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Ethical and public health implications of genetic testing for suicide risk: family and survivor perspectives

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Abstract

Purpose: Death from suicide has an estimated heritability of ~50%. Research may soon allow calculation of polygenic risk scores (PRS) for suicide death, which could be marketed directly to consumers. This raises ethical concerns. Understanding how consumers will utilize this information is urgent.

Methods: We conducted three focus groups involving suicide attempt survivors (“survivors”) and family members of suicide decedents (“family members”) to gauge their reactions to this technology. Questions focused on positive and negative implications of PRS results. Qualitative research methods were used to summarize studio results.

Results: Eight survivors and 13 family members participated. Both groups postulated benefits of suicide PRS, including prevention and reduced stigma. Their concerns ranged from increased stigma to adverse psychological effects. They suggested that suicide PRS should be accompanied by extensive education and counseling. Participants experienced no adverse effects.

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DATA AVAILABILITY

Research data are not shared.

DISCLOSURE

The authors declare no conflicts of interest.

Conclusion: Many ethical, legal, and social implications of genetic testing for suicide risk are highly salient to community stakeholders. Our participants hoped that suicide PRS could have significant individual and community-level benefits, but had concerns about effects in several domains, including stigma, access to insurance and employment, and increased anxiety and depression.

Keywords

polygenic risk score; direct-to-consumer genetic testing; suicide; ethics

INTRODUCTION

Genetic suicide research in an era of direct-to-consumer genetic testing

Suicide claims the lives of over 47,000 persons annually in the United States, and the national rate has increased by 33% between 1999 and 2017.[1] While environmental stressors are undeniably important, genetic factors also play a major role in suicide risk, with an estimated heritability of close to 50% for suicide death[2,3] and up to 30% for suicide attempt.[4] Over the past decade, research has begun to characterize genetic variation associated with suicide and suicide attempts, including high-impact work at Vanderbilt University and within the Psychiatric Genomics Consortium,[5–8] and recent work at the University of Utah (unpublished data). Notably, this genetic risk seems independent of variants associated with developing depression or other mental illnesses.[9] Like other psychiatric genetic research, suicide research has not yet identified well-replicated genes and gene pathways leading to functional mechanisms. However, increasing momentum and support for large-scale research suggests that researchers are rapidly approaching this goal. Even before specific risk genes and pathways are discovered, studies of suicide risk may allow the calculation of polygenic risk scores for suicidality. Once these data are available, they may be rapidly commercialized and marketed to the public as direct-to-consumer testing that is currently not subject to extensive regulation. Indeed, research has already suggested that excessive simplification of research results for marketing purposes is an issue affecting some types of direct-to-consumer genetic testing.[10] Given these rapid developments, it is urgent that we understand how people may interpret and act on this information. To that end, we report here the results of initial focus group research related to knowledge about and perceived acceptability of genetic testing for suicide risk among suicide attempt survivors and family members of persons who died of suicide.

Urgent need for comprehensive understanding of ethical issues

Aspects of community members' use, or prospective use, of genetic information about suicide risk that would be important to characterize fall into multiple domains. First, it would seem important to characterize community members' baseline understanding of genetic information and genetic risk estimates. There is substantial evidence from other domains that community members have low levels of understanding of genetic information,[11] but also desire to learn more from experts.[12] Other research suggests that community members have difficulties understanding the concept of genetic risk and often mistake susceptibility for inevitability.[13] It is also important to consider what ethical and practical

concerns about the availability of such information are salient to community members.[14] Community surveys regarding genetic testing for conditions such as Alzheimer disease and Huntington disease suggest that community members have concerns about the privacy of genetic information, the potentially stigmatizing effects of such information,[12,15] and the effect of genetic information on employment and insurance.[16] Other studies suggest that genetic testing may have psychological adverse effects, as genetic testing of children with increased risk of medical conditions increases parental anxiety.[17] Community members also might have concerns about payment for and access to genetic testing for suicide risk, concerns about the practical usefulness of such tests, and concerns about how to interpret the data, among others.

