized to other locations or other diagnoses.

Future research could improve understanding of these concerns by measuring their frequency in this population, and comparing them with other clinical and non-clinical populations. Research could also examine how genetic counseling might inform and shape participants' concerns. A mixed methods study might divide participants into those with and without a family history of psychosis to examine ways that family history might influence beliefs about genetic testing.

Conclusions

We interviewed young adults at clinical high-risk for psychosis regarding their concerns about genetic testing. Many of their concerns were reasonable and nuanced and echo concerns frequently highlighted by ethicists. Notable differences in participants' responses from the current ethics literature include little consideration of whether to reveal genetic

information to biological relatives, and occasional willingness to disclose genetic information to employers. These findings suggest opportunities for clinicians and genetic counselors to provide education and support to this vulnerable population.

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Table 1

Demographic characteristics of participants

Sex	N
Female	4
Male	11
Self-Reported Race or Ethnicity	N
White	5
African-American	4
Hispanic	3
Arabic	1
Chinese	1
South Asian	1
Education	N
Did not complete high school	2
Completed high school	1
Attended some college	9
Completed college	2
Completed graduate degree	1
Age (years)	
Mean: 22.27, Range 18–29	

Table 2

Individuals that participants would and/or would not tell about having an increased genetic risk for schizophrenia *

	Participant would tell this individual of an increased genetic risk	Participant would not tell this individual of an increased genetic risk
Parent(s)	#1, 2, 3, 4, 5, 6, 9, 11, 13 14	#8
Siblings	#5, 6, 12	#2
Aunt(s)/Uncle(s)/Cousin(s)	#2, 14	#2
Grandmother	#2, 4	#13, 14
Close Friend(s)/Best Friend(s)	#1, 5, 6, 8, 9, 10, 12, 13, 14	
Significant other	#6, 8	#14
Acquaintances/not-close friends		#3, 5, 9, 11, 14
Clinician(s)	#1, 13, 14	#1
School Administrator	#15	
School teachers		#2, 8
School peers		#15
Random people		#3, 9, 13
The government		#3
Employers		#4, 8, 15
Coworkers		#14
Tell nobody		#7

* Numbers are the identification number for each interview