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**Genetic Counselors' Attitudes Toward and Practice Related  
to Psychiatric Genetic Counseling**

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Suggested running head: Genetic Counselors' Attitudes Toward and Practice Related to Psychiatric Genetic Counseling

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**Abstract** Despite the high demand for psychiatric genetic counseling among people with psychiatric conditions (>90%), surveys show that genetic counselors rarely receive primary referrals for psychiatric cases. The purpose of this study was to further investigate potential deterrents to accessing psychiatric genetic counseling services, focusing specifically on the prevalence and impact of psychiatric stigmatization among genetic counselors. Board-certified, practicing genetic counselors were invited to participate in an anonymous survey via the National Society of Genetic Counselors (NSGC). Survey measures included a validated psychiatric stigmatization scale (OMS-HC) and questions assaying genetic counselors' experiences with and opinions of psychiatric genetic counseling. Correlations between psychiatric stigmatization and psychiatric genetic counseling outcomes were analyzed using Pearson correlations ( $p < 0.05$ ). Of the majority of respondents who believed they should provide psychiatric genetic counseling (90.3%), only 44.6% reported providing this service. On average, respondents scored neutrally on psychiatric stigma scales; however, higher stigma levels were associated with less frequent psychiatric discussions ( $p < 0.046$ ), less counselor comfort and perceived qualification ( $p < 0.003$ ) and perceptions of having insufficient psychiatric genetic data ( $p < 0.016$ ), resources ( $p < 0.019$ ) and time ( $p < 0.024$ ). Compared to a similar assessment by Monaco et al. 2009, in this study, genetic counselors were more likely to report the perception that psychiatric discussions would be more frequent with the availability of clinical genetic testing and individualized risk assessments (+8.4% and +10.1% respectively). This study suggests that the limits of psychiatric genetics research and unavailability of genetic testing lead many genetic counselors to doubt the utility of psychiatric genetic counseling. Should this mindset persist, without the intervention of psychiatric education and training, the field of genetic counseling risks continuing to inadequately serve a historically underserved population.

**Keywords** Psychiatric genetic counseling, psychiatric disorders, mental illness, stigmatization, genetic testing

## Introduction

Psychiatric disorders affect approximately 11 million adults in the United States and encompass a wide array of conditions including major depression, bipolar disorder, schizophrenia, and obsessive compulsive disorder (NIMH, 2017). The causes of psychiatric disorders are largely misunderstood by those who are affected, their family members, and healthcare providers alike. Studies suggest that at least half of people with psychiatric disorders and their relatives overestimate the genetic contribution to their condition (Austin et al. 2006; DeLisi and Bertisch 2006). This kind of misunderstanding can have negative implications for people with psychiatric disorders. Consequential ideas of fatalism and hopelessness lead to decreased adherence to psychiatric treatments, higher incidences of risk behaviors and a more restrictive outlook on

family planning (Austin et al. 2006; Austin et al. 2007). These outcomes are downstream consequences of inadequate support around these issues. Without formal education or counseling, individuals with psychiatric disorders develop their own explanatory model for their illness. As noted, these explanatory models can be incomplete and/or inaccurate and often lead to misattributed guilt and shame (Skirton et al. 2003). Self-Regulation Theory implies that by providing people with psychiatric disorders accurate information about their illness, including its nature and its causes, we can increase the likelihood that these patients react and adapt more positively to their diagnoses (Leventhal et al. 1997). Thus, interventions dedicated to helping people make meaning of genetics while relaying its relevance to psychiatric disorders should be integrated into routine care for people with psychiatric disorders.

Genetic counseling has been endorsed as an intervention to counsel patients regarding the factors associated with psychiatric disorders, address common misconceptions, promote help-seeking behavior and increase patients' perceived sense of control over their illnesses (Austin et al. 2007). Studies have shown the effectiveness of genetic counseling in the psychiatric context, with positive impacts in patient empowerment and knowledge, self-efficacy, and risk perception reported (Hippman et al. 2016; Inglis et al. 2015). Furthermore, more than 90% of individuals with psychiatric disorders and their relatives desire genetic counseling services (DeLisi and Bertisch 2006; Lyus 2007; Quaid et al. 2001). Despite the high demand, psychiatric disorders rarely constitute a primary indication for referral within genetic counseling. In 2009, 83% of genetic counselors reported that they rarely or never saw patients referred for a psychiatric condition (Monaco et al. 2010). This number has remained relatively static - in 2018, only 14.1% of post-graduates reported having received a primary referral for a psychiatric disorder (Low et al. 2018). These statistics raise the question of what factors are barring this population's access to genetic counseling.