Primary aim: assessment of stakeholders' views

One well-established approach to answering questions about public understanding and attitudes is to conduct focus groups among primary stakeholders.[18–21] Although the concerns of a broad range of community members, including health-care professionals, would ultimately be important to understand, it is often most informative to start with groups whose opinions might be most polarized or are informed by personal experiences. To that end, we assessed the views of community members who had either had a personal experience with suicide attempts—suicide attempt survivors—or who had a family member die by suicide. Our goals were to collect community perspectives on a broad range of topics: stakeholders' understanding of concepts related to genetic risk for suicide, concerns about data privacy, concerns about data interpretation by patients or families, expected psychological impacts, and potential for institutional discrimination.

MATERIALS AND METHODS

Ethics statement

The study was approved by the University of Utah Institutional Review Board and each participant provided written informed consent prior to the start of the studio.

Community engagement studios

We held three community engagement focus groups (henceforth, "studios") designed to elicit community members' in-depth opinions about the ethical, legal, and social implications of genetic testing for suicide risk. Community engagement studios provide a format for researchers to consult with community experts, i.e., persons who have expertise about a particular topic from their lived experience.[22] Our participants were recruited through in-person referrals with the assistance of the local chapters of the American Foundation for Suicide Prevention (AFSP) and the National Alliance on Mental Illness (NAMI). Local board members of the AFSP and NAMI were contacted by email and asked to disseminate a paragraph about the study to their members, who were invited to contact the studio coordinator. Recruitment also involved flyers, existing community partnerships, word of mouth, social media, and referrals from past participants. Screening was conducted by telephone and email. Potential participants were considered for inclusion if they were adults able to speak and read English fluently, had the ability to come in person to attend the studio, and were either themselves a survivor of a suicide attempt (henceforth: "survivor"),

or the family member of someone who died of suicide (henceforth: “family member”), or both. They were regarded as ineligible if they were actively suicidal, if the relevant suicide event (their own or that of a family member) had occurred less than one year prior to recruitment, or if another family member was participating in the study. The purpose of these exclusion criteria was to minimize clinical risks to individuals discussing suicide.

In each studio, the following questions were asked:

1. What does the idea of genetic risk for suicide mean to you?
2. Would you want to know this information about yourself? (2a) What about your family members (including parents, siblings, children)? Why or why not?
3. If someone were tested for a suicide genetic risk factor, how would a positive test result impact you and your family? (3a) How would a negative test result impact you and your family?
4. What do you see as potential benefits and (4a) risks of knowing this information?

These questions used lay language to target the points previously described in “Primary aim: assessment of stakeholders’ views.” They were open-ended when possible, were not compound, avoided negative or positive bias, and allowed for any amount of self-disclosure. The questions were intended to be partially redundant to limit the impact of framing effects on the diversity and breadth of responses. Participants received a short description of the study and the questions at least a week before each studio.

The three studios were held on 19, 22, and 26 June 2019. Two sessions involved family members of persons who had died by suicide and one session involved participants who had survived a suicide attempt. During each 2-hour studio, the studio coordinator, who was independent of the research team, facilitated discussion of the questions with the aim of eliciting responses from all studio participants; a scribe summarized the discussion on large paper as part of the facilitation. Several members of the research team observed the discussion. Sessions were audio-recorded and transcripts derived from the recordings were de-identified. All other data were de-identified. studio participants were provided with a meal and a $75 gift card in exchange for their time.

Because we had little information regarding the potential impact of the studio discussions on participants’ emotional states, and aimed to minimize clinical risk, we implemented several safety measures. First, the observers for each studio included at least one clinician who was qualified to provide crisis intervention services, including real-time suicide risk assessment and triage to appropriate medical services if indicated. Second, we endeavored to assess the emotional impact of the studio by having each participant complete the Profile of Mood States (POMS) questionnaire before and after the session.[23] For this study, the POMS short form (POMS-SF), which comprises 36 questions, was used.[24] The POMS-SF assesses mood and emotion across seven domains (tension, anger, fatigue, depression, esteem-related affect, vigor, and confusion), which can be combined to give a total mood disturbance score.

Qualitative research methods.[25] were used to summarize the studio results. Initially, participants’ comments were documented by hand, sometimes having been abbreviated

slightly to help with recording. Audio recordings of the sessions were later reviewed by two members of the study team to ensure that all significant comments had been documented and that the documented comments were accurate. Thematic coding of the comments was performed by the first author and then verified by all other members of the study team, with recoding occurring until consensus was achieved. Participant comments included in the tables of results are direct quotes, except that they have been edited for brevity. Statistical analysis was limited to the assessment of basic demographic data and *t*-tests to compare POMS-SF scores before and after the studios. Analyses were conducted using SAS 9.4 (SAS Institute, Cary, NC, 2018).

