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What do Teenagers Think about Precision Psychiatry?

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Abstract The variable etiology of psychiatric illness makes it a useful target for precision medicine, a healthcare model that customizes medical care to an individual’s genetic, environmental, and lifestyle factors with the goal of improving health outcomes. The specific environmental and genetic contributions to one’s psychiatric illness risk are unknown; however, new discoveries of the genetic contributions to psychiatric illness prompt questions as to how genetic-based psychiatric illness risk can be translated into mental health benefit for an individual. Specifically, precision psychiatry must motivate behavioral change in response to genetic risk information to accomplish its goal. The adolescent population is a useful target of precision psychiatry because psychiatric illnesses often begin during this life stage, earlier diagnosis and treatment improves long-term outcomes of psychiatric illness, and adolescents are generally less intolerant of uncertainty. Therefore, adolescents’ willingness to make behavioral changes upon receiving psychiatric genomic risk information is a growing area of interest. This study aims to assess teenagers’ willingness to make behavioral changes in response to the distribution of psychiatric genetic risk information. Recommendations for genetic counseling---an effective tool to improve patient knowledge, alleviate stress and anxiety associated with genetic testing results, and reduce uncertainty of genetic risk---are proposed.

Key Words Precision psychiatry, teenagers, self-efficacy, empowerment, intolerance to uncertainty, health behavior, genetic counseling
Introduction

Precision medicine is defined as a healthcare model that focuses on tailoring medical care to an individual’s unique genetic and environmental factors, with the goal of improving health outcomes through disease prevention, personalized behavior change, and treatment. Where evidence-based medical models typically utilize average data in a one-size-fits-all approach, precision medicine aims to provide customized treatment (1). Precision psychiatry, a targeted approach to treating psychiatric illness based on an individual’s genetic characteristics, environment and lifestyle, has been a growing area of interest in adults. Genome-wide association studies have identified hundreds of loci associated with psychiatric disorders suggesting an aggregate effect of genetic variants (2-4). These studies, along with whole exome sequencing, have been the subject of considerable interest for their potential to aid in the development of novel effective psychotropic treatments (2). Additionally, prevention strategies in the form of internet-based interventions, such as online therapists or coaches; mindfulness practices, such as yoga, meditation, and tai chi; and interventions in occupational settings, like school or work have been shown to benefit individuals with a higher risk for developing psychiatric illness (5). Early successes exist in identifying certain genetic changes that are associated with reducing symptoms from antipsychotic medications, as well as antipsychotic-induced weight gain (6). However, studies focusing on adolescent precision psychiatry are lacking.

The adolescent population is a critical population to study with regards to precision psychiatry because most mental illnesses begin in adolescence during the critical period of psychological and social development. Specifically, half of diagnosable mental illnesses begin by the age of 14-years, and three-fourths begin by 24-years (7). In addition, the youngest age
WHAT DO TEENAGERS THINK ABOUT PRECISION PSYCHIATRY?

group assessed, 16-24-year olds, makes up the largest proportion of the two-thirds of individuals who meet the criteria for a mental illness and do not seek professional medical help (8). Early help-seeking is critical in preventing adverse social, educational and vocational outcomes (7).

The adolescent population is also interesting to study because of its lower intolerance of uncertainty. Intolerance of uncertainty is defined as an individual’s tendency to view uncertainty in a negative way on an emotional, cognitive, and behavioral level (9). Individuals with a higher intolerance of uncertainty are more likely to perceive ambiguous information as threatening and therefore avoid ambiguous situations (10). High intolerance of uncertainty may also affect problem-solving skills, rendering individuals with higher scores less likely to take action in these situations (10). An individual with lower intolerance of uncertainty may be more receptive to ambiguous information, such as mental illness genetic risk information. Previous studies have identified that adolescents are less averse to ambiguity than adults (11). Therefore, the effects of communicating mental illness genetic risk information to the adolescent population, particularly in relation to behavior change, is an area of interest.

Other variable aspects of personality that can affect the success or failure of precision psychiatry are self-efficacy, empowerment, and sensation-seeking. Generally, self-efficacy refers to a person’s ability to perform effectively when exposed to stressful situations. Individuals with a higher level of self-efficacy will choose to take on more challenging tasks (12). Adolescents with a perceived high self-efficacy will take charge of areas of their life such as academics, and withstand peer pressures that encourage negative behaviors (13). Empowerment occurs as those who lack certain resources attain access to and control those resources. When adolescents have a higher level of empowerment, they are more likely to improve their quality of life, and are inclined to promote a positive change in order to succeed
WHAT DO TEENAGERS THINK ABOUT PRECISION PSYCHIATRY?