Although psychiatrists and family physicians may be the primary gatekeepers for people with psychiatric disorders to be referred directly for genetic counseling services, genetic counselors have the ability to directly increase the number of individuals that receive genetic counseling for psychiatric disorders by asking patients referred for other indications about personal and family psychiatric history. However, this appears not to be standard practice, as 40% of genetic counselors surveyed reported "rarely" or "never" asking about psychiatric illness when taking a family history (Monaco et al. 2010). Given the positive outcomes of psychiatric genetic counseling, this assessment should be integrated into genetic counselors' routine practice. This process would provide both increased awareness of and access to psychiatric genetic counseling, and would be an effective intervention to combat the underutilization of the field. To advocate for this integration, it is important to understand what factors prevent genetic counselors from asking patients and families about personal or family history of psychiatric conditions.

Several studies have focused on genetic counselors' attitudes regarding psychiatric disorders and psychiatric genetic counseling. Data from such a study indicated that some (33%) genetic counselors feel uncomfortable asking about psychiatric disorders, while others view that the uncertainty associated with psychiatric etiology makes discussion more worrisome than helpful (Monaco et al. 2010). Societal attitudes toward psychiatric disorders have also been shown to impact genetic counselors' decision to discuss psychiatric components of a condition

with families. In the context of 22q11.2 deletion syndrome, 85% of surveyed genetic counselors reported disclosing psychiatric risks to families at the initial or follow-up session; however, the remaining 15% would omit psychiatric manifestations entirely (Martin et al. 2012). When questioned regarding hesitancy in disclosing psychiatric information, 74% of genetic counselors stated stigma to be the root – both fear of societal stigmatization for the child, and for fear of differential treatment of this child by their parents, albeit subconsciously. Psychiatric disorders are highly stigmatized within society, and genetic counselors are not immune.

The abovementioned studies paint a picture of the limited utilization of psychiatric genetic counseling and shed light on the effects of stigmatization of psychiatric disorders within healthcare. Societal stigmatization of psychiatric disorders directly impacts the care of patients at risk for developing psychiatric conditions - genetic counselors are both aware and fearful of the implications of this stigmatization for their patients. However, questions still remain: Do genetic counselors harbor significant stigmatization themselves? If so, how does their perception of psychiatric disorders affect patient care in the context of psychiatric genetic counseling? To narrow this knowledge gap, the goal of this study is to assess the extent and impact of stigmatization on genetic counselors' perceptions of and practices related to psychiatric genetic counseling. We hypothesized that increased stigmatization of psychiatric disorders correlates with a lower frequency of in-session psychiatric assessments and discussions and less perceived value of psychiatric genetic counseling. Additionally, as an exploratory study, we hypothesize that increased stigmatization of psychiatric disorders correlates with differential approaches to counseling in psychiatric versus non-psychiatric scenarios.

## **Methods**

### **Participants and Procedure**

Institutional review board approval was obtained for this study from Stanford University (42893). Two recruitment emails were distributed to genetic counselors via the National Society of Genetic Counselors' (NSGC's) Student Research Survey Program. This program grants genetic counseling trainees access to all NSGC members to increase survey response rates and provide exposure to a variety of genetic counselors. Survey responses were collected between December 2017 and January 2018. The recruitment email was sent to all NSGC members (N = ~4,100). Participants who self-reported to be board-certified genetic counselors actively counseling patients at the time of survey distribution met inclusion criteria. As incentive, participants were eligible to enter a raffle for one of five \$20 Amazon gift cards.

### **Instrumentation**

The survey was divided into 5 sections. Section 1 assessed demographic information including genetic counseling specialty and practice, gender and age. In Section 2, genetic counselors were asked to report the frequency (always, often, sometimes, rarely, or never) with which they ask about psychiatric disorders during personal and family history collection and, when there is a relevant history, how often they provide information about psychiatric disorders

to their patients. In Section 3, respondents were asked to indicate their level of agreement with statements pertaining to the utility and effectiveness of psychiatric genetic counseling. A portion of these statements were adapted from Monaco et al. 2009, a study surveying genetic counselors' perceptions of and attitudes toward schizophrenia. This section included a total of nineteen statements that gathered perspectives on nine different aspects related to psychiatric genetic counseling: indication, responsibility, relevance, qualification, comfort level, significance/value, available data/resources, time, and outcome. Agreement level was indicated using a 7-point Likert scale (1 = strongly agree, 2 = agree, 3 = somewhat agree, 4 = neither agree nor disagree, etc.). Section 4 consisted of a 20-item, validated psychiatric disorder stigmatization scale – the Opening Minds Scale for Health Care Providers (OMS-HC). Developed by Kassam et al., 2012 and used by Morris et al., 2013, this scale measures the level of stigmatizing attitudes toward psychiatric conditions among healthcare providers. Higher scores indicate greater stigma toward psychiatric disorders. In Section 5, participants were asked to respond to two hypothetical genetic counseling scenarios. These scenarios aimed to assess how genetic counselors approach patient guilt and self-blame in psychiatric and non-psychiatric contexts. For each scenario, genetic counselors were asked to respond to an open-ended prompt and to indicate how likely it was that they would tell their patient that they were not to blame for their illness (**Table 1**). This scenario-style study tool was used to explore whether useful information might be obtained from such a tool for future study designs. In order to maintain consistent language with the OMS-HC stigma scale, the term “mental illness” was used interchangeably with “psychiatric disorders” in our study tools.