RESULTS

Initially, 11 suicide survivors and 20 family members committed to participating in the studios. Three studios were conducted; one studio ($n = 8$) included suicide attempt survivors and two studios ($n = 13$) included family members of suicide decedents. Of the participants who had been recruited but did not participate, all failed to appear on the day of the studio; none of the participants who attended the studio were excluded. The majority of participants in both the survivor group (75.0%) and the family group (76.9%) were women. Likewise, most participants in both the survivor group (75.0%) and the family group (76.9%) were Caucasian. Other demographic data for both groups are reproduced in Table 1.

Participants' attitudes about the significance of genetic risk

Responses to the studio questions for the survivor group are summarized in Table 2, while those for the family member groups are summarized in Table 3. We anticipated that the question "What does the idea of genetic risk for suicide mean to you?" would elicit participants' understanding of the notion of genetic risk. Instead, participants either addressed their belief in the idea that suicide could be a heritable condition, or spoke about the personal significance of testing for suicide risk.

With respect to the positive personal significance of genetic testing, survivors reported that knowing that they had genetic risk for suicide could reduce stigma and validate their struggles. They also noted that knowing that you have a genetic risk for suicide seems to give you actionable information. On the negative side, they reported that genetic testing might not be useful because it would merely reproduce what was already known from their family histories. With respect to the positive personal meaning of genetic testing, family members echoed many of the survivors' comments. Unlike the suicide survivors, family members reported that thinking that suicide risk has a genetic component could change their thoughts about their loved one's death, and reduce any feelings of blame that they might have experienced. On the negative side of personal meaning, family members, like survivors, reported that genetic testing would not add much information. They worried about adverse effects of the testing, both with respect to increased stigma, discrimination, and various psychological adverse effects.

Participants' views about personal testing

For the question "Would you want to know this information about yourself? Why or why not?," suicide survivors gave mixed responses. Many said "yes" for a variety of reasons, including ideas about reduced stigma and increased acceptance, better access to treatment, or preventative approaches. Other survivors opposed genetic testing for themselves. They worried that such knowledge would have made them feel hopeless, or that the effects of the knowledge on behavior would be difficult to predict. Some differentiated between testing for suicide risk and testing for mental illnesses: "[I am] not sure if I would want to know genetic risk for suicide…[but] would want to know for mental illness." Other family members also gave mixed responses to the question about whether they would want to know their own test results. Some said "yes" because they felt such information would enable them to access treatment or preventive services more easily, or increase their motivation to do so. On the other hand, other family members were opposed to getting this information about themselves, because they were not sure that they would use it well. Family members also mentioned worries about broader, dystopian social impacts, referencing *Gattaca* (a 1997 film by Andrew Niccol, in which genetic status is used to classify people into social hierarchies). Again noting fears about the impact of this information on self-concept, several worried that genetic information could result in a self-fulfilling prophecy. Those who were uncertain seemed torn between the above considerations, since they thought that testing could be positive because it could improve access to treatment, but also negative because of the psychological effects.

On knowledge of risk in loved ones

In contrast to the reactions to the question about personal testing, survivors were generally more favorable in their answers to the question "Would you want to know this information about your family members? Why or why not?" They noted that information about genetic suicide risk could help prevention. Participants likened the information to screening for colon cancer. On a different note, they reiterated and expanded ideas about how information about genetic suicide risk would increase awareness about and acceptance of mental health issues by encouraging more open discussion of them. Survivors did, however, raise some worries about testing family members. They wondered how testing would affect the selection of romantic partners, decisions to marry, and decisions to have children. Again, they worried about the adverse psychological effects of believing that one's genetic risk of suicide is increased.

Family members had similar ideas about testing loved ones. Those in favor noted that it could improve treatment and reduce stigma. They worried, though, that there would be adverse psychological effects and that excessive focus on genetic risk could distract from positive lifestyle-based interventions.

On the impact of knowledge for the individual and the family

When asked "How would a positive test impact you and your family?" suicide survivors identified mostly positive implications. They thought that it could, again, tend to promote preventive behaviors and earlier intervention. They also had a variety of ideas about how it would impact their feelings about themselves or other affected persons, e.g., by increasing

self-compassion and strengthening intimate relationships. They emphasized that testing would probably increase acceptance and reduce stigma. On the negative side, survivors thought that with a positive test there was a risk of adverse psychological effects, such as increased perceived burdensomeness.

Family members had similar thoughts about prevention, but were less focused on the effects on stigma and validation. They thought that a positive test would encourage them to be more proactive and to provide more support. They worried, however, that the information could produce increased feelings of depression or anxiety, and also lead to excessive worry and "helicopter parenting."

Regarding the question "How would a negative test result impact you and your family?" suicide survivors overall seemed to think it would have little impact, both because they would discount such a negative result based on personal or family history, and because they recognized that a negative result did not mean the absence of risk. While some family members thought that a negative test result would give them a feeling of relief, they also thought they would be skeptical about it.

In answering the final question about potential benefits of knowing information about genetic risk for suicide, suicide survivors again emphasized the importance of prevention and combating stigma. In addition, they thought that it could increase funding for mental health services, particularly in schools. Family members also reported that genetic testing could reduce stigma and that it would increase school and community support for mental health treatment. They speculated that such testing could help increase gun control and reduce mass shootings.

Perspectives on personal and institutional discrimination

With respect to the risks of knowing information about genetic suicide risk, survivors worried about stigma and exclusion. They thought that testing could lead to repercussions in insurance and employment. They seemed more concerned than family members about the negative psychological impact of testing, again emphasizing fears of a self-fulfilling prophecy for positive results, while also worrying about the invalidation of personal struggles that might come from a negative result.

At the end of each studio, participants were asked to provide researchers with their top recommendations or takeaway points regarding genetic testing for suicide risk. Suicide survivors highlighted the need for advocacy, support, and education, while working to increase community and personal dialogues about mental illness. They emphasized the importance of addressing concerns about privacy and employment. Finally, they emphasized that genetic testing should be accompanied by counseling from trained health-care providers. Family members recommended that researchers should facilitate broader use of testing (even making it part of routine health exams).

Participant clinical ratings

POMS-SF—Prior to the studios, survivor POMS-SF ratings showed low to moderate total mood disturbance (TMD) with mean scores of 105.8 (SD: 14.9). Pre-studio family member

POMS-SF scores were only slightly lower, with TMD scores averaging 95.3 (SD: 27.8). After the studios, neither group exhibited significant changes from baseline, though in many domains, especially esteem-related affect, there was a trend toward improvement. Overall, the studios appeared to have a neutral or slightly positive impact on participants' emotional tone. Two participants in the survivors' studio, however, did reveal that they were very distressed after the studio. Both were assessed by one of the mental health clinicians present and were able to engage in safety planning. It was determined that their distress was primarily related to factors external to the studio.

DISCUSSION

Our community engagement studios yielded significant information about the hopes and concerns of community experts regarding the possibility of genetic testing for suicide risk. These findings highlight the importance of extensive engagement with potential stakeholders before such genetic technologies are made available for clinical or public use. Individuals in both groups speculated about a variety of benefits of genetic testing for suicide risk, and also emphasized the need for extensive education for those who might seek testing or who have been tested, and both groups expressed ambivalence about whether such testing would be helpful or wanted. Most importantly, many ethical concerns related to such testing loomed large for our participants, including concerns about the negative impact of genetic testing on stigma, the psychological adverse effects of tests results, and the potential for misuse of such information by third parties ranging from employers to insurers to neighbors.

Researchers who focus on the ethical, legal, and social implications (ELSI) of genomics have long raised the kinds of concerns described by our participants. Notably, consistent with our findings, most Americans would like to have genetic risks for disease disclosed to them, and find the information empowering in some way. Genetic information is not automatically empowering, however. If the results are not carefully communicated, patients may be confused about their impact, and unsure of what steps to take next.[26]

Our studios deliberately discussed the concept of genetic risk in terms of receiving a "positive" or "negative" result for suicide risk. It is therefore not surprising that participants described the genetic risk as binary, which is consistent with lay tendencies found in previous research.[27] While this framing might be a helpful heuristic for decision-making, the genetic risk for complex phenomenon such as suicidality is more nuanced. One respected model for suicidal behavior treats it as a complex trait that develops when the effects of many helpful and hurtful genetic variants, together with those of environmental stressors, cross a certain liability threshold.[8] Because of this, and because genetic literacy and numeracy varies,[28] thorough genetic counseling will be necessary to put the results of any polygenic risk score into context.[20] Further, the uncertainty regarding penetrance of the phenotype may cause greater anxiety in practice than what we observed in the studios.