(14). Lastly, sensation-seeking refers to a need for complex sensations and experiences that leads to risk-taking behavior. Previous studies have shown that adolescents aged 11- to 20-years old with high levels of sensation-seeking will engage in more risky health behaviors such as reckless or drunk driving, smoking, and crime (15, 16).

Psychiatric illness has been suggested as a potentially useful target of precision medicine because of its high heritability, its high morbidity -- with one to four percent of the population worldwide affected -- and its heterogeneous nature, which is also its greatest challenge (17). The etiology of psychiatric illnesses like schizophrenia, bipolar disorder, depression, and anxiety, is complex, involving multiple genetic and environmental factors rather than possessing one specific cause (1). However, it has been observed that psychiatric illnesses cluster in families; and it is estimated that the risk of developing certain psychiatric illnesses has a strong genetic component, with estimates of heritability of 40-70% for major depressive disorder, 60-85% for bipolar disorder, and 50-80% for schizophrenia (18). Therefore, genetic markers utilized in the context of precision medicine are suggested as helpful in identifying individuals at risk of developing a psychiatric illness.

Genetic risk information may be a strong motivator for change because of its highly personalized nature (19). Some studies report that adults value genetic risk information for behavior change and decision-making, particularly genetic risk information that could prompt preventive action to reduce risk, including noninvasive interventions like medicine or close monitoring (20). This study reports on adolescents’ willingness to make behavioral changes in response to psychiatric genetic risk information. We hypothesize that information about the genetic and environmental contributions to mental illness will be a stronger motivator of risk-
WHAT DO TEENAGERS THINK ABOUT PRECISION PSYCHIATRY?

reducing behavioral change among adolescents than information about the genetic contributions to mental illness alone.

Methods

This study was approved by the Institutional Review Boards of the New York State Psychiatric Institute and Sarah Lawrence College.

Figure I. Study Design Flowchart
WHAT DO TEENAGERS THINK ABOUT PRECISION PSYCHIATRY?

Participant Recruitment

A nationally representative sample of 417 teenagers between the ages of 14- and 17-years old were recruited via Touchstone Research, Inc, a professional survey firm. Parents of the adolescents were registered with the panel and were invited to participate in the study. Only adolescents who provided assent and logged into TSR’s study page through their parents’ TSR account or email invitation were included in the study. TSR offered online study participants 10,000 credited points (equivalent to $10) redeemable for cash or e-reward as preferred by participants for their participation.

Survey Instrumentation

Participants first completed an online survey comprised of four questions measuring self-efficacy, empowerment, intolerance to uncertainty, and sensation-seeking levels. The participants were then randomly assigned to one of two psychiatric illness educational brochures: 1) Genetics and Mental Illness, primarily centered around the genetic contributions to psychiatric illness; and 2) Genetics, Environment and Mental Illness, discussing the genetic and environmental interactions contributing to psychiatric illness. After reading the assigned educational brochure, study participants completed a 20-25-minute, anonymous, online survey.

The post-intervention survey was comprised of questions that focused on participant’s views on information provided in the handout and intention to modify behavior in response to the psychiatric illness risk information presented. This study will focus on four of the post-intervention survey questions. First, participants answered questions regarding their views on the importance of knowing the information they were presented with, and how this could influence behavioral changes, treatment options, and other family members. Individuals then reported on negative aspects of knowing the information presented or why it was not important for them at
WHAT DO TEENAGERS THINK ABOUT PRECISION PSYCHIATRY?

the time of the survey. Next, participants’ belief that they have control over the development of mental illness was measured. Finally, study participants were asked to consider having a large number of factors contributing to mental illness, and how this would affect behavioral changes in their lives, such as eating habits, exercise routine, stress levels, as well as tobacco and alcohol consumption.

At the end of the survey, participants who received the Genetics and Mental Illness brochure were debriefed and given information on the environmental factors related to mental illness.