## **Data Analysis**

Surveys with the majority of questions answered were considered complete and entered into SPSS. Descriptive statistics were calculated for demographic data as well as for the frequency- and utility-related questions. Each statement on the OMS-HC scale is rated on a five-point anchored Likert scale (1 = strongly disagree; 5 = strongly agree). An overall score is calculated by summing statement scores and dividing by the number of statements answered. Missing data points were taken into account in calculating the average stigma scores by matching the denominator to the number of statements answered. To assess the correlation between stigma and the frequency with which counselors ask about psychiatric conditions during patient sessions, a Pearson correlation test was used to compare the OMS-HC scale scores between each frequency category: always, often, sometimes, rarely and never. This same analysis was used to assess whether scores on the OMS-HC scale correlate with perceptions of effectiveness of psychiatric genetic counseling. For each of the nineteen utility-related statements, a Pearson correlation test was used to assess the relationship between OMS-HC scale scores and each agreement category: strongly agree, agree, somewhat agree, etc. For every correlation, the relationship (positive, negative, neutral) between the OMS-HC stigma scores and responses was noted along with the statistical significance. Correlations with  $p < 0.05$  were considered suggestive of statistical significance. Given the large number of analyses run in this study, statistical significance would require a lower cut-off that was not applied to this study, whose purpose was more explanatory in nature.

The open-ended responses within this section were analyzed by the first author using inductive thematic analysis. Co-author MC served as data supervisor for the initial, coding round of analysis. Co-author LC independently coded 20% of the data with a kappa value of 0.563, indicating moderate agreement between coders. In the second round of analysis, co-author JA guided the identification of themes.

To analyze whether stigma impacts counseling approaches between psychiatric and non-psychiatric contexts, Pearson correlations were again used to compare the OMS-HC scale scores between genetic counselors' likelihood (extremely likely, somewhat likely, etc.) of answering the statements addressing self-blame and guilt from Section 5 with our provided prompts. Inductive thematic analysis was used to identify overlapping counseling strategies. The frequency with which each strategy was used was calculated separately for the psychiatric and non-psychiatric scenario.

## **Results**

### **Demographics**

A total of 255 surveys were submitted, 175 of which were deemed complete and submitted by eligible, practicing genetic counselors. Demographic statistics are listed in **Table 2**. Ages ranged from 23 to 60 years, with approximately 93% of respondents being female. Counselors' roles were primarily clinical in nature, with an average of 81% of work time dedicated to counseling patients. The largest majority of respondents worked in prenatal (33.1%), cancer (31.4%) and pediatric genetics (25.7%). Psychiatric genetic counselors made up less than 1% of respondents (0.6%). The remainder of respondents worked in cardiology, laboratory/industry, medical genetics, metabolic, neurology and preconception/fertility (9.2%).

### **Current Practices Relating to Psychiatric Genetic Counseling**

Of the 175 respondents, 35.5% reported "rarely" or "never" asking about personal and/or family history of psychiatric disorders when taking a family history, and only 36.6% reported "always" or "often" asking for this information. In the context of a relevant family history, less than half of respondents (44.6%) reported regularly providing information about psychiatric disorders to their patients.

### **Perceptions and Attitudes Toward Psychiatric Genetic Counseling**

A summary of survey responses can be found in **Table 3**. Approximately 90% of respondents agreed that discussion of psychiatric disorders is indicated when there is a relevant personal and/or family history. Nearly a third (30.8%) agreed with the statement that this discussion is only warranted when a psychiatric condition is the primary referral reason. Roughly 25% of respondents agreed with there being enough time in a session to address the topic of psychiatric disorders.

As for the responsibility to discuss the risk for psychiatric disorders to patients, 63.5% of respondents agreed that responsibility lied with other healthcare professionals. Only ¼ (25.1%) of respondents agreed that there is sufficient data on the genetics of psychiatric disorders, while a minority (17.7%) agreed with there being enough resources on the topic of psychiatric genetic counseling. More than half of respondents (67.4%) agreed that psychiatric disorders are a relevant topic of discussion within the realm of genetic counseling.