When people consider genetic risks for disease, they tend to discount the continued role of the environment.[29] This is referred to as "genetic determinism" and was identified as a concern by both community groups. By identifying variants that make small causal contributions to the overall risk of suicidality, providers, social institutions, and parents

might ignore important environmental contributions to suicide, such as early childhood stress, financial difficulties, or access to firearms. To avoid this sort of outcome, those receiving genetic risk information should be counseled on the risks of false positives, false negatives, low penetrance, and the limited predictive value of a particular genetic variant.

Explaining behaviors in terms of genetic susceptibility has the potential to both increase and decrease the stigma and blame associated with the disorder.[30] While our participants echoed the double-edged nature of genetic risk information, whether or not it ultimately contributes to greater or lesser stigma will depend on how our social systems incorporate this type of information. If it is used to develop precision treatments or improve access to preventive supports, it may be destigmatizing. If it is used somehow to limit legal entitlements for those affected, then the information may be stigmatizing.

Despite some legal protections, concerns about genetic discrimination remain prominent. The Genetic Information Non-Discrimination Act (GINA) was passed by Congress and enacted into law in 2008, and prohibits employers or health insurance companies from using genetic risk information, for individuals or their family members, in their hiring and coverage decisions.[31] The types of responses we observed from our participants suggest that they are not familiar with this legislation and what it prohibits, as they remained concerned that employers or insurance companies might engage in prohibited behavior. Even so, the risk of improper discrimination did not disappear with the passage of GINA, as GINA has many loopholes and the interpretation of “genetic information” has been far from uniform.[32] It is also often difficult to prove that an employer’s hiring or firing of an individual was made on an improper basis, as opposed to the pretextual reason given.

Because genes are immutable, and we are still unlocking the secrets of our genome, our participants were understandably concerned about protecting the privacy of their genetic information. Some researchers have argued for the patient’s “right not to know” about their risk of genetic diseases, which particularly impacts children.[33] Communication about genetic risk is not always straightforward. While individuals may feel obligated to share genetic information with their family members, this may be weighed against the desire not to cause worry or alarm.[34]

Although it provides important preliminary information about community members’ beliefs about genetic testing for suicide risk, our study had limitations. First, although adequate for qualitative research of this type, the sample size was relatively small. Likewise, the participants were all drawn from the local community, and so may not be representative of the views of persons in other communities. Indeed, because about half of the participants were recruited through AFSP and NAMI, their views may not represent the views of persons who are less engaged with mental health advocacy. Because of local demographic factors, our sample was relatively homogeneous with respect to race/ethnicity. Also, men were underrepresented. One purpose of the studios was to determine whether the questions posed would capture the information desired, to allow us to reformulate them for later, larger surveys. We found that one question, “What does the idea of genetic risk for suicide mean to you?” did not elicit the desired types of answers (e.g., information about what participants know about genetic testing), but instead led participants to talk about the personal

significance of such testing. Accordingly, our study was unable to produce much information about participants' understanding of key concepts like genetic testing, gene x environment interactions, and whether test results are informative for individual suicide risk. This is a limitation we hope to correct in future work.

The assessment of primary stakeholders' hopes and concerns about the possibility of genetic testing for suicide risk is an essential step in evaluating the real-world impact of this work across ethical, legal, and social dimensions. Our results indicate that although community members are hopeful that such research could have significant individual and community-level benefits, they also have important concerns about the ramifications of such information for employment, insurance, self-concept, stigma, and its effects on mental health. Our study suggests the need for further clarification of these issues as well as the importance of continued engagement with community members as plans to provide such testing are developed.

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Table 1

Demographic characteristics of community engagement studio participants.