**Validated Scales**

Validated scales were adapted from Schwarzer and Jerusalem’s Generalized Self-Efficacy scale (21), Michigan Diabetes Center’s Diabetes Empowerment Scale- Short Form (22), Carleton et al.’s short version of the Intolerance of Uncertainty Scale (23), and Hoyle et al.’s Brief Sensation Seeking Scale (24).

**Data Analysis**

Results of the survey were compared among groups as well as to self-efficacy, empowerment, intolerance to uncertainty, and sensation-seeking scales. Descriptive statistics were applied to the demographic data, and SAS software was used for statistical analysis. Proc SurveyReg for ANOVA was used to determine differences between the Genetics and Mental Illness and Genetics, Environment and Mental Illness groups. Scores for the self-efficacy, empowerment, intolerance to uncertainty, and sensation-seeking scales were used as covariates to identify the effect that these individual factors had on participant’s responses to the post-intervention survey.
WHAT DO TEENAGERS THINK ABOUT PRECISION PSYCHIATRY?

Results

Participants that scored higher for empowerment and intolerance to uncertainty were more likely to find positive aspects in the information presented in the educational brochure (Table I. Empowerment: \( P>|t| = <0.0001 \); Intolerance to Uncertainty: \( P>|t| = 0.0130 \)), as well as less likely to find negative aspects in the information presented (Table II. Empowerment: \( P>|t| = 0.0127 \); Intolerance to Uncertainty: \( P>|t| = <0.0001 \)).

Higher summary scores for empowerment and sensation-seeking were associated with higher scores for reducing risk to develop mental illness and improve outcomes (Table III. Empowerment: \( P>|t| = 0.0002 \); Sensation-Seeking: \( P>|t| = 0.0183 \)). Therefore, participants who felt more empowered and scored higher on the sensation-seeking behavior scale were more likely to believe they have control about the development of mental illness.

Higher scores for empowerment were also associated with higher scores for making behavioral changes if they had a large number of factors contributing to mental illness (Table IV. \( P>|t| = 0.0001 \)), indicating that those participants who felt more empowered were more likely to believe they will make behavioral changes to reduce factors impacting mental illness.

The type of brochure that participants received had no significant impact on the importance participants placed on knowing factors that contribute to the development of mental illness (\( P>|t| = 0.1731 \)); the importance of not knowing the factors that contribute to the development of mental illness (\( P>|t| = 0.2162 \)); the belief that changes in lifestyle, diet, and exercise as well as mental health support and treatment can reduce a person’s chances of developing mental illness and improve outcomes (\( P>|t| = 0.8906 \)); and willingness to make behavioral changes if they were found to have a large number of known genetic factors (\( P>|t| = 0.3816 \)).
WHAT DO TEENAGERS THINK ABOUT PRECISION PSYCHIATRY?

Discussion and Conclusions

The growing application of precision medicine to various fields in healthcare, including psychiatry, prompts the need to understand how personalized genetic information can best be utilized to motivate risk-reducing behavior among patients (19). Some studies have shown that adults are willing to make health behavior changes in response to genetic information. For example, adults that learn that they have a genetic risk factor for late-onset Alzheimer’s disease are more likely to report the adoption of health behavior changes specific to Alzheimer’s disease (25); and individuals with an inherited genetic risk for developing cancer are more likely to take appropriate screening measures, such as obtaining mammograms (19).

Other studies propose that individual traits affect the behavioral response to genetic risk information. A study of 22 adults at high risk of developing type 2 diabetes, a complex, polygenic disease, found that the impact of genetic risk results on behavior change is mediated by an individual’s motivation at baseline (26). Individuals with a higher level of motivation prior to genetic testing reported that they would be further motivated by a higher genetic risk result and would not let a lower genetic risk result take away from their risk-reducing behavior goals (26). Individuals with a lower level of motivation at baseline that received a lower genetic risk test result were more likely to choose not to engage in risk-reducing health behaviors.

A separate study of 108 overweight patients at risk for type 2 diabetes demonstrated that provision of a high risk genetic test result- based on 36 single nucleotide polymorphisms- did not significantly improve motivation to adopt diabetes prevention behaviors or increase adherence to a prevention program (27).