Nearly equal proportions of respondents disagreed with the statement that they feel comfortable (22.5%) and/or qualified (23.4%) initiating a discussion about psychiatric disorders with patients. Even if respondents themselves felt comfortable and/or qualified discussing this topic, approximately 30% agreed with the statement that most patients are uncomfortable being asked about psychiatric disorders in general.

A great majority of genetic counselors agreed that they would discuss family histories of psychiatric disorders in more detail if genetic testing were available (84.4%) and/or if an individual risk calculation could be provided to patients (90.1%). More than a third of counselors (40.1%) agreed with the sentiment that patients are frustrated with the inability of genetic counselors to provide an individual risk for developing psychiatric disorders.

For context, respondents were given the opportunity to elaborate on their answers to this section's statements in a free-response text box. Several themes were identified including "genetic counseling as safety net", "assuming negative patient impact" and "shifting responsibility". Notable quotes are listed by topic in **Table 4** with their corresponding themes.

### **OMS-HC Stigma Scale and Correlates**

On a scale of 1, being the lowest stigma score, and 5, being the highest stigma score, the average stigma score among respondents was 3.0, with a maximum score of 3.5. **Table 5** summarizes the notable correlations described in this section. Respondents with higher stigma scores were less likely to ask patients about personal and/or family histories of mental illness ( $p = 0.046$ ), felt less qualified ( $p = 0.003$ ) and less comfortable ( $p = 0.003$ ) initiating a mental illness discussion and felt that most patients were uncomfortable being asked about personal and/or family history of mental illness ( $p = 0.027$ ). Higher stigma scores correlated with beliefs that there is insufficient data from research ( $p = 0.016$ ) and resources ( $p = 0.019$ ) on the topic of genetic counseling for mental illness. Stigma scores were higher in respondents who reported having insufficient time in a session to address mental illness ( $p = 0.024$ ). Stigma scores were higher in respondents who believed discussing patient-specific risk assessments in families at risk for mental illness is more worrisome to patients than it is useful ( $p = 0.033$ ).

### **Exploratory Analyses – Hypothetical Scenarios**

The majority of genetic counselors were "extremely likely" or "moderately likely" to tell their hypothetical patients that they "are not to blame" for developing cancer (69.7%) and schizophrenia (78.9%). Counseling responses to patient guilt were compared between the psychiatric and non-psychiatric scenarios and are summarized in **Table 6**. Overall, genetic counselors were equally likely to avoid or to address patient guilt regardless of whether patient guilt was in the psychiatric or non-psychiatric context. However, when analyzed based on specific counseling strategies, genetic counselors were less likely to normalize patient guilt

(14% vs 25%) but were more likely to directly combat patient blame (22% vs 14%) in the psychiatric context.

## Discussion

### *Stigmatization and Psychiatric Genetic Counseling*

Previous literature identified the discrepancy between patient demand for psychiatric genetic counseling and how often it is provided. The present study looked inward, identifying another discrepancy – how many genetic counselors believe they *should* provide psychiatric counseling (90.3%) when there is relevant history and how many counselors *actually do* (44.6%). Revisiting the purpose of this study, we ask - could stigma be a contributing factor? When analyzed at the surface, the answer is deceiving. The average score on the OMS-HC was neutral, broadly suggesting that the majority of genetic counselors do not have explicit biases related to mental illness. However, this study identified that while overall neutral, any increase in stigma scores was statistically significantly associated with fewer discussions about psychiatric disorders, feelings of discomfort and unqualification, reports of insufficient data, resources and time, and the belief that psychiatric risk assessments are more worrisome than helpful.

This in-depth analysis suggests that genetic counselors' opinions of and experiences with psychiatric genetic counseling is at least partially informed by stigmatization, however minimal this degree of stigma may seem. Some of the relationships in this study make sense – genetic counselors with higher levels of stigmatization feel less comfortable discussing mental illness with patients. This discomfort could lead counselors to ask fewer questions, or none at all, in regards to a patient's personal and/or family history of psychiatric disorders, even when relevant. Other correlations from this study are open to interpretation. Genetic counselors with higher stigma scores were more likely to report feeling less qualified to discuss mental illness with patients. Interestingly, genetic counselors with higher stigma scores were also more likely to report there being insufficient data and resources on psychiatric genetic counseling. It could be possible that mental illness stigmatization impacts psychiatric education among genetic counselors. Genetic counselors who stigmatize mental illness may not actively seek out information on psychiatric disorders, making them feel less prepared to engage in psychiatric conversations with patients. Lastly, reports of patient discomfort, the worrisome nature of psychiatric risk assessments and lack of time were all linked to greater degrees of stigmatization. The issue of time is valid – genetic counselors often must compact complex information into short sessions. However, the negative correlation between stigmatization and time is nonrandom and could imply that "limited time" is a. The final two correlations pertaining to discomfort and worry may be the product of countertransference. Genetic counselors who are uncomfortable with mental illness discussions themselves might assume their patients share the same sentiment.

