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Identifying Interest in and Barriers to Psychiatric Genetic Counseling

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IDENTIFYING INTEREST IN AND BARRIERS TO PSYCHIATRIC GENETIC
COUNSELING

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COUNSELING

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IDENTIFYING INTEREST IN AND BARRIERS TO PSYCHIATRIC GENETIC COUNSELING

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Mental illness is common in the United States and genetic counseling for psychiatric indications can help individuals understand multifactorial inheritance, recurrence risk estimates, and identify ways to protect their future mental health. Despite interest in and efficacy of the service documented in populations outside of the United States, individuals with personal and/or family histories of psychiatric conditions are very rarely accessing psychiatric genetic counseling services. The purpose of our study was to identify interest in and barriers to psychiatric genetic counseling with the hopes of better characterizing this population and improving access to this beneficial service in the future. An online survey was developed to assess exposure to genetic counseling, perceived causes of psychiatric conditions, and level of interest in, reasons for, and barriers to psychiatric genetic counseling. Individuals with self-reported personal and/or family histories of any mental illness were invited to participate via emails and advertisements to local Houston support groups, psychiatry and maternal fetal medicine clinics, and other platforms. Categorical variables were compared using contingency tests. Overall, 87% of respondents reported being extremely, very, or somewhat interested in psychiatric genetic counseling. There was no significant difference in the level of interest in psychiatric genetic counseling for individuals with a family history of serious mental illness, such as schizophrenia, when compared to those with a family history of any type of mental illness. Similarly, degree of relation and number of affected family members was not associated with significant differences in the level of interest. Any patient with a personal and/or a family history of any type of psychiatric condition(s) may be interested in and benefit from this service.

The most common reasons for interest in psychiatric genetic counseling were “to understand more about the condition” and “recurrence risk” (71% and 66% of respondents respectively). The most common perceived barriers to psychiatric genetic counseling were “cost/insurance coverage” and “time” (80% and 38% of respondents respectively). This study provides important insight into this population, confirms interest levels reported by prior studies, and provides information for genetic counselors and other providers interested in increasing access to psychiatric genetic counseling.

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Abbreviations

AMI	Any Mental Illness
FDR	First Degree Relative
NAMI	National Alliance on Mental Illness
SARDAA	Schizophrenia and Related Disorders Alliance of America
SDR	Second Degree Relative and Greater
SMI	Serious Mental Illness

Introduction

According to the National Institute of Mental Health, it is estimated that one in five U.S. adults lives with a mental illness in a given year (2017). Within that population, one in twenty-five adults will live with a severe or serious mental illness (SMI), conditions such as schizophrenia, bipolar disorder, and severe depression that result in serious functional impairment impacting major life activities (National Institute of Mental Health, 2017). As mental illness impacts such a large percentage of the population, understanding the causes of these conditions is an important area of research. Research to discover the complex etiology of psychiatric disorders is still ongoing, but studies show involvement of genetic components (Shih, Belmonte, & Zandi, 2004). Studies assessing the heritability of schizophrenia and bipolar disorder in particular have shown heritability estimates ranging from 64-85% and 59-89% respectively (Cardno et al., 1999; Lichtenstein et al., 2009; McGuffin et al., 2003; Merikangas et al., 2013). These ranges encompass estimates from twin studies and studies outside of twin populations including the family study approach. Additional studies have assessed the heritability of mental illness across diagnoses. While having a parent with a psychiatric condition of any kind increases the risk for any mental illness (AMI) in children, research has shown having two affected parents or having a SMI in either parent increases those risks even further (Dean et al., 2010).

Outside of genetic and familial factors, studies assessing the interaction between genes and environment have also contributed to our understanding of mental illness. The presence of strong environmental factors and the high heritability of SMI suggests that a significant amount of SMI may be attributed to the synergy between genetic and environmental factors (Shih et al., 2004; Uher, 2014). Some examples of environmental factors that have been associated with increased risks for SMI include cannabis use in adolescence, childhood maltreatment, and season of birth (Fuller Torrey, Miller, Rawlings, & Yolken, 1997; Moore et al., 2007; Varese et al., 2012). While studies indicate complex interactions between these factors as underlying causes of mental illness, individuals and family members impacted by psychiatric conditions may not hold

the same beliefs.

Previous studies have examined patient and family perceptions of the causes of their psychiatric condition(s). A 2006 study surveyed clinical psychiatrists, researchers, and families who had at least two family members affected with schizophrenia and found that more family members than clinicians and researchers thought the cause of schizophrenia was only genetic (39.6% compared to 18.8% and 11.7% respectively)(Delisi & Bertisch). A 2013 study in the Netherlands found that a majority of participants believed a multifactorial or polygenic etiology explained bipolar disorder in their families, while a minority considered genes alone to be the cause of the disorder (Baart & Widdershoven). Studies showing the variability in patient and family understanding of the causes of psychiatric disorders prompted research into the interest in and the perceived benefits of psychiatric genetic counseling, a service that addresses the topic of etiology with patients and families.

Psychiatric genetic counseling is an emerging area within the field of genetic counseling in the United States. In general, the purpose of genetic counseling is to provide individuals and families information about genetic conditions and support as patients make decisions regarding genetic health. Historically, this service involves discussing genetic testing for Mendelian conditions for which there is a known genetic cause. Similar to genetic counseling in other specialties, psychiatric genetic counseling involves obtaining family history information, helping patients and family members understand the causes of mental illness, discussing recurrence risk estimates for those interested in learning about the chance for mental illness to occur again in a family, and helping individuals identify ways to protect future mental health (National Society of Genetic Counselors, 2008). Unlike many other genetic counseling specialties, at this time, psychiatric genetic counseling rarely involves clinical genetic testing.

As early as 2003, studies have supported genetic counseling for individuals and families with psychiatric disorders (Biesecker & Peay). Since then, several studies have reported that individuals with personal and/or family histories of mental illness report interest in psychiatric genetic counseling services (Austin & Honer, 2008; Costain, Esplen, Toner, Hodgkinson, & Bassett, 2014; Delisi & Bertisch, 2006; Lyus, 2007; Quaid, Aschen, Smiley, & Nurnberger, 2001). However, after years of research supporting patient and family interest in the service, very few individuals are receiving psychiatric genetic counseling. In a 2007 study of individuals with a personal or family history of schizophrenia, a majority of affected participants and half of all relatives had never heard of genetic counseling. The study reported that 0% of affected individuals and just 5% of family members had received genetic counseling, while a majority of the respondents indicated they were interested in the service and thought they would benefit from it (Lyus).

Just as with genetic counseling in other specialties, studies have shown the efficacy of psychiatric genetic counseling. Inglis et al. found that participants had increased levels of self-efficacy, empowerment, and risk perception accuracy after attending a psychiatric genetic counseling session (2015). Costain et al. found that patients had increased knowledge of the subject and a decreased sense of stigma after receiving psychiatric genetic counseling (2014). Additionally, a study assessing the utility of psychiatric genetic counseling or an educational booklet for those with SMI found that knowledge increased for both the psychiatric genetic counseling and booklet groups, but the accuracy of risk perception was increased at follow up in the genetic counseling group alone (Hippman et al., 2016). A more recent meta-analysis of the current literature on the efficacy of psychiatric genetic counseling concluded that this service is effective for multiple reasons, citing improvements in both psychological and knowledge based areas for both patients and family members (Moldovan, Pinte, & Austin, 2017).

Another study reviewing genetic counseling referrals for a schizophrenia indication concluded that, “for British Columbia, individuals affected with schizophrenia and their family members are rarely referred for psychiatric genetic counseling. There is a need to identify barriers to psychiatric genetic counseling and develop strategies to improve access” (Hunter, Hippman, Honer, & Austin, 2010).