	Suicide attempt survivors	Family members
Number of participants recruited	11	20
Number of participants appearing	8	13
Female participants *n* (%)	6 (75.0)	10 (76.9)
Age range (years)	29–75	38–69
Race/ethnicity		
Not reported	1 (12.5)	0
Caucasian *n* (%)	6 (75.0)	10 (76.9)
Hispanic *n* (%)	1 (12.5)	1 (7.7)
Pacific Islander *n* (%)	0	1 (7.7)
Native American *n* (%)	0	1 (7.7)
Religious affiliations		
None/not reported *n* (%)	5 (62.5)	8 (61.5)
Catholic *n* (%)	0	2 (15.4)
Latter Day Saints *n* (%)	3 (37.5)	3 (23.1)
Approximate household income		
Not reported	2 (25.0)	1 (7.7)
<$10,000 *n* (%)	0	1 (7.7)
$40,000–49,999 *n* (%)	2 (25.0)	3 (23.1)
$50,000–74,999 *n* (%)	2 (25.0)	5 (38.5)
>$75,000 *n* (%)	2 (25.0)	3 (23.1)
Educational level		
Not reported	1 (12.5)	0
High school or equivalent *n* (%)	0	1 (7.7)
Some college or vocational school *n* (%)	1 (12.5)	2 (15.4)
College graduate *n* (%)	3 (37.5)	6 (46.2)
Graduate or professional degree *n* (%)	3 (37.5)	4 (30.8)
Number of members in household		
Not reported *n* (%)	4 (50.0)	8 (61.5)
Lives alone *n* (%)	3 (37.5)	0
One other person *n* (%)	0	3 (23.1)
Two other persons *n* (%)	1 (12.5)	1 (7.7)
More than two others *n* (%)	0	1 (7.7)

Table 2

Suicide survivor responses to questions about polygenic risk score testing for suicide.

Theme	Example quotes (edited for brevity)
Question 1: What does the idea of genetic risk for suicide mean to you?	
Confusion or skepticism	It's hard to believe there's genetic risk for suicide—it's easier to believe for other health issues.
Less stigma or more acceptance	More self-compassion, if struggling—risk is something out of your control.
Better treatment or prevention	Having a genetic risk tells you something that you can do something about now.
Not useful or informative	For those with generational mental illness, we already know this; they're aware that they need to address this early.
Question 2: Would you want to know this information about yourself? Why or why not?	
Yes: Better treatment or prevention	Want to know as much as I can to be aware and preventative.
Yes: Less stigma or more acceptance	Want society to be more educated about mental illness.
No: Unknown effects	Not sure what it would be like to have this in my head.
No: Psychological adverse effects	If had known this, I would have pulled the trigger—I would have said I'm done.
Question 2a: Would you want to know this information about your family members? Why or why not?	
Yes: Better treatment or prevention	Would want to know about my children so I could offer help…to monitor for certain behaviors and have a dialogue about it.
Yes: Less stigma or more acceptance	In so many religions, suicide is condemned. This is a way to open discussion.
	Depression doesn't have a visible identity, which can make it more challenging for family members to recognize.
Maybe: Uncertain effects	Would it impact decisions about marrying if both partners had mental health challenges? Not sure if would want to pass genetic risk on to children.
	Would like to know and have a test, but it might trigger depression.
Question 3: If someone was tested for a suicide genetic risk factor, how would a positive test result impact you and your family?	
Less stigma or more acceptance	To know this would make me more loving to myself and who I am.
	If people knew that something was a vulnerability, hopefully they wouldn't hold it against me.
Better treatment or prevention	Maybe it would have given me pause before engaging in high risk behaviors.
	Knowing that my child was diagnosed with attention deficit disorder enabled me to advocate for them…. This would be similar.
Psychological adverse effects	Would have seen myself as a burden and isolated myself (earlier).
Not useful or informative	It is what it is.
Question 3a: How would a negative test result impact you and your family?	
Not useful or informative	Negative result doesn't mean you won't be suicidal.
	It wouldn't make a difference one way or the other.
	We should treat everyone as if they are at risk.
Useful or informative	Part of me would be relieved, particularly if I had kids.
Question 4: What do you see as potential benefits of knowing this information?	