### *Genetic Testing for Psychiatric Disorders: All-or-Nothing?*

In terms of providing psychiatric genetic counseling, the lack of clinical genetic testing for psychiatric disorders is causing genetic counselors to hesitate. A majority of genetic counselors



(84.4%) agreed that genetic testing availability would increase the frequency of psychiatric discussions with patients. Counselors who felt adequately prepared to counsel on psychiatric disorders still felt that their counseling was incomplete without the option of offering testing. These findings are troubling in the sense that counseling strategies appear to be taking a backseat to genetic testing. Although the development of genetic testing has enhanced its practice, genetic testing does not define the field of genetic counseling. Genetic counseling has been described as “a process of helping people to understand and adapt to the medical, psychological and familial implications of genetic contributions to disease” (Resta et al. 2006). Even without the option of genetic testing, genetic counselors can make a meaningful difference to people who live with psychiatric disorders through discussing heritability, causes, early signs and symptoms, and prevention. [add citations]

### *Uncertainty – Discomfort and Education*

Without genetic testing to offer patients, discussions of psychiatric disorders with patients must involve a level of uncertainty. As quoted in this study, a portion of genetic counselors are uncomfortable addressing uncertainty, especially without the aid of genetic testing to provide clarity. Likely frustrated themselves, genetic counselors overestimate their patients’ frustration when faced with uncertainty. In this study, over a third (40.1%) of genetic counselors believed that their patients would be frustrated by the inability to provide individualized risk calculations for psychiatric disorders. However, from the perspective of patients with psychiatric disorders, the uncertainty associated with psychiatric genetic counseling does not significantly detract from its value. In a survey of individuals with a diagnosed psychiatric disorder who received psychiatric genetic counseling, 52% reported that they had expected the uncertainty (Hippman et al. 2013).

If patients welcome the uncertainty associated with psychiatric genetic counseling, genetic counselors must as well. Education on psychiatric genetics, with focus on counseling about uncertainty, is necessary to increase counselors’ comfortability with mental illness discussions. Unfortunately, education on psychiatric disorders and uncertainty is inconsistently incorporated into graduate curriculum. Despite some programs providing exceptional psychiatric genetic counseling training, a survey of recent and current graduates reflects that 37.6% feel that their psychiatric training was inadequate (Low et al. 2017), with 30.1% expressing a need for more instruction in this area. As a result, less than half (42%) of trainees and recent graduates feel “somewhat prepared” or “very prepared” to address psychiatric disorders in a genetic counseling session. Thus, graduate training curricula require much needed growth in terms of preparing counselors for discussions on psychiatric disorders.

### *Exploratory Analysis: Counseling Responses to Guilt*

Although genetic counselors were no less likely to address patient guilt in the context of schizophrenia, there was a notable difference in the types of counseling strategies used most often. Interestingly, genetic counselors were less likely to normalize and validate the guilt expressed by the patient with schizophrenia. Instead, counselors were more likely to jump straight to trying to dissolve this guilt with statements such as “you are not to blame for your diagnosis.” This finding may be the result of participants being primed by the sequencing of

survey items - that is they had already completed the cancer scenario which proposed the statement “you are not to blame for developing cancer.” Another possibility involves the potential of differential counseling of psychiatric disorders. Less validation and normalization may reflect counselor discomfort engaging with psychiatric-related guilt on a more intimate, psychosocial level, or may suggest counselors use fewer empathetic statements in psychiatric contexts. Inexperience with psychiatric disorders may influence how and how often genetic counselors engage psychosocially with their patients.

### *Psychiatric Genetic Counseling – Then vs Now*

The adapted statements from Monaco et al. 2009 used in this study allowed for the comparison of genetic counselors’ attitudes toward and practices related to psychiatric genetic counseling over time. Over a decade, some perceptions have remained relatively stable. The proportion of genetic counselors reporting no sense of discomfort with mental illness conversations is identical (71% in 2009 vs 71.7% in 2019). The proportion of counselors who believe patients are uncomfortable being asked about personal and/or family histories of psychiatric disorders has not changed significantly (33% in 2009 vs 30% in 2019), as is the case for the fraction of genetic counselors who view psychiatric risk assessments to be more worrisome than helpful (14% in 2009 vs 13.2% in 2019). Notable differences in perceptions include the proportion of genetic counselors who feel personally uncomfortable initiating mental illness conversations with patients (13% in 2009 vs 22.3% in 2019). Approximately 5-6% more genetic counselors report routinely asking about psychiatric disorders when taking family histories than was reported in 2009. However, this difference is overshadowed by another substantial shift identified in this study - the weight given to genetic testing and personalized risk assessments. The belief that available genetic testing would increase the frequency of mental illness discussion increased 8.4% since 2009, with individualized risk assessments increasing this same sentiment by 10.1%. Technically speaking, more genetic counselors appear to be talking about psychiatric disorders; however, an even greater number of genetic counselors feel uncomfortable discussing mental illness, possibly exacerbated by today’s reliance on clinical genetic testing and concrete risk assessments.