The interest in and benefits of psychiatric genetic counseling are well documented, yet uptake of this service remains low. As several studies assessing psychiatric genetic counseling interest involved a Canadian population, we thought it important to research this topic further in our patient population in the Southern United States exposed to a different health care system. Our study aimed to describe interest in and barriers to psychiatric genetic counseling, thus increasing our understanding of this population and moving towards improving access to and knowledge of this valuable service.

Methods

The study protocol was approved by the Institutional Review Board of the University of Texas Health Sciences Center at Houston (IRB number HSC-MS-18-0540).

Instrumentation

An online survey was developed by the study team to assess participants’ previous exposure to genetic counseling, personal and/or family history of psychiatric conditions, beliefs about the etiology of these conditions, and interest in, motivations for, and barriers to psychiatric genetic counseling services (see Appendix for complete copy of survey). To our knowledge, there exists no validated research tool that addressed our specific aims. Survey questions also included information regarding participant demographics.

Procedures

Access to an online Qualtrics survey was provided to individuals with self-reported personal diagnoses and/or self-reported family histories of any psychiatric condition. Survey responses were collected from September 2018 through January 2019. Individuals 18 years and older, English speaking, with self-reported personal diagnoses and/or family histories of any psychiatric condition were eligible to participate. Individuals were invited to participate via local and national support groups, as well as local clinics. The Greater Houston chapter of the National Alliance on Mental Illness (NAMI) distributed the invitation via their email listserv and their Facebook page. The Schizophrenia and Related Disorders Alliance of America (SARDAA) published an informational advertisement regarding the study on one of their national monthly newsletters. Additionally, flyers were placed at UT Maternal Fetal Medicine Clinics, UT McGovern Medical School Building, and UT Psychiatry Clinics and shared by UT clinicians, as well as advertised on the UTHHealth Center of Excellence on Mood Disorders Facebook page. Interested participants could access the survey via URLs and/or QR codes provided in the email or flyers.

Individuals provided consent by reading and agreeing to the consent form on the first page of the survey. Respondents had the opportunity to participate in an Amazon.com gift card drawing by providing an email address at the end of the survey. Twenty \$20 gift cards were awarded at random. Participation in the drawing was not required. Grant funding for the gift card incentive was awarded by the National Society of Genetic Counseling Psychiatric Special Interest Group.

Data Collection and Analysis

Anonymous survey responses were collected via the secure survey platform Qualtrics (Qualtrics, Provo, UT) and uploaded to the statistical analysis software Stata (v. 13, College Station, TX) for analysis. Descriptive statistics were used to describe the demographics of the respondents. Respondents were included in analysis if they met inclusion criteria and at least

completed the survey section on their opinions regarding genetic counseling. All diagnostic information was self-reported by respondents. Participants were instructed to only report on psychiatric conditions that were formally diagnosed by a doctor or other mental health professional.

Our questions on psychiatric genetic counseling interest were assessed on a 5 point Likert scale ranging from 0 (not at all interested) to 4 (extremely interested). Questions on the impact of both personal and/or family member's psychiatric condition were assessed on a 5 point Likert scale ranging from 0 (no impact at all) to 4 (life altering). Questions about the perceived level of importance of each etiology factor were assessed on a 4 point Likert scale ranging from 0 (not at all important) to 3 (very important). The free response question was assessed for themes and coded independently by the PI and committee chair, and compared for consistency.

Categorical data was described as frequencies (and percentages). Quantitative statistical comparisons were made between the various categorical variables and the three diagnostic groups: individuals with a personal history only, individuals with a family history only, and individuals with both personal and family histories of any psychiatric condition. Categorical variables were compared using contingency tests (Chi-square or Fisher exact). Since respondents with a positive family history of psychiatric conditions reported the impact on family life separately for each of their relatives, an overall impact score was calculated as the mean of the Likert score for each family member. These overall impact scores along with the impact scores of a respondent's personal diagnosis of a psychiatric condition were reported as mean (with standard deviation, sd). Spearman correlation coefficients were calculated to compare the correlation between a respondent's level of interest in psychiatric genetic counseling and the impact on their life due to their personal or family history of psychiatric illnesses. Paired t-tests were utilized to compare each respondent's personal impact score at the time of their diagnosis to

the current impact score. A p-value of <0.05 was considered statistically significant for all analyses.

Results

Demographics

A total of 106 individuals initiated the Qualtrics survey. Of those individuals, 95 met our eligibility criteria. Six consented and dropped out of the study, four reported no personal history and reported “unsure” for their family history, and one individual reported no personal and no family history, thus, these respondents were removed from the cohort. 88 (93%) females and 7 (7%) males participated in the survey. Our population was highly educated with 76% of individuals report having a four year college degree or greater. More than half of the participants (56%) report being employed for wages or salary. Our population was also relatively wealthy with more than half of participants (55%) reporting an estimated household income of greater than \$60,000. The average age of the participants was 40 (sd: 14), with the youngest participant reporting an age of 18 and the oldest reporting an age of 79. The study population was predominantly non-Hispanic whites (60%). Full demographic information is reported in Table 1. A majority of the participants were recruited through the NAMI Greater Houston email listerv (34%) and through the “other” sources (28%) such as a NAMI Facebook post, an advertisement in the McGovern Medical School Building, or on the UTHealth Center of Excellence on Mood Disorders Facebook page that were write in options.

Table 1 Demographics

Table 1 Demographics	Frequency	Percent
Gender		
Female	88	93
Male	7	7
Ethnicity		
non-Hispanic White	57	60
Hispanic	18	19
Asian	9	10
African American	5	5
Multiracial	4	4
Hawaiian/Pacific Islander	1	1

Prefer not to answer	1	1
Estimated Household Income		
\$80,000 or More	35	37
\$60,000-79,999	17	18
\$40,000-59,999	17	18
\$20,000- 39,000	12	13
Less Than \$20,000	7	7
Prefer Not to Answer	7	7
Employment		
Employed for Wages/Salary	53	56
Student	10	11
Self Employed	9	10
Homemaker	8	8
Retired	7	7
Unable to Work	4	4
Out of Work and Looking	2	2
Out of Work But Not Looking	1	1
Prefer Not to answer	1	1
Marital Status		
Married or Domestic Partnership	50	53
Single Never Married	20	21
In a Relationship (Not Married)	13	14
Divorced	8	8
Separated	3	3
Widowed	1	1
Education		
Doctorate	9	10
Professional Degree	23	24
4 Year Degree	40	42
Some College	13	14
2 Year Degree	7	7
High School Graduate	3	3
Recruitment Site		
NAMI Greater Houston Email	32	34
Advertisement at UT Clinic	23	24
UT Clinician	8	8
SARDAA Newsletter	5	5
Other	27	28

Psychiatric Diagnoses

60% of participants reported having both personal and family histories of psychiatric conditions. 26% of participants reported having a family history of psychiatric conditions only.

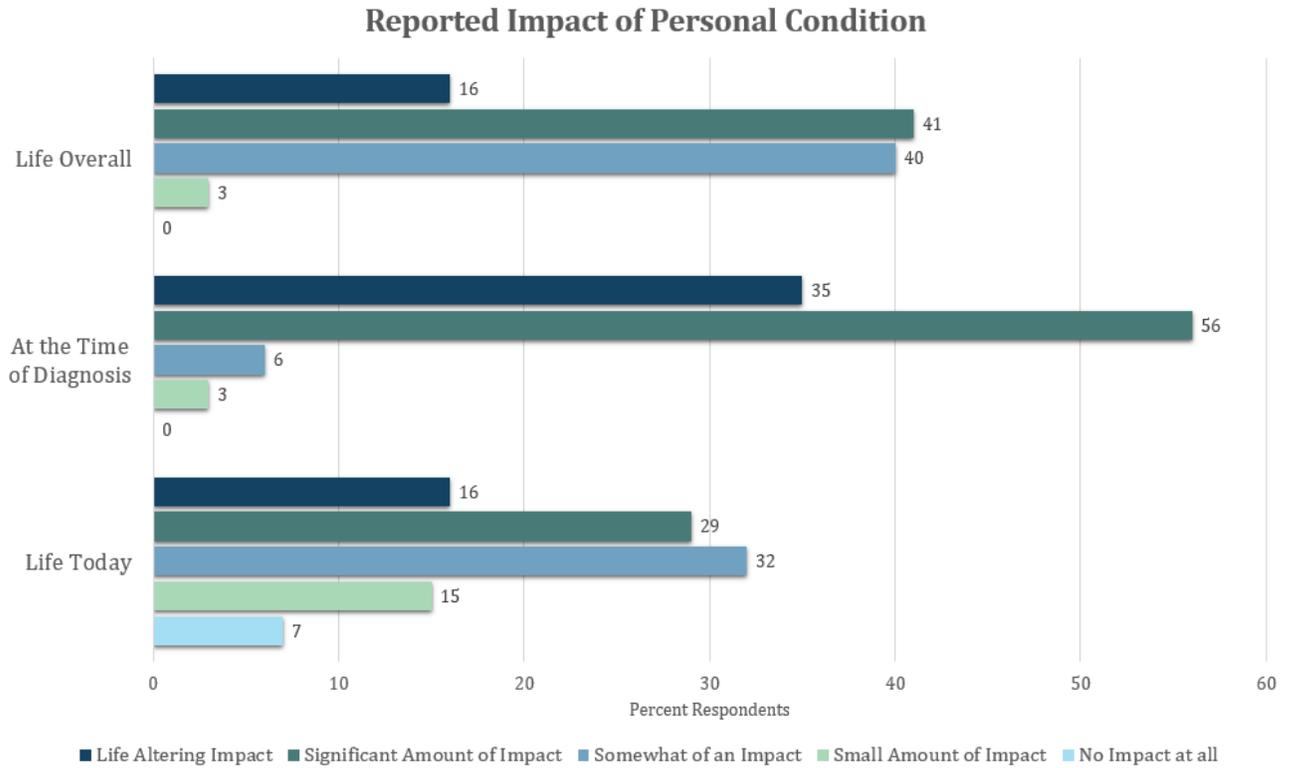
Just 12% of participants reported having personal histories of psychiatric conditions only. Two individuals reported having personal histories and did not answer the question about their family history status.

Self-reported personal diagnoses included depression (76%), anxiety disorders (70%), bipolar disorder (20%), schizophrenia (11%), alcohol use (6%), substance use (4%), and ADHD (9%). Other diagnoses such as Borderline personality disorder, dissociative identity disorder, autism, and an eating disorder were all reported a single time. Individuals were able to report multiple diagnoses. 63% of respondents with a personal history reported having two or more comorbid psychiatric conditions. Individuals were also asked to report the perceived level of impact their psychiatric condition had on their lives today, at the time of diagnosis, and life overall. This is outlined in Figure 1. On a scale of 0 to 4, with 2 being "somewhat" impactful, the mean impact of their own personal psychiatric condition on their life today was 2.3 (sd: 1.1). This was significantly lower than their reported impact of their psychiatric condition on their life at the time of their diagnosis (mean: 3.2, sd: 0.7, $p < 0.001$). More than half of the respondents with a personal history ($n=37$, 54%) reported a lower impact today than at the time of the diagnosis, while the majority of the remainder ($n=27$, 40%) reported no difference in impact between the two time points.

Individuals with a personal history were asked questions about any treatments they have received for their condition(s). Of the individuals with a personal history of a psychiatric condition, a majority reported taking medication and having participated in individual psychotherapy (93% and 84% respectively). 39% reported practicing yoga or mindfulness, 29% reported participating in cognitive behavioral therapy (CBT), 26% reported participating in family therapy, 23% reported participating in group psychotherapy, 17% reported participating in an in person support group, 7% reported participating in an online support group, 1% had

undergone electroconvulsive therapy (ECT), and 1% had undergone transcranial magnetic stimulation (TMS). Individuals were able to select multiple treatment modalities.

Figure 1 Reported Impact of Personal Psychiatric Condition



Respondents with family histories of psychiatric conditions provided the number of affected family members. 28% reported having only one affected family member, 25% reported having two affected family members, 13% reported having three affected family members, 13% reported having four affected family members, and 20% reported having five or more affected family members. Individuals with an affected family member also provided the degree of relation of individual family members. 29% of respondents reported having a first degree relative(s) (FDR) only, 19% reported having a second degree relative(s) (SDR) or greater only, and 53% of individuals report having at least one FDR and another SDR or greater with a diagnosis of a psychiatric condition. Of the respondents with a family history of a psychiatric condition, 68% reported having at least one family member with a Serious Mental Illness (SMI). Reported family diagnoses were assigned to the SMI category, if not obvious based on the reported diagnosis by

consultation of the committee. Conditions such as schizophrenia, bipolar disorder, personality disorders, and postpartum depression/psychosis were categorized as SMI. Depression was categorized as SMI when respondents reported it as “severe.” Of note, participants were not formally instructed to provide that information. As information obtained regarding specific family member diagnoses may not always reflect what constitutes a serious functional impairment or SMI, all respondents with a family history reported on the perceived degree of impact each individual family member’s diagnosis had on the family life overall. On a scale of 0 to 4, with 2 being “somewhat” impactful the mean score of the average of the impact of the family member's diagnosis on the respondent's family life overall was 2.8 (sd: 0.9).

Respondents were also asked to report on the perceived causes of their personal condition(s) and/or their family’s psychiatric conditions. Respondents ranked each etiology factor on a Likert scale from 0 (not at all important) to 4 (very important). Participants ranked the following factors: substance use, brain changes/brain chemistry, genetics/inheritance/running through the family, trauma (rape, physical abuse), life circumstances (divorce, job loss, high work load), and personality/temperament. This list was formulated based on literature as well as National Alliance on Mental Illness online resources easily accessible by the general public that discuss the causes of mental illness (Illness, 2017). A majority of respondents, 71%, with both a personal and a family history of psychiatric conditions reported genetics as moderately or very important in contributing to both their own and their family’s diagnoses. In contrast to the impact of substance use on the perceived etiology of psychiatric conditions, where about half reported the same impact rankings across both personal and family history and the remainder were more likely to indicated a higher degree of influence of substance on the development of psychiatric conditions in relatives than in themselves. 24% ranked substance use as moderately to very important in the development of their personal condition where 44% ranked it as moderately or very important in the development of their family member’s conditions. The reported moderate or very important ranking of genetics in the development of personal psychiatric condition(s) was

slightly lower among respondents who had a personal history only (55%) compared to those with both personal and family histories of psychiatric conditions (70%). However, this difference failed to reach statistical significance ($p=0.409$). Individuals with a family history of SMI were more likely to select brain chemistry/changes as moderately or very important in the development of their family member's psychiatric conditions in comparison to those without SMI history (76%, $p=0.037$). All etiology factor rankings are reported in Figure 2.

Figure 2 Level of Importance for Development of Family and/or Personal History of Psychiatric Condition(s)

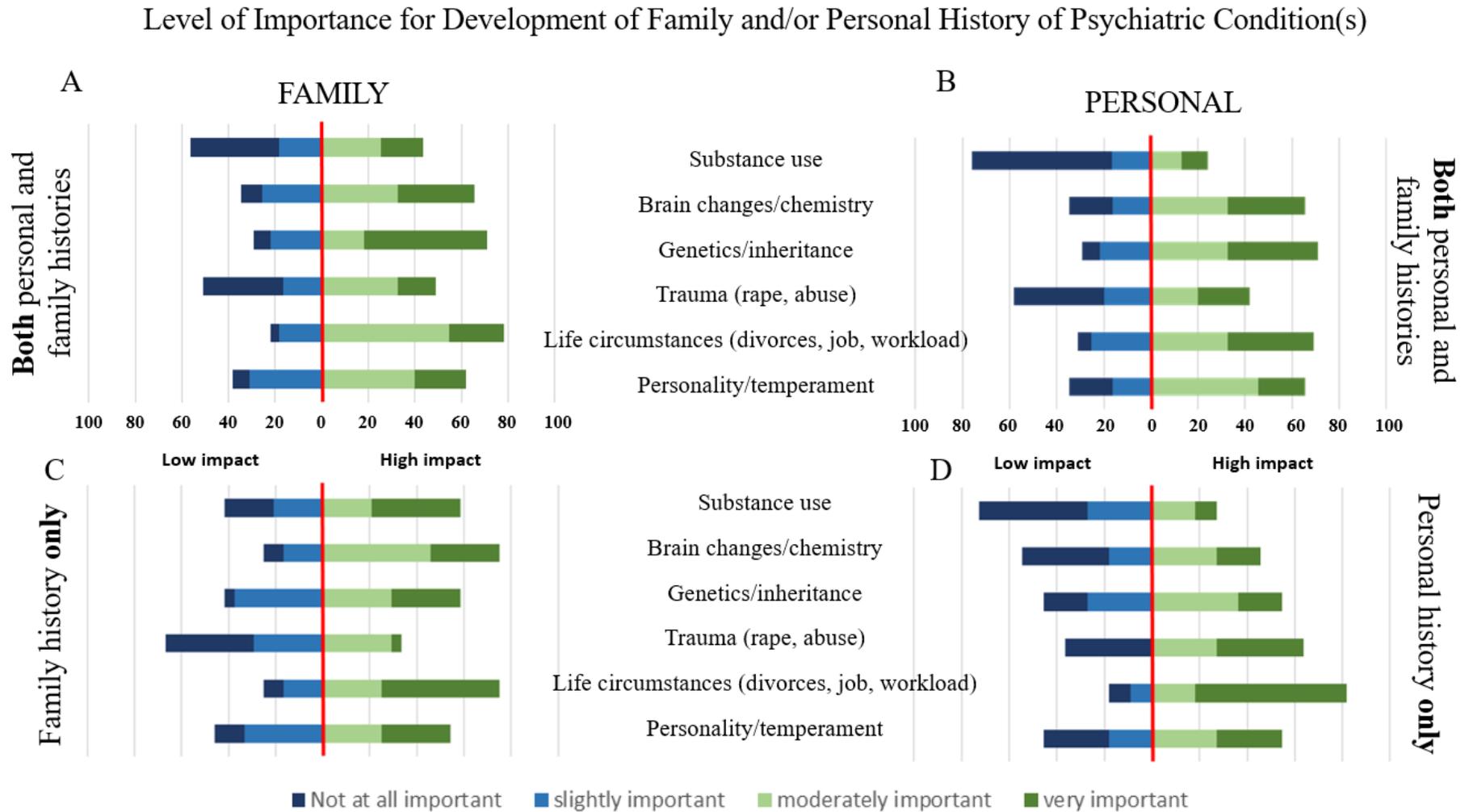


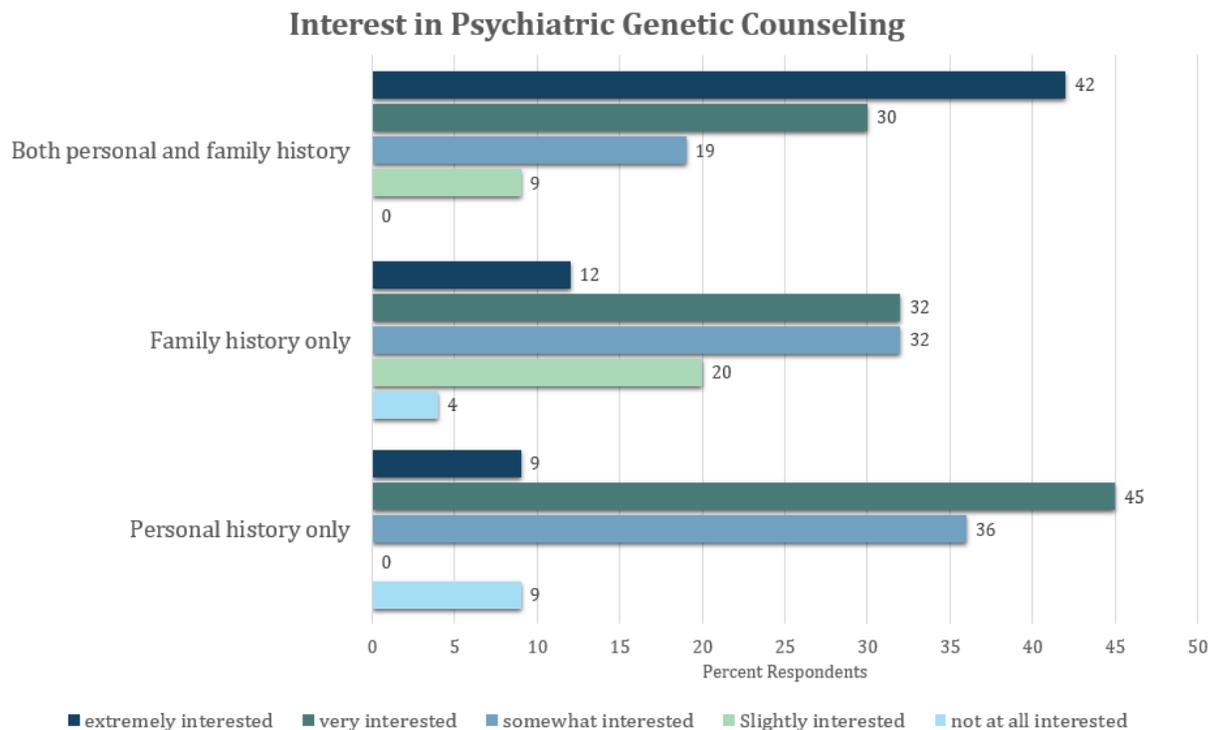
Figure 2
 Participants were asked to rank the level of importance each factor had in the development of their personal condition(s) and/or their family member's condition(s).
 Figure 2a represents the ranking of etiology factors for the development of respondent's family member's psychiatric conditions for those with both a personal AND a family history.
 Figure 2b represents the ranking of etiology factors for the development of respondent's personal psychiatric conditions for those with both a personal AND a family history.
 Figure 2c represents the ranking of etiology factors for the development of respondent's family member's psychiatric conditions for those with a family history ONLY.
 Figure 2d represents the ranking of etiology factors for the development of respondent's personal psychiatric conditions for those with a personal history ONLY.

Respondents had the option to provide information in a free response question at the end of the survey. 63% of participants provided comments in this section. A majority of those comments conveyed information about their perceived etiology of psychiatric conditions and cited both genetic and environment factors. We reviewed these responses for unique opinions not covered by the previous etiology Likert scale questions. Some of these unique comments about the causes of personal and/or family mental illness included hormone shifts/changes, religious upbringing, and maternal tobacco use during pregnancy/secondhand smoke exposure throughout childhood.

Genetic Counseling

Prior to this survey, 66% of respondents had heard of genetic counseling before. Only 27% had never heard of the service and 6% of individuals were unsure if they had heard of it. Respondents reported hearing about genetic counseling predominantly through medical professionals (54%), the internet (33%), and personal experience (30%). Of the respondents who had heard of genetic counseling previously, 24% reported actually having participated in a genetic counseling session previously.

Figure 3 Interest in Psychiatric Genetic Counseling by Diagnosis Group



We assessed interest level in psychiatric genetic counseling services through a Likert scale. Overall, 63% of respondents reported being very or extremely interested in psychiatric genetic counseling, 24% of respondents reported being somewhat interested, 11% were slightly interested, and just 2% of respondents reported not being interested at all. Please see Figure 3 above for information about interest levels by diagnosis group: personal history only, family history only, and both personal and family history of psychiatric conditions. Diagnostic group was found to significantly associate with the respondent's reported level of interest in psychiatric genetic counseling. Individuals with both a personal and a family history were more likely to report being very or extremely interested in the service in comparison to those with a personal history only or a family history only ($p=0.015$).

Interestingly, the number of affected family members, the degree of relation of those family members (FDR, SDR, both), or the presence of a family history of SMI was not associated with respondent's reported interest in psychiatric genetic counseling services ($p=0.751, 0.927, 0.197$ respectively). What was associated with reported interest levels were respondent beliefs about the etiology of their family's condition(s). There was a statistically significant trend of increasing interest in psychiatric genetic counseling with increasing perception the role genetics plays in the development of the psychiatric condition in family members ($p=0.027$). This same association was not found to be significant when assessing respondent's etiology beliefs about their own personal diagnosis and the impact of genetics. Additionally, respondents with a family history of psychiatric condition(s) reported the contribution of genetics/running through the family with increasing importance as their number of affected family members increased ($p= 0.009$).

Other personal and family etiology factors were assessed for association with interest levels and were not found to be significant. Average scores for total level of factor importance in relation to the development of family members' psychiatric conditions were calculated. The average total level of importance for all etiology factors were significantly increased amongst those who were very or extremely interested in psychiatric genetic counseling compared to those who were only moderately or

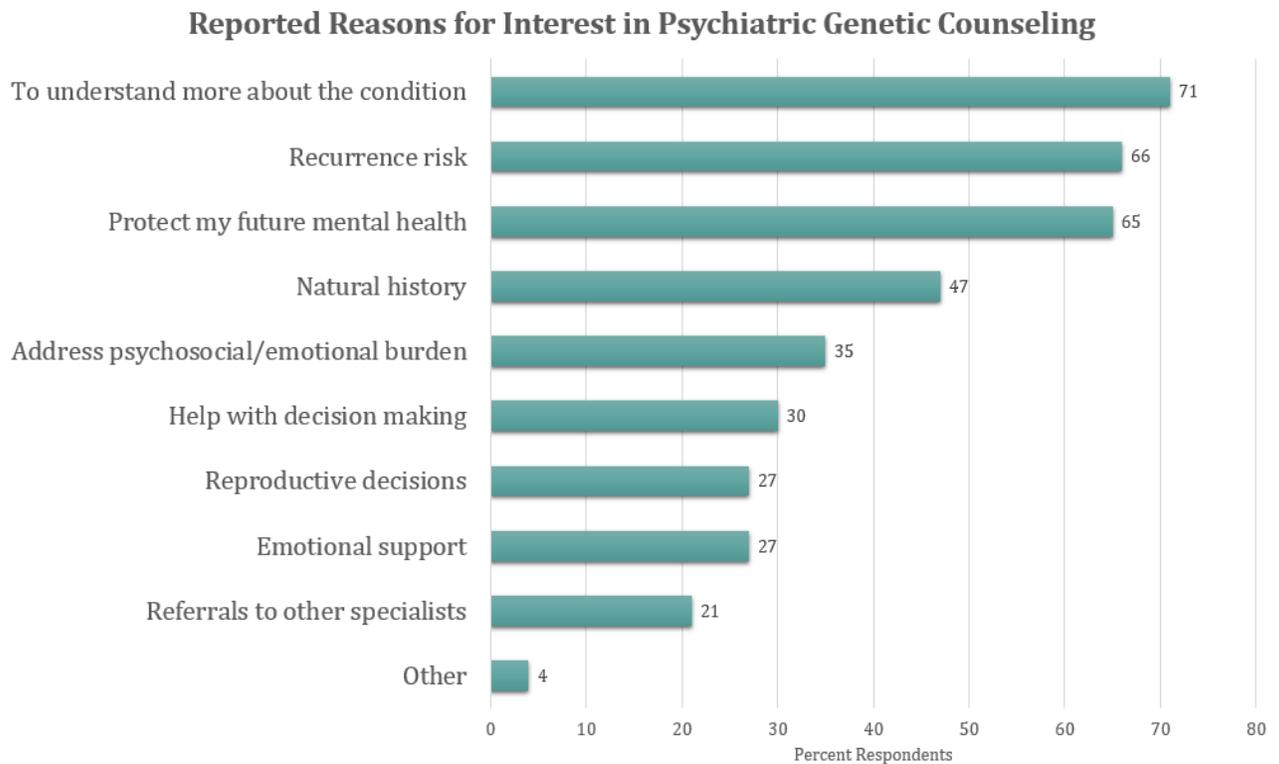
slightly interested ($p=0.0325$).

Among respondents with a family history of psychiatric conditions, there was no significant correlation between their interest in psychiatric genetic counseling and either the average impact score their affected family member's diagnoses had on family life overall or the maximum impact score their affected family member's diagnoses had on family life overall ($p=0.929$ and $p=0.485$ respectively). However, a respondent's perceived impact of their personal condition on their life today was weakly correlated with their interest in psychiatric genetic counseling ($\rho=0.29$, $p=0.016$). This weak association was not evident when impact at the time of diagnosis was compared to their interest in genetic counseling ($\rho=0.06$, $p=0.622$).

Reasons for Interest in Psychiatric Genetic Counseling

Respondents selected many reasons for pursuing psychiatric genetic counseling services. The most common reasons were “to understand more about the condition” (71%), followed by “recurrence risk/risk to family members” (66%), and “identify ways to protect my future mental health” (65%). Other reasons participants wrote in as motivations for interest in psychiatric genetic counseling included “identify ways to protect future children's mental health” and “treatment”. See Figure 4 for complete list. Individuals with both a personal and a family history of psychiatric conditions selected recurrence risk information as a reason for interest in psychiatric genetic counseling services more often than respondents with a personal history alone or a family history alone ($p= 0.002$). 79% of individuals with both a personal and family history cited recurrence risk information as a reason for interest in the service. Individuals with a family history of SMI were more likely to cite “to understand more about the condition” as a reason for interest in psychiatric genetic counseling services in comparison to those with a family history of AMI alone (77%, $p = 0.022$).

Figure 4 Reasons for Interest in Psychiatric Genetic Counseling

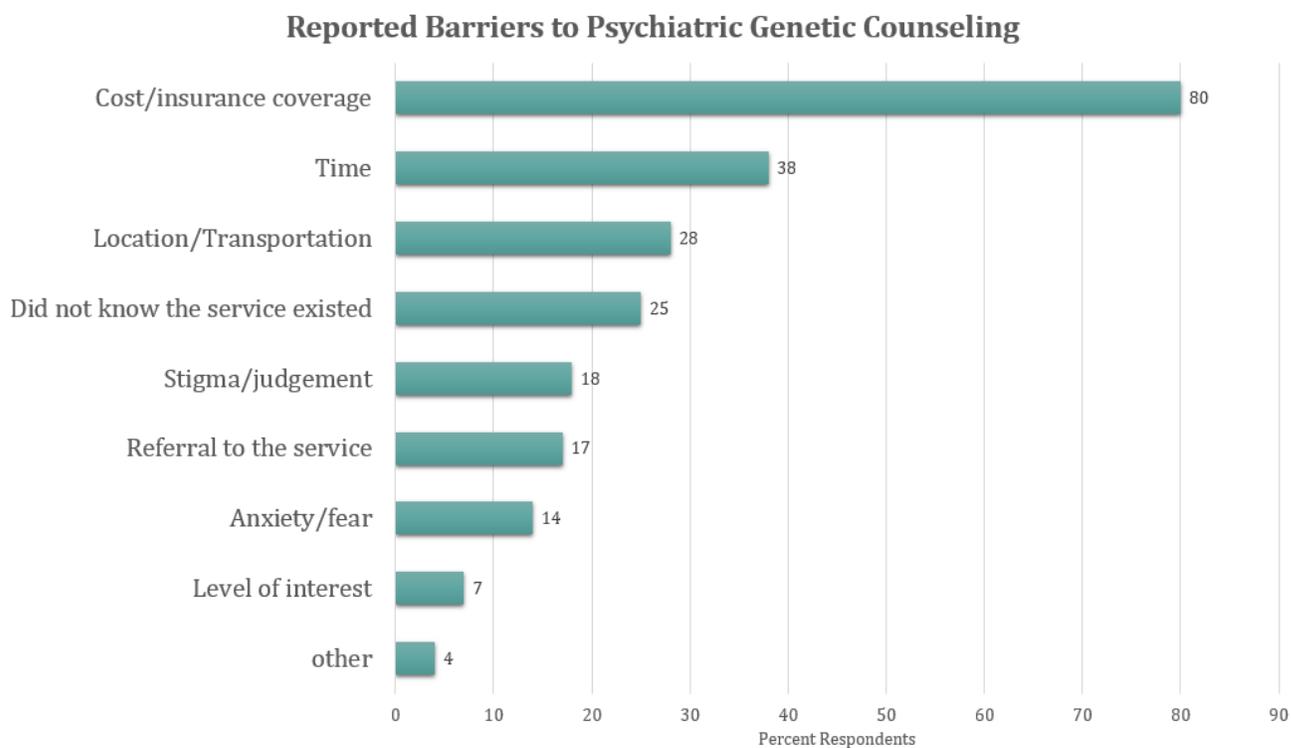


Barriers to Psychiatric Genetic Counseling

To address the second aim of our study, respondents were asked to select provided barriers that may prevent them from seeking psychiatric genetic counseling services. The most common barriers reported were cost/insurance coverage (80%), time (38%), and location/transportation (28%). Please see Figure 5 for a complete list of reported barriers. Individuals with both a personal and a family history of psychiatric conditions cited cost/insurance coverage as a perceived barrier to psychiatric genetic counseling more often than respondents with a personal history alone or a family history alone ($p = 0.004$). 91% of individuals with both a personal and a family history cited cost as a barrier to obtaining this service. 62% of those with a personal history only and 64% of those with a family history reported cost as a perceived barrier.

Additionally, the degree of relation of the family member had an impact on whether a respondent cited cost as a perceived barrier. 91% of participants with affected FDRs only and 90% of participants with at least one FDR and another affected relative (SDR or greater) cited cost/insurance coverage as a perceived barrier to genetic counseling.

Figure 5 Reported Barriers to Psychiatric Genetic Counseling



Discussion

Previous studies have assessed interest levels for psychiatric genetic counseling services for those with a personal and/or family history of various conditions. Studies have shown interest estimates ranging from 72%-75% (Lysus, 2007; Quaid et al., 2001). Our study found similar rates of interest in those with both personal and family histories of any psychiatric condition, with 72% of this group being extremely or very interested in psychiatric genetic counseling. Despite the reported interest in psychiatric genetic counseling, as mentioned previously, research shows low rates of referral to this service (Hunter et al., 2010; Lysus, 2007). Interestingly, our respondents did not list referral to the service or awareness of the service as major barriers (just 17% and 25% respectively). A study of the uptake and impact of a Canadian psychiatric genetic counseling clinic found that about three-quarters of patients were self-referred (Inglis et al., 2015). Perhaps the model of self-referral may be implemented alongside a general push to increase awareness among patients and clinicians to improve access to psychiatric genetic counseling in the United States. A 2016 study assessing physician psychiatric genetic counseling referral practices commented on increasing physician awareness about the role genetic counseling plays complementary to psychotherapeutic counseling about the causes of mental illness (Leach et al., 2016).

A pilot study in British Columbia assessing psychiatric genetic counseling for parents of individuals with psychotic disorders gathered information regarding participant motivations for attending the session. The study found that the most common reason cited was to increase understanding of their mental illness (Austin & Honer, 2008). Similarly, the most common reason for interest in psychiatric genetic counseling cited in our study was to understand more about the condition. This finding indicates that motivations for psychiatric genetic counseling may remain consistent across study populations and over time.

Another study assessing reasons for motivation in psychiatric genetic counseling in a population of individuals who had a personal or family history of bipolar disorder found that in general, participants were interested in information and counseling rather than a quantified risk assessment based on family history (Peay, Hooker, Kassem, & Biesecker, 2009). However, our study found that a majority of participants cited recurrence risk information as a reason for interest. Potential reasons for this difference is that individuals may be more interested in family risk information while deciding to start a family, at the time of raising children, or that our assessment included individuals with personal and family histories beyond bipolar disorder as well as differing recruitment strategies.

80% of participants reported “cost/insurance coverage” as a perceived barrier to psychiatric genetic counseling services in our study. This information is important for clinicians and potential self-referring patients as many insurance plans provide coverage for genetic counseling services, but it is always important for patients to inquire with their insurance providers prior to a genetic counseling appointment if they have concerns (National Society of Genetic Counselors, 2019). This potential barrier is something to address with patients and the wider mental health community as there may be a misconception about access to genetics services being out of reach. Patients and clinicians may equate genetic counseling with clinical genetic testing and perceive cost associated with testing to be a significant barrier. As stated previously, clinical genetic testing is not typically a part of psychiatric genetic counseling services and many insurance plans cover genetic counseling services (Counselors,

2019). This is an important factor for referring providers to consider and address with interested patients as they may be discouraged from psychiatric genetic counseling out of a fear of exorbitant costs. Additionally, individuals with both personal and family histories of psychiatric conditions were more likely to report cost as a barrier in comparison to other diagnosis groups. Potentially, individuals with both personal and family histories may incur greater financial burden associated with their personal and family diagnoses in comparison to those with a personal or family history alone. Additionally, individuals with psychiatric conditions are less likely to have health insurance (Walker, Cummings, Hockenberry, & Druss, 2015). Therefore, cost as well as access to insurance may explain the barrier for the group with both personal and family histories in particular.

In assessing the barriers and reasons for interest in psychiatric genetic counseling, previous studies assessing barriers for cancer genetic counseling were reviewed. Reasons for attending cancer genetic counseling and obtaining cancer genetic testing and the reasons for not having genetic counseling or genetic testing slightly differed from the results of our study. The most common cited reason to pursue cancer genetic counseling and/or testing was to “benefit my family’s future” followed by “wanted to know my future risk of cancer” (Anderson et al., 2012). These motivating factors could possibly translate to “recurrence risk/risk to family members” as described in our study, which was found to be the second most common reason for interest cited. Anderson et al., also reported on factors that increased access to cancer genetic counseling. The most frequently reported factor that made it easier to attend the session was “my medical insurance covered the visit” (68% of respondents). When reporting barriers to the cancer services, only 23% reported “medical insurance coverage issues” as a reason for not having cancer genetic counseling (Anderson et al., 2012). This differs greatly from our percentage of participants reporting a perceived barrier of “cost/insurance coverage.”

Clinical Implications

One of the goals of this study was to better describe what types of individuals are interested in psychiatric genetic counseling. Individuals do not need to have an extensive family history of psychiatric

conditions in order to be interested in or benefit from psychiatric genetic counseling services.

Additionally, the specific diagnoses should not influence which patients are referred. There was no significant difference in interest level between individuals with personal or family histories of SMI when compared to the presence of AMI in family history in general. While we have reliable empiric data that indicates stronger recurrence risks when assessing a family history with SMI, this does not dictate interest in or benefit from psychiatric genetic counseling services overall. Thus, any patient with a personal and/or a family history of any type of psychiatric condition(s) may be interested in and benefit from a referral to this service.

Other clinical implications involve genetic counselors potentially providing services for psychiatric indications. The top three reasons for pursuing psychiatric genetic counseling services found in our study are well within the scope of the average genetic counselor's practice. Respondents reported interest in understanding more about the condition, recurrence risk information, and identifying ways to protect one's future mental health. As genetic counselors are well versed in exploring multifactorial etiology with patients, this concept should translate smoothly into counseling for psychiatric indications. Genetic counselors trained to interpret empiric data regarding psychiatric conditions should be able to provide accurate, personalized risk counseling. Finally, helping patients identify ways to protect future mental health may involve providing resources such as support groups, discussing healthy lifestyle choices and discussing the role of environmental stressors, all of which fall within the scope of a genetic counselor's practice. A recent study assessing training to provide psychiatric genetic counseling found that genetic counselors report feeling uncertain and unprepared to counsel psychiatric indications (Low, Dixon, Higgs, Joines, & Hippman, 2018). We hope that as training opportunities increase for psychiatric genetic counseling, genetic counselors may feel more comfortable and understand that patients are interested in aspects of this service most genetic counselors are already capable of providing.

Study Limitations

Our study was not representative of the wider population impacted by mental illness. Given a majority of our participants were female, this may be a result of where our survey was advertised (MFM clinics), gender ratio in online support group members in general for having more female participants, and the overall perceived self-stigma for men and mental illness potentially impacting their participation in support groups or presentation to psychiatry clinics (Latalova, Kamaradova, & Prasko, 2014; Nimrod, 2012). Of note, in evaluating the types of patients receiving psychiatric genetic counseling services, a previous study found that a majority of their participants (85%) were female (Inglis et al., 2015). This is relatively comparable to the percentage of females (93%) that participated in our study.

Additionally, our study participants were a relatively educated, wealthy, and Caucasian group. This is not necessarily representative of the general population of people with mental illness in the United States, however this could be reflective of the population accessing services such as support groups and psychiatry clinics, as these individuals are often from higher socioeconomic groups, have had some college education or degree of higher education, and are Caucasian (McGuire & Miranda, 2008; Turner, 2017). Also, this may represent a self-selection bias as individuals who have obtained higher education may be more familiar with the term “genetics” and more inclined to participate in research. The study population was majority non-Hispanic white which may be a reflection of who typically participates in support groups or present to clinics as well as a reflection of who typically participates in research (McGuire & Miranda, 2008). Of note, recruitment was done primarily through Houston, Texas clinics and local support groups. Individuals who accessed the survey from the advertisement in the SARDAA September 2018 newsletter (5% of participants) and individuals who accessed the survey through the NAMI Greater Houston or UTHealth Center of Excellence on Mood Disorders Facebook page could potentially have been from outside the Houston area, but demographic location information was not obtained. This may have also influenced our study population as access to mental health care and treatment in Texas may not reflect access nationally, as about 23.5% of Texans ages 19-64 are uninsured

compared to national uninsured rate of 12.3% (U.S. Census Bureau, 2017).

Additionally, a majority of our respondents had a family history of psychiatric conditions (86%) and a small percentage of respondents had only a personal history of psychiatric conditions (12%). This limitation provided a challenge in assessing the differences between the three groups, personal history only, family history only, and those with both a personal and a family history of psychiatric conditions. Of note, we were unable to account for two participants who had personal histories but did not complete the family history portion of the survey. Specific family relationship was limited as the options for “son” and “daughter” were inadvertently left off of the survey options. When additional information was provided by the participant about the specific relationship in the free response, that information was updated and reflected in data analysis. We do not believe this oversight impacted the results of our study significantly.

Further Recommendations

While this study was able to capture some individuals with personal and/or family histories of psychiatric conditions, further research into a larger and more generalizable population would be beneficial to add to our initial findings. Additionally, improvements could be made to increase awareness of psychiatric genetic counseling for both patients and mental health providers. Through educating referring providers and the general population about the purpose of the service and the individuals who may benefit from genetic counseling, we can help improve access to this valuable service.

Appendix

Copy of Qualtrics Survey

Title: Identifying Interest in and Barriers to Psychiatric Genetic Counseling
Letter of Information (IRB NUMBER: HSC-MS-18-0540)
Primary Investigator: Samantha Montgomery

You are invited to take part in a research study called, “Identifying Interest in and Barriers to Psychiatric Genetic Counseling.” This thesis research is being conducted by Samantha Montgomery for partial fulfillment of the requirements for the degree of Master of Science in the Graduate School of Biomedical Sciences, UTHealth. For this research project, she will be called the Principal Investigator or PI. The purpose of this study is to identify interest in and barriers to psychiatric genetic counseling. You are invited to take part in this study because you or a family member has a mental health problem. If you decide to take part in the study the estimated time commitment is 15 minutes.

If you agree to take part in this research, you will agree to complete a survey via the survey tool, Qualtrics. Participation in this study is voluntary. Due to survey design, all questions must be answered. However, participants have the option to cease participation at any time. Exceptions for this rule include all demographic questions, apart from participants age, which must be collected to ensure they are of 18 years or older. A decision not to take part in this study will not change the services you receive. Confidentiality will be maintained to the degree permitted by the technology used. Your participation in this online survey involves risks similar to a person’s everyday use on the internet. Due to the topic of the survey, there is a potential risk for participants to become emotionally distressed. If you are in need of psychiatric services, please contact the UT Psychiatry Department at (713) 486- 2700 or If you are experiencing an emergency, please call 911 and contact the National Suicide Prevention Lifeline at 1-800-273-8255.

You may not receive any benefit from taking part in this study. The information you provide will help us better understand the potential interest in and barriers to psychiatric genetic counseling. There are no known risks to take part in this study apart from the previously mentioned potential risk of emotional distress or breach of confidentiality. This information collected will not contain identifying information apart from your email address, should you wish to provide it. Participants who choose to provide an email address will be entered to win 1 of 20 \$20 Amazon gift cards. Email addresses and survey responses will not be linked. You may choose not to provide an email, or not to take part in this study, and you can withdraw at any time. There is no cost and you will not be paid to take part in this study. You will not be personally identified in any reports or publications that may result from this study. Any personal information about you that is gathered during this study will remain confidential to every extent of the law. Funding for this research was provided by the National Society of Genetic Counselors via the Psychiatric Special Interest Group. By completing this survey you are agreeing to participate in the research. This research project has been reviewed by the Committee for the Protection of Human Subjects (CPHS) of the University of Texas Health Science Center at Houston (HSC#) For any questions about research subjects rights call CPHS at (713) 500-7943.

If you have any questions about this project please contact Samantha Montgomery at Samantha.montgomery@uth.tmc.edu or Lauren Murphy at Lauren.Murphy@uth.tmc.edu

- I have read the information and I am at least 18 years old
- Click here to exit the survey if you are not 18 years and older or do not wish to participate

How did you hear about this study?

- NAMI email
- SARDAA email
- UT clinician
- Advertisement at UT clinic
- other: _____

What is your age in years?

- Please type in your age _____

What gender do you identify with?

- Male
- Female
- other: _____
- Prefer not to answer

Please specify what you identify as your ethnicity/race. Select all that apply.

- White
- Black or African American
- American Indian or Alaska Native
- Asian
- Native Hawaiian or Pacific Islander
- Hispanic or Latino
- Other: _____
- Prefer not to answer

What is the highest degree of school you have completed (if currently enrolled, check highest degree received)?

- Less than high school
- High school graduate

- Some college
- 2 year degree
- 4 year degree
- Professional degree (M.S. or PhD)
- Doctorate
- Prefer not to answer

What is your marital status?

- Married or domestic partnership
- Widowed
- Divorced
- Separated
- Single, never married
- In a relationship (not married)
- Prefer not to answer

What is your employment status?

- Employed for wages or salary
- Self-employed
- Out of work and looking for work
- Out of work but not currently looking for work
- Homemaker
- Student
- Military
- Retired
- Unable to work
- Prefer not to answer

What was your estimated household income last year?

- Less than \$20,000
- \$20,000 - \$39,999
- \$40,000 - \$59,999
- \$60,000 - \$79,999

- \$80,000 or more
- Prefer not to answer

Let's talk about Genetic Counseling

Prior to this survey, had you ever heard of "genetic counseling"?

- No
- Unsure

Where did you hear about genetic counseling?

Please select all that apply.

- Medical professional
- Friend
- Family member
- Internet
- Personal experience
- Educational event
- Other: _____

Have you participated in a genetic counseling session before?

- Yes
- No

What specialty in genetic counseling did you see?

Please select all that apply.

- Cancer
- Pediatric/Medical genetics
- Prenatal/Pregnancy
- Other: _____
- Not sure

“Genetic counselors are healthcare professionals with unique specialized graduate degrees and experience in the areas of both medical genetics and counseling. Genetic counselors work as members of a healthcare team, providing risk assessment, education, and support to individuals and families at risk for, or diagnosed with, a variety of inherited conditions. Genetic counselors also interpret genetic testing, provide supportive counseling, and serve as patient advocates”

-National Society of Genetic Counselors

Genetic counselors can work in a variety of specialties including cancer, prenatal, pediatric and even psychiatric settings. The area of psychiatric genetic counseling is an emerging field.

If offered, would you be interested in attending a psychiatric genetic counseling session? Please rate your level of interest by selecting an answer on the following scale.

- Not at all interested
- Slightly interested
- Somewhat interested
- Very interested
- Extremely interested

For which personal reasons would you pursue psychiatric genetic counseling? **Please select all that apply.**

- To understand more about the condition
- Natural history/age of onset/severity of symptoms prediction
- Identify ways to protect my future mental health
- Emotional support
- Help with decision making
- Recurrence risk/risk to family members
- Reproductive decisions
- Address psychosocial/emotional burden (guilt, stigma, etc.)
- Referrals to other specialists
- Other: _____
- Not interested in psychiatric genetic counseling

What concerns may prevent you from seeking psychiatric genetic counseling? **Please select all that apply.**

- Referral to the service
- Time
- Cost/insurance coverage
- Level of interest

- Location/Transportation
- Anxiety/fear
- Stigma/judgment associated with mental health
- Did not know the service existed
- Other: _____

Tell us about your personal and/or family history of mental health conditions

Have you ever received a diagnosis (diagnosed by a doctor or other mental health professional) of a mental health condition including but not limited to depression, anxiety disorders, bipolar disorder, schizophrenia, and alcohol or substance use disorders?

- Yes
- No

Please select which condition(s) you have received a diagnosis of

- Depression
- Anxiety disorders
- Bipolar disorder
- Schizophrenia
- Alcohol use disorder
- Substance use disorder
- Other: _____

At what age were you diagnosed with depression?

- Age: _____
- Do not recall

At what age did you experience your first symptom of depression?

- Age: _____
- Do not recall

At what age were you diagnosed with your anxiety disorder?

- Age: _____
- Do not recall

At what age did you experience your first symptom of your anxiety disorder?

- Age: _____
- Do not recall

At what age were you diagnosed with bipolar disorder?

- Age: _____
- Do not recall

At what age did you experience your first symptom of bipolar disorder?

- Age: _____
- Do not recall

At what age were you diagnosed with schizophrenia?

- Age: _____
- Do not recall

At what age did you experience your first symptom of schizophrenia?

- Age: _____
- Do not recall

At what age were you diagnosed with alcohol use disorder?

- Age: _____
- Do not recall

At what age did you experience your first symptom of alcohol use disorder?

- Age: _____
- Do not recall

At what age were you diagnosed with substance use disorder?

- Age: _____
- Do not recall

At what age did you experience your first symptom of substance use disorder?

- Age: _____
- Do not recall

At what age were you diagnosed with the "other" condition?

- Age: _____
- Do not recall

At what age did you experience your first symptom of this condition?

- Age: _____
- Do not recall

What would you consider your **main** mental health problem?

- Depression
- Anxiety disorders
- Bipolar disorder
- Schizophrenia
- Alcohol use
- Substance use
- Other: _____

To what degree has your main mental health problem impacted your life?
Please rank the impact on each of the following categories

	No impact at all	a small amount	somewhat	a significant amount	life altering
your life today	<input type="radio"/>				
your life at the time of diagnosis	<input type="radio"/>				
your life overall	<input type="radio"/>				

Have you ever received treatment for your mental health condition(s)?

- Yes
- No

What types of treatment?

Please select all that apply.

- Medication
- Individual psychotherapy
- Group psychotherapy
- Family therapy
- Meditation/yoga/mindfulness
- In person support group
- Online support group
- Cognitive behavior therapy (CBT)
- Bright light therapy
- Electroconvulsive therapy (ECT)
- Transcranial magnetic stimulation (TMS)
- Vagus nerve stimulation (VNS)
- Other _____

Do you have a **family member** with a diagnosis of a mental health condition including but not limited to depression, anxiety disorders, bipolar disorder, schizophrenia, and alcohol or substance abuse?

- Yes
- No
- Unsure

How many family members with a clinical diagnosis of a mental health condition do you have?

- 1
- 2
- 3
- 4
- 5 or more

Please fill out the following table with information about **each family member** with mental health conditions by selecting or typing in your answers

	Family member(s) relationship to you	Condition(s)	Currently living	For each family member please answer to what degree have these diagnoses impacted your family's life overall				
				No impact at all	a small amount	somewhat	a significant amount	Life altering
		If they have more than one diagnosis, please list what you consider as the "main" condition first						
Family Member 1	▼ Mother ... Other		▼ Yes ... Unsure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family Member 2	▼ Mother ... Other		▼ Yes ... Unsure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family Member 3	▼ Mother ... Other		▼ Yes ... Unsure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family Member 4	▼ Mother ... Other		▼ Yes ... Unsure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family Member 5	▼ Mother ... Other		▼ Yes ... Unsure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family Member 6	▼ Mother ... Other		▼ Yes ... Unsure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Tell us about your beliefs about the causes of you and/or your family's mental health condition(s)

To what extent did the following factors contribute to the development of **your personal** condition(s)?

	Not at all important	Slightly important	Moderately important	Very important
Personality/Temperament	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Life Circumstances (ex. Divorce, job loss, high work load)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Trauma (ex. rape, physical abuse)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Genetics/Inheritance/Running through the family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Brain changes/brain chemistry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Substance use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

To what extent did the following factors contribute to the development of your **family's** condition(s)?

	Not at all important	Slightly important	Moderately important	Very important
Personality/Temperament	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Life Circumstances (ex. Divorce, job loss, high work load)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Trauma (ex. rape, physical abuse)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Genetics/Inheritance/Running through the family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Brain changes/brain chemistry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Substance use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please elaborate about your answers to the previous questions in the space below:

Please feel free to provide an email address (to be kept separately from your survey responses) if you would like to enter to win 1 of 20 \$20 Amazon gift cards.

- Email address: _____
- Prefer not to provide email address

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Vita

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