A systematic review with meta-analysis to assess the impact of communicating DNA based risk estimates on risk-reducing health behaviors and motivation to engage in them, looked
WHAT DO TEENAGERS THINK ABOUT PRECISION PSYCHIATRY?

at 18 studies of adults with a mean age of 30-56 years. These studies communicated genetic risks for lung or esophageal cancers to smokers, risks for Crohn’s disease to smokers, risks of cancers with alcohol consumption, risks of melanoma, colorectal cancer, risk for type 2 diabetes, risk for heart disease, Alzheimer’s disease, and obesity. This review found that communicating DNA based risk and changes in behavior is not supported by existing evidence. However, the studies in this review had an unclear risk of bias, and evidence was not of high quality (28).

Overall, there is some evidence that adults will adopt risk-reducing behavior in response to genetic risk information, although the results are not conclusive. However, adolescents’ willingness to engage in risk-reducing behaviors in response to genetic risk information is relatively unknown.

Adolescence marks the time in which the majority of psychiatric illnesses begin, making it an interesting population to target for precision psychiatry (7,8). This study addressed adolescents’ willingness to make behavioral changes in response to psychiatric genetic risk information. Although our hypothesis that information about the genetic and environmental contributions to mental illness would be a stronger motivator of risk-reducing behavioral change than information solely on genetic contributions to mental illness was not supported, adolescents who scored higher for empowerment were significantly more likely to believe they would change their behavior to reduce factors impacting mental illness.

Empowerment occurs when one believes to have control over determinants that affect a person’s quality of life such as health, autonomy, confidence, and opportunity (29). The connection between empowerment and health behavior change is supported by studies of adults. A previous study focusing on adults with diabetes mellitus hypothesized that promoting community empowerment by giving this group the tools to manage their health, would in turn,
increase empowerment at an individual level. The adults were given health education by community health workers to understand the disease mechanism and the importance of positive health behavior, as well as other interventions including dietary and physical guidance. The patients improved their health behavior by reducing carbohydrates and increasing physical activities; and their blood glucose levels decreased over the 8 weeks these were measured (30).

In previous studies with adolescents, empowerment was also shown to be a critical factor in reducing high-risk behaviors by increasing an individual’s capability to promote positive changes. Higher levels of empowerment in adolescents has been indicative of better outcomes in academics, health, psychological, and behavioral settings (14). Our study found that adolescents who felt more empowered were more likely to think that they have control over the development of mental illness and more control over improving outcomes. They were also more likely to find positive aspects in the information presented in the educational brochure, and similarly, less likely to find negative aspects in the information presented.

Prior to our study, it was suggested that adolescents with lower intolerance to uncertainty would be more receptive to ambiguous information, such as mental illness genetic risk information; however, in our study, adolescent subjects more intolerant to uncertainty were more likely to find positive aspects in the information and less likely to find negative aspects in the information presented. This is in contrast to previous studies illustrating that adolescents with a higher intolerance to uncertainty may be more likely to avoid situations with a high amount of uncertainty and less likely to take action (11).

As adolescents transition from childhood to adulthood, they gain more independence and have to manage biological, educational, and social changes in their lives. During this time, sensation-seeking, the need for varied, novel, and complex experiences, peaks; and adolescents
are more prone to experiment in risky behaviors (31). Our study found that adolescents with higher scores on the sensation-seeking behavior scale were more likely to believe they have control about the development of mental illness. Higher levels of sensation-seeking in adolescents occur when they rate the benefits of the risk higher than its cost. Although sensation-seeking has primarily been associated with risk behaviors, it also predicts engagement in more positive risks, like attempting to learn new skills (31).

Overall, adolescents with higher levels of empowerment and intolerance to uncertainty were more likely to respond positively to information about the genetic risk of psychiatric illnesses. Adolescents with higher levels of empowerment and a higher tendency to sensation-seeking were more likely to believe that they have control over the development of mental illness; and increased empowerment was also associated with the belief that they would change their behavior to reduce factors contributing to mental illness.

**Genetic Counseling: Future Considerations**

Understanding what traits make adolescents more receptive to precision psychiatry information raises the issue of how to appropriately communicate such genetic risk information. Future studies may consider the potential utility of genetic counselors in this endeavor.