### *Empowering Psychiatric Conversations*

A hope of this research is to motivate and empower genetic counselors to engage in conversations about psychiatric disorders with their patients. This study is not meant to shame genetic counselors for their hesitations and biases. Such biases and stigmatizations are prominent in society and, as remarked previously, genetic counselors are not immune. Why should we combat these biases? Genetic counselors shared the positive impacts of psychiatric discussions. Counselors remarked that initiating these conversations with patients served to validate psychiatric disorders as serious health issues. Counseling on psychiatric disorders has the power to educate patients on the causes of these conditions, correct misinformation patients may be harboring, and encourage patients to monitor early signs and symptoms of psychiatric disorders. To reiterate from this study – “rarely, patients need a number. They more often than not, just need someone to care enough to ask the question”.

## **Study Limitations**

Limitations of this research include the possibility of selection bias, as genetic counselors more interested in or experienced with psychiatric conditions may have been more likely to participate. A greater representation of genetic counselors seasoned in psychiatric genetic counseling might shift study results in favor of: (1) less stigmatizing attitudes toward psychiatric disorders, (2) greater comfortability discussing psychiatric disorders with patients, and (3) increased frequency of psychiatric disorder discussions with patients. The survey-based nature of this research might have resulted in response bias, causing participants to respond to psychiatric-related questions in a manner perceived as acceptable. In addition, the limited response rate restricts how generalizable these study results are to the entirety of the genetic counseling profession.

## **Research Recommendations**

Future research may include detailed interviews to gather more rich data on genetic counselors' attitudes toward and hesitations regarding psychiatric genetic counseling. Such interviews might explore what knowledge gaps genetic counselors perceive to be hindering their ability to provide meaningful psychiatric counseling. Based on these reports, psychiatric genetic counseling guidelines could be established to improve genetic counselors' comfortability, confidence and proficiency regarding psychiatric topics. These guidelines might specify tools for counseling on uncertainty as a means to reduce dependency on the availability of genetic testing.

## **Conclusion**

The prevalence of psychiatric disorders in the United States guarantees that genetic counselors will interact with patients with personal and/or family histories of one or more psychiatric conditions. However, the majority of genetic counselors do not ask about or discuss the genetics of psychiatric conditions on a regular basis. Stigmatization of psychiatric disorders was proposed as a possible deterrent to psychiatric genetic counseling. Genetic counselors as a whole may not have overt, explicit stigmatizing views of psychiatric disorders; however, this study suggests that more subtle, implicit biases may be negatively affecting and informing genetic counselors' perceptions of and practices related to psychiatric genetic counseling. Although the majority of genetic counselors do not regularly assess for psychiatric conditions, the minority who do defend its benefits. The perspectives of this subgroup serve as a reminder that the value of genetic counseling extends beyond genetic testing, and that the scope of genetic counselors in assessing genetic health includes acknowledgement of mental health. In order to properly serve a historically underserved psychiatric patient population, psychiatric conversations must be normalized within the genetic counseling field. Early and repeated exposure to psychiatric topics in genetic counseling graduate training is desperately needed to validate and enrich psychiatric discussions, shifting these conversations from optional and seldom to necessary and worthwhile.

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**Conflict of Interest** Stephanie Booke, Jehannine Austin, Laurel Calderwood and MaryAnn Campion declare that they have no conflict of interest.

**Ethical Approval** The Institutional Review Board at Stanford University approved the study.

**Human Studies and Informed Consent** Consent was implied with completion of the anonymous survey (in accordance with IRB approval). All authors consented to the submission of this manuscript. 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 (5).

**Animal Studies** No animal studies were carried out by the authors for this article.

**Authorship Contributions** Stephanie Booke provided substantial contributions to the conception, design and drafting of this work and agrees to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. Jehannine Austin, Laurel Calderwood and MaryAnn Campion provided substantial contributions to the conception, design and drafting of this work, aided in revising the work critically for important intellectual content, and provided final approval of the version to be published.

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**Table 1:** Hypothetical, open-ended prompts for psychiatric and non-psychiatric scenarios

While counseling your patient, Kate, you gather her personal and family history. Kate reports that she recently received a diagnosis of cancer. She feels guilty because she believes her diagnosis must be due to bad lifestyle choices. Kate's personal risk factors are minimal, but you note a striking family history. How would you respond to Kate about her feelings of guilt? What sorts of things might you say?

- A. [free response]
- B. How likely is it that you would respond to Kate with the following statement? "Kate, you are not to blame for developing cancer."
  - Extremely likely
  - Moderately likely
  - Neither likely nor unlikely
  - Moderately unlikely
  - Extremely unlikely

While counseling your patient, Sarah, you gather her personal and family history. Sarah reports that she recently received a diagnosis of schizophrenia. She feels guilty because she believes her diagnosis must be due to bad lifestyle choices. Sarah's personal risk factors are minimal, but you note a striking family history of mental illness. How would you respond to Sarah about her feelings of guilt? What sorts of things might you say?

- C. [free response]
- D. How likely is it that you would respond to Sarah with the following statement? "Sarah, you are not to blame for having schizophrenia."
  - Extremely likely
  - Moderately likely
  - Neither likely nor unlikely
  - Moderately unlikely
  - Extremely unlikely



**Table 2:** Demographic information of genetic counselors (n = 175)

<b>Characteristic</b>	<b>n</b>	
<b>%</b>		
Gender		
Male	162	92.6
Female	13	7.4
Age		
<30 years	100	57.1
31-40 years	55	31.4
41-50 years	12	6.9
51-60 years	8	4.6
Specialty		
Prenatal	58	33.1%
Cancer	55	31.4%
Pediatrics	45	25.7%
Other <sup>1</sup>	16	9.2%
Psychiatric	1	0.6%

<sup>1</sup>Cardiology, laboratory/industry, medical genetics, metabolic, neurology, preconception/fertility

**Table 3:** Frequency data: perceptions and attitudes toward psychiatric genetic counseling

<b>Statement</b>	<b>Total in agreement, N<sup>+</sup> (%)</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Somewhat agree</b>
Genetic counseling for mental illness has value to patients and their families	<b>163<sup>1</sup> (94.2%)</b>	46 (26.6%)	78 (45.0%)	39 (22.5%)
Discussion of mental illness is indicated if there is a relevant personal and/or family history	<b>158 (90.3%)</b>	47 (26.9%)	77 (44.0%)	34 (19.4%)
Genetic counselors would discuss a family history of mental illness in more detail if an individual risk calculation could be provided	<b>155<sup>2</sup> (90.1%)</b>	38 (22.1%)	66 (38.4%)	51 (29.7%)
Genetic counselors would discuss a family history of mental illness in more detail if genetic testing were available	<b>146<sup>1</sup> (84.4%)</b>	41 (23.7%)	56 (32.3%)	49 (28.3%)
It is an appropriate use of a genetic counseling session to counsel on mental illness	<b>138<sup>1</sup> (79.8%)</b>	26 (15.0%)	66 (38.2%)	46 (26.6%)
I feel comfortable initiating a discussion about mental illness with patients	<b>124<sup>1</sup> (71.7%)</b>	17 (9.8%)	56 (32.4%)	51 (29.5%)
I feel qualified to initiate a discussion about mental illness with patients	<b>122 (69.7%)</b>	9 (5.1%)	54 (30.9%)	59 (33.7%)
Mental illness is a relevant topic in my field of practice	<b>118 (67.4%)</b>	31 (17.7%)	44 (25.1%)	43 (24.6%)
It is the responsibility of other healthcare professionals to discuss the risk for mental illness	<b>111 (63.5%)</b>	8 (4.6%)	47 (26.9%)	56 (32.0%)
In the context of genetic counseling, mental illness is a significant issue	<b>109 (62.2%)</b>	13 (7.4%)	38 (21.7%)	58 (33.1%)
Most patients feel comfortable being asked about personal or family history of mental illness	<b>85 (48.6%)</b>	4 (2.3%)	38 (21.7%)	43 (24.6%)

Patients often feel frustrated with the inability of genetic counselors to provide an individual risk calculation for mental illness	<b>69 (40.1%)</b>	6 (3.4%)	24 (13.7%)	39 (22.3%)
<b>Statement</b>	<b>Total in agreement<sup>1</sup>, n = 175</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Somewhat agree</b>
Discussion of mental illness is indicated only when personal and/or family history of mental illness is the primary referral reason	<b>54 (30.8%)</b>	10 (5.7%)	20 (11.4%)	24 (13.7%)
There is sufficient data from research about the genetics of mental illness	<b>44 (25.1%)</b>	2 (1.1%)	13 (7.4%)	29 (16.6%)
There is enough time in a session to address mental illness	<b>43 (24.6%)</b>	1 (0.6%)	13 (7.4%)	29 (16.6%)
There are enough resources on the topic of genetic counseling for mental illness	<b>31 (17.7%)</b>	0 (0.0%)	6 (3.4%)	25 (14.3%)
Discussing patient-specific risk assessment in families at high risk for mental illness is more worrisome to patients than it is useful	<b>23<sup>1</sup> (13.3%)</b>	1 (0.6%)	5 (2.9%)	17 (9.7%)
Discussing the known genetics of mental illness and their patterns of inheritance for patients at high risk is more confusing than it is helpful	<b>15<sup>1</sup> (8.7%)</b>	0 (0.0%)	1 (0.6%)	14 (8.1%)

\*N = 175 unless otherwise noted

<sup>1</sup>N = 173

<sup>2</sup>N = 172

**Table 4:** Qualitative snapshot – perceptions and attitudes towards psychiatric genetic counseling

Topic	Quotation	Theme
Genetic testing	<p>“I think that genetic counselors understand that our practice is not purely based on genetic testing. However, we are more comfortable with counseling about genetic testing because it is more likely to give a more concrete answer. I think that multifactorial inheritance is something that should be addressed more in training programs so that new GCs are more comfortable discussing this kind of uncertainty.”</p> <p>“Personally, I do not think we need genetic testing to provide comprehensive genetic counseling but in this day and age there is a huge focus on genetic testing.”</p> <p>“I know empiric risks exist, but I’m not really aware of any genetic testing available for any ways of preventing/reducing risk for a diagnosis (such as bipolar, schizophrenia, etc).”</p> <p>“Personally, I do not think we need genetic testing to provide comprehensive genetic counseling but in this day and age there is a huge focus on genetic testing and I believe many counselors would feel uncomfortable counseling on conditions where so little is still known about the genetics and there is no genetic testing to offer.”</p> <p>“I feel like I have the training and tools to counsel a patient about mental illness (MI), but I typically do not initiate a conversation unless it is relevant to the referral indication or if the patient asks about it. This is partly because we can’t offer much in terms of genetic testing or interventions for MI risk.”</p> <p>“...we are more comfortable with counseling about genetic testing because it is more likely to give a concrete answer. I think that multifactorial inheritance is something that should be addressed more in training programs so that new GCs are more comfortable discussing this kind of uncertainty.”</p>	Genetic testing as safety net

Handling	<p>"I treat this like I do other genetic conditions - if indicated by family history, consider a referral to a different specialty clinic."</p>	Shifting responsibility
Patient experience	<p>"I feel like people often want more concrete answers than I can provide."</p> <p>"GCs in my experience often inaccurately assume that patients will be frustrated by the lack of risk calculation and hard numbers, but in my personal experience this isn't the case at all."</p>	Assuming negative patient impact
Value	<p>"Although presymptomatic genetic testing is not available, I think the discussion validates mental illness as a serious health issue and encourages families to address early presentation of symptoms."</p> <p>"Rarely, patients need a number. They more often than not, just need someone to care enough to ask the question. To normalize the information. To care. I do think if we had a number, more GCs would address it... But for what reason, to give a number. The benefit of a GC is not the number, but helping the family through the uncertainty."</p> <p>"I have mixed feelings about the value of GC for mental illness- if we are telling someone that there is up to a 30% chance that their children would have bipolar disorder, is that really helpful information? Does that benefit the patient or their family?"</p>	Justification of psychiatric discussions

**Table 5:** Summary of possible correlations: OMS-HC stigma score vs responses ( $p < 0.05$ )

Question/statement	Sig ( $p$ )	Correlation
How often do you ask patients about personal and/or family histories of mental illness?	Negative <sup>1</sup> -0.153	0.046
I feel qualified to initiate a discussion about mental illness with patients	Negative -0.227	0.003
I feel comfortable initiating a discussion about mental illness with patients	Negative -0.227	0.003
Most patients feel comfortable being asked about personal or family history of mental illness	Negative -0.170	0.027
There is sufficient data from research about the genetics of mental illness	Negative -0.184	0.016
There are enough resources on the topic of genetic counseling for mental illness	Negative -0.180	0.019
There is enough time in a session to address mental illness	Negative -0.173	0.024
Discussing patient-specific risk assessment in families at high risk for mental illness is more worrisome to patients than it is useful	Positive <sup>2</sup> 0.164	0.033

<sup>1</sup>Higher stigma scores correlate with lower frequency (rarely, never), less agreement (disagree, strongly disagree)

<sup>2</sup>Higher stigma scores correlate with more agreement (agree, strongly agree)

**Table 6:** Summary of counseling strategies in psychiatric and non-psychiatric contexts

Avoidance of guilt			Addressing guilt		
Counseling strategy	Frequency in schizophrenia scenario	Frequency in cancer scenario	Counseling strategy	Frequency in schizophrenia scenario	Frequency in cancer scenario
Intellectual response to guilt	29%	27%	Normalization of guilt	14%	25%
Redirection of guilt	7%	6%	Probing about guilt	25%	25%
Referring to specialist	3%	3%	Combating blame	22%	14%