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Theme	Example quotes (edited for brevity)
Better treatment or prevention	Increase in funding…. Put more mental health services in schools.
	Getting support earlier.
Less stigma or more acceptance	Increase the vocabulary for people to talk about feelings.
Question 4a: What do you see as potential risks of knowing this information	
More stigma or discrimination	Discriminated by employers, risk of losing health insurance.
	Neighbors might not let their kids be at my house.
Top recommendations	
• Provide advocacy and support	
• Figure out why we don't talk about suicide now	
• Legitimize mental illness…destigmatize it	
• Address concerns about privacy and loss of employment	
• Increase education, all the way…Hope Squad, other peer mentor	
• This information needs to come from a trained health-care provider, along with resources	

Table 3

Family member responses to questions about polygenic risk score testing for suicide.

Theme	Example quotes (edited for brevity)
Question 1: What does the idea of genetic risk for suicide mean to you?	
Confusion or skepticism	How can genes predict behavior?
	I don't understand how a behavior can be a genetic risk.
Less stigma or more acceptance	Could assist health-care providers to take patients seriously.
More stigma or discrimination	Could make people feel abnormal if they knew they had a risk.
Better treatment or prevention	It means the capacity to find an alternative, to find help.
Not useful or informative	Already assumed this because of family experience.
Useful or informative	Adds a piece of the puzzle.
Question 2: Would you want to know this information about yourself? Why or why not?	
Yes: Better treatment or prevention	I can fight harder. It would make me empowered to work on mental health.
	Could improve access to care, just like knowledge of family history of substance use is helpful.
No: Unknown effects	Where is the line? Can we really handle this information?
No: Psychological adverse effects	Danger of self-fulfilling prophecy. Ignorance can be bliss.
No: More stigma or discrimination	Health insurance companies may deny or increase premiums.
	Gattaca-like impact.
No: Not useful or informative	Already know I'm at higher risk.
Question 2a: Would you want to know this information about your family members? Why or why not?	
Yes: Better treatment or prevention	Would help me to help them.
Yes: Less stigma or more acceptance	Provides frame of reference for others if the risk is inherited.
No: Psychological adverse effects	Negative effects from being treated differently. Could cause "helicopter" parenting.
No: More stigma or discrimination	Health insurance issues (pre-existing conditions).
No: Not useful or informative	Prefer lifestyle based on preventative measures.
Question 3: If someone was tested for a suicide genetic risk factor, how would a positive test result impact you and your family?	
Less stigma or more acceptance	Opens conversations about suicide and mental health.
	Understand loved ones better.
Better treatment or prevention	Would keep an eye out for strong triggers, especially in those with extra risks.
	Create a checklist of self-care…diet, exercise, social, etc.
	Knowledge is power!
Psychological adverse effects	Positive results can cause difficulties, fear, and bullying.

Theme	Example quotes (edited for brevity)
	Misunderstand result as destiny.
Not useful or informative	Would not make a difference in communicating with children as we already have these conversations.
	How much does the measure really impact the end result?
Question 3a: How would a negative test result impact you and your family?	
Not useful or informative	Would question the reliability of the test.
	No change because of previous experience with suicide.
Useful or informative	Relief, confidence in health.
Better treatment or prevention	Would focus on environmental risks more.
Psychological adverse effects	Might make people overconfident and not take other risks seriously.
	Loss of hope, especially for those affected by suicide.
Question 4: What do you see as potential I	**benefits of knowing this information?**
Better treatment or prevention	Policy changes—like increased programs and funding for mental health.
	Expanded insurance benefits.
	Gun safety, reduce mass shootings, reduced gun sales.
Less stigma or more acceptance	Allow people to feel comfortable experiencing a range of emotions.
	Could lead to increased scientific, genetic, and medical studies.
Question 4a: What do you see as potential I risks of knowing this information?	
More stigma or discrimination	“Get over it” attitude with negative results. Misuse of test by jobs, government, health care, etc.
	Life insurance denial or premium increase.
Psychological adverse effects	Risk of giving up—ignoring things a person can change.
	Would be used to exaggerate and manipulate family.
	Isolation, not living life to the fullest.
	Reading too much into unhappiness or depression.

Top recommendations

- Don’t turn a blind eye to a negative result
- Reduce stigma, increase tolerance of people with differences
- Scientific, concrete information would destigmatize suicide and mental health research
- A positive result is not destiny
- Provide awareness about absolute truth versus individual choice and personality
- Provide education on other risk factors
- Expand access to resources

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Theme	Example quotes (edited for brevity)
• Sharing hope is important	
• Make the test part of annual health check-up	
• Make genetic knowledge accessible to all demographic groups	