Genetic counselors are medical specialists who’s roles include: communicating genetic risk information to individuals and their families; contributing to the understanding and adaptation to medical, psychological, and familial implications of diseases; and facilitating health behavior decision-making (32). Genetic counseling serves as an effective tool to improve patient knowledge, alleviate stress and anxiety associated with genetic test results, and reduce any uncertainty with regard to genetic risk (33). These interventions have been shown to enhance
WHAT DO TEENAGERS THINK ABOUT PRECISION PSYCHIATRY?

patient adherence to medical recommendations, presumably because they help people understand how choosing to follow recommendations can help mitigate genetic risk (34).

With increased understanding of the genetic contributions to psychiatric illness, such as specific susceptibility loci, precision psychiatry may be utilized more widely, creating an increased need for genetic counselors to provide psychiatric services (33). Genetic counseling for risk of psychiatric disease has been demonstrated to help patients better understand the etiology of psychiatric illnesses, including the non-deterministic influence of genes and how environmental factors modify an individual’s risk of developing a psychiatric illness. Previous studies suggest that genetic counseling can provide a more accurate genetic risk perception that may empower patients to make informed decisions about managing their mental health (17).

Our study illustrates the value of increased empowerment in the adolescent population as a tool for increasing the potential of precision psychiatry to reduce the risk of psychiatric disease. Future studies might look at psychiatric genetic counseling for adolescents and its effect on empowerment and uptake of risk-reducing behaviors.

**Study Limitations** One limitation of the study is the insufficiency of racial diversity among the participants to account for differences in our findings (77.2% white, 13.9% African American, 5.3% Asian, 2.2% Native American, 1.4% Native Hawaiian). Another limitation is the assumption that adolescents will follow through and engage in behavior changes, such as healthier eating, increasing physical activity, and attempting to reduce stress, as indicated on the survey. A follow-up study could measure adolescents’ actual behavior change in response to genetic risk information. An additional limitation of this study is the uncertainty of whether health literacy levels of the participants had an effect on their understanding of the information
WHAT DO TEENAGERS THINK ABOUT PRECISION PSYCHIATRY?

Presented. Further studies could compare the understanding of genetic risk between adolescents with lower health literacy versus higher health literacy.

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**Compliance with Ethical Standards**

**Conflict of Interest** Erika Brockhoff and Fiorella Herrera declare that they have no conflict of interest.

**Human Studies and Informed Consent** All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all participants for being included in the study.
WHAT DO TEENAGERS THINK ABOUT PRECISION PSYCHIATRY?

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WHAT DO TEENAGERS THINK ABOUT PRECISION PSYCHIATRY?


WHAT DO TEENAGERS THINK ABOUT PRECISION PSYCHIATRY?


WHAT DO TEENAGERS THINK ABOUT PRECISION PSYCHIATRY?


Table I. Importance for knowing information such as behavioral changes, treatment options, family (Find positive aspects in info)

|                          | t Value | Pr>|t| Value |
|--------------------------|---------|----------|
| Self-efficacy            | 0.25    | 0.8032   |
| Empowerment              | 7.37    | <.0001   |
| Intolerance to uncertainty| 2.49    | 0.0130   |
| Sensation seeking        | 0.90    | 0.3707   |
Table II. Importance for **NOT** knowing information (Find negative aspects in info)

|                                | t Value | Pr>|t| Value |
|--------------------------------|---------|-----------|
| Self-efficacy                 | 0.59    | 0.5524    |
| Empowerment                   | -2.50   | 0.0127    |
| Intolerance to uncertainty    | 4.02    | <.0001    |
| Sensation seeking             | 1.95    | 0.0519    |
Table III. Reducing a person’s chances of developing mental illness and improving outcomes (Participants’ belief that they have control about the development of mental illness)

|                                | t Value | Pr>|t| Value |
|--------------------------------|---------|----------|
| Self-efficacy                  | 1.80    | 0.0733   |
| **Empowerment**                | **3.80**| **0.0002**|
| Intolerance to uncertainty     | 1.03    | 0.3048   |
| Sensation seeking              | 2.37    | 0.0183   |
Table IV. Behavioral changes if individual were to have a large number of factors contributing to mental illness (Participants’ belief they will make behavioral changes to reduce factors impacting mental illness)

|                              | t Value | Pr>|t| Value |
|------------------------------|---------|---------|
| Self-efficacy                | -0.54   | 0.5921  |
| Empowerment                  | 3.86    | 0.0001  |
| Intolerance to uncertainty   | -0.53   | 0.5990  |
| Sensation seeking            | -1.34   | 0.1794  |