Discussing History of Mental Illness During Prenatal Genetic Counseling: Patient Interest and Comfort

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ABSTRACT

Purpose: This study aimed to explore patient interest in and comfort with discussing a personal and/or family history of mental illness with a genetic counselor during a prenatal genetic counseling session.

Methods: Participants included pregnant women who met with a genetic counselor for routine prenatal screening/testing counseling at Palmetto Health USC Medical Group Department of OB/GYN. Following their appointment, they were given a copy of the invitation to participate, questionnaire, and mental health resource page by the genetic counselor who performed their genetic counseling.

Results: Forty participants completed questionnaires. 70% of participants indicated some level of interest in discussing mental illness with a genetic counselor. There was no significant difference in level of interest in discussing mental illness with a genetic counselor between those who did and did not have a personal or family history of mental illness (p=.220). Similarly, there was no significant difference in Edinburgh Postnatal Depression Scale score between those who were interested and those who were not interested in discussing mental illness with a genetic counselor (p = 0.14). Of the participants who were directly asked by the genetic counselor about a personal and/or family history of mental illness, 90% reported some level of comfort with being asked. Of the participants who were not directly asked, 90% reported they would have felt comfortable if asked about a personal and/or family history of mental illness.

No
participants indicated they would feel very uncomfortable to be asked about or to discuss mental illness in their prenatal genetic counseling session.

Conclusion: These results suggest that patients are interested in and comfortable with discussing a personal and/or family history of mental illness with a genetic counselor during prenatal genetic counseling. Overall, participants were as interested in discussing mental illness as they were about chromosome conditions, single gene conditions, and isolated birth defects. Prenatal genetic counselors should routinely ask about mental illness while taking the family history and be prepared to discuss information regarding the genetic components of mental illness.
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CHAPTER I

BACKGROUND

1.1 INTRODUCTION

In 2015, approximately 43.4 million American adults reported experiencing symptoms of a mental illness, representing 17.9% of the population (Center for Behavioral Health and Statistics and Quality, 2016). On a global scale, mental illness is one of the most substantial causes of death (Walker, McGee, & Druss, 2015). Due to the commonality and healthcare burden of these conditions, much medical research has been spent trying to understand the etiology of these conditions. Twin studies have consistently revealed high heritability for such disorders, suggesting that mental illness is a complex disorder resulting from the varying interactions between an individual’s genes and their environment.

Despite the complexity of its inheritance and the lack of clinical genetic testing, genetic counseling services have been developed to provide patients diagnosed with a psychiatric condition and their families information regarding topics such as recurrence risk, the role of genetics and environment, and protective factors. Research has shown that such services can increase patient knowledge of risk perception, self-efficacy, and empowerment (Hippman et al., 2016; Inglis, Koehn, McGillivary, Stewart, & Austin, 2015).

Even with the creation of dedicated clinics, psychiatric conditions are not a common indication of referral for genetic counseling; however, they can frequently be
uncovered within the context of the family history in a prenatal genetic counseling session because they are so prevalent in the general population (Inglis, Morris, & Austin, 2017). When this occurs, a discussion is warranted by the prenatal genetic counselor for two reasons. First, a family history of a psychiatric condition remains the leading risk factor for one to develop a mental health condition (Havinga et al., 2017). Second, a maternal history (personal or family) of mental illness increases the chