

Acceptability of a brief personalized prevention model for reducing alcohol and other substance use risk among youth: findings from a qualitative study



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Background

Humans are compelled by biological vulnerability to disease, driving direct-to-consumer genetic testing. Substance use disorder (SUD) is an area of peak interest, especially among adolescents, who stand to benefit greatly from early preventive interventions. Still, little is known about the acceptability of a personalized brief intervention involving return of personal genetic risk information to adolescents to motivate alcohol risk limiting behaviors.

Objectives

To explore acceptability of a model of returning individual genetic testing information to adolescents to motivate risk reducing behaviors.

Methods

Using a semi-structured interview guide, adolescents, young parents and grandparents were interviewed about personalized prevention and their interest in receiving personalized genetic test results for SUD.

Participant Selection: Participants (>15 years) from previous studies that had consented for re-contact were recruited through email outreach. Compensation was \$20 gift cards.

Data Collection: From January to July 2022, 30-45-minute-long interviews were conducted in English by trained researchers. With participant consent, interviews were recorded and transcribed using a HIPAA-compliant service and coded using NVivo software. The interview involved open-ended questions, non-judgmental probes, and brief, standardized explanations about genetics, the concept of precision prevention, and the association between genetics and SUD.

Data Analysis: The study team created a coding framework, coded interview data, and identified major themes. The team reviewed each full transcript, grouping textual responses into themes and subthemes. Interviews were double coded and held to a consensus standard for interpretation. Although all identifiers have been removed from study data, quoted data are annotated with study ID, gender and age in years.

Results

Table 1. Characteristics of Sample (N=13)

Total	N	%
Biological Sex		
Female	8	(61.5)
Gender		
Female	7	(53.8)
Age		
15-24	5	(38.5)
25-34	5	(38.5)
35-44	1	(7.7)
45+	2	(15.4)
Race/Ethnicity		
White	8	(61.5)
Black or African American	2	(15.4)
Asian	1	(7.7)
Hispanic	2	(15.4)

- 23.1% reported diagnosis of SUD for self or nuclear family
- 23.1% reported diagnosis of SUD for extended family
- 38.5% had received genetic testing
- 38.5% had a family member who had received genetic testing

Attitudes were strongly favorable toward the model (Figure 1). Most participants explored the tension between determinism and actionability of genetic information about SUD risk. Perceived benefits included:

- ✓ behavior change: informing decisions to modify behavior early in life to avoid future risk
- ✓ family health knowledge: opportunity for sharing health information with family for their protection
- ✓ personal health knowledge: confirmation of and insight into health problems.

Many participants appreciated the complexities of test results and potential for psychological harms from social isolation, anxiety, and depression (Figure 2) and cognitions and emotions that could impact behaviors and risk, such as feeling hopeless or powerless to prevent SUD/harm (fatalism) or holding a false perception of no risk or "false immunity" or "free pass" from SUD with a negative genetic test result (Table 2).

Figure 1. Interest in Genetic Testing for Substance Use Disorder

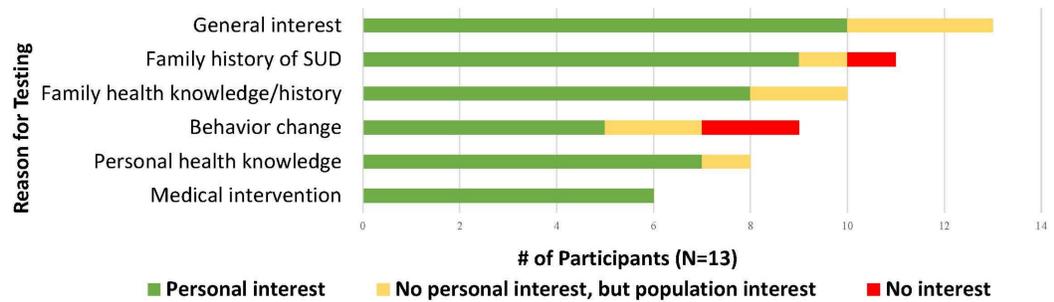


Table 2. Cognitive Implications of Perceived Risk and Health Decision Making

	Perception of Increased Risk	Perception of No Increased Risk
False Immunity and Free Pass		
Would negative genetic test results give individuals a false sense of protection from addiction (false immunity)?	<p>"...[if an individual found out they did not have an increased genetic risk] there could be a risk of individuals letting their guard down because they don't perceive an issue with their habits." (001, female, 22)</p> <p>"...I can see how people [without genetic risk for SUD] would use that as an excuse to be like, I can do whatever I want." (011, male, 27)</p> <p>"[Even if someone thought they had immunity] that doesn't mean you can't get addicted. This kind of reminds me of how people view marijuana... even though people think that it's a green light, it's still dangerous and can have harmful effect." (002, female, 16)</p>	<p>"I feel like stressors in people's lives... influences with friends, family members, peer pressure, things like that are more triggers to use [than finding out you don't have a genetic risk for SUD]." (010, female, 48)</p> <p>"You're not predisposed to it but that doesn't mean you can't become addicted. I think just learning more about what the substance use disorder world is, how quickly you can get addicted and how hard it is to get off of it. If the education component went along with it [testing], then I think that might be helpful, but I don't think it would give anybody a free pass." (005, female, 63)</p>
Would negative genetic test results increase substance use (free pass)?	<p>"I think that [receiving negative genetic test results for SUD] can make people [increase their substance use] because they're like, "I'm not at risk, I'm not prone to having a disorder." So, they overtake the substance... that can be a disadvantage of finding out because they become carefree." (003, male, 36)</p> <p>"I don't think [people who receive negative genetic test results for SUD] would go...crazy, but I feel like they would be able to feel a little more comfortable trying something, sure." (013, male, 27)</p>	<p>"If I already drink socially and if someone was like, oh you don't have increased risk, I don't think I would go wild. I think I would just be like, okay, cool." (013, male, 27)</p> <p>"I guess sometimes people will think like, well, you're going to put the idea in their head. It wouldn't have occurred to them to go out and drink and do drugs if you hadn't said anything [about their genetic risk for SUD]. But I think people use that argument in a lot of situations where it doesn't seem true, like we're seeing with queer, sex-ed, that kind of thing across the country." (011, male, 27)</p>
Fatalism		
Would positive genetic test results cause someone to feel hopeless and lead to increased substance use?	<p>"I could see [genetic testing for SUD] being a goldmine for bullies...because that happened to me... From the day I dropped out [of high school], everyone that I had gone to school with perpetuated the story that I had dropped out to become a heroin dealer. And it certainly didn't make me pick up heroin. But when I did get around heroin, it was a lot easier to go, 'Well, no one's gonna be surprised.'" (004, male, 25)</p> <p>"[Genetic test results] get in their head, okay, my family is predisposed to alcoholism. If that's the road that my family is going down, that affects me. Thinking... I'm going to end up becoming an alcoholic, and they just start drinking very heavily... they could be feeling hopelessness, that's their destiny, that's just going to automatically happen regardless. They'll feel like they'll be drawn to that substance, no matter what, because it's in their genetic makeup." (010, female, 48)</p>	<p>"There's nothing I can do about that susceptibility [to substances]. But it's not like a thing with 100% certainty that it is going to happen to me. And I can always just avoid situations or whatever thing I'm more susceptible to." (006, male, 17)</p> <p>"I mean, I would kind of have the thought that [their fate] is not actually sealed...Also, both my grandmothers have had melanoma a couple of times like skin cancer definitely runs in our family so like, personally, I just wear like sunscreen a lot more" (002, female, 16)</p> <p>"But substance use disorder, you have to go out and have that substance for it to become a problem for you, it's not in the air. So, you have to make a choice... If there are alternative medications [to opioids] you can take. I think you would choose those. So, I can't imagine that you would feel hopeless about that." (005, female, 63)</p>

Figure 2. Psychological Impacts of Precision Prevention Model

"The anxiety...would be mostly around, oh no, this is likely to happen to me. Maybe knowing you might have an increased risk of addiction and never drinking or doing any drugs might feel a little extreme, but **I think I would feel more comfortable and driven by my anxiety to take...that more zero tolerance stance.**" (011, male, 27)

"Seems like, just the knowledge of [genetic risk for SUD] could be anxiety inducing for some individuals...**if someone learned that they had a predisposition to alcohol addiction, they might just avoid social events with friends at those kinds of establishments entirely.**" (001, female, 22)

Discussion

High interest in and acceptability of a personalized prevention model were found, along with appreciation for how understanding genetic risk for alcohol and other SUDs might motivate health decision making and risk modifying behaviors. Areas of concern for ensuring safety were identified, including psychological harms, false beliefs and perceptions regarding heightened risk and immunity.

Implications

Precision prevention of SUD holds promise and work to elucidate operational, ethical, and communications strategies to advance the model are needed.

Limitations

This exploratory study was undertaken on a small opt-in sample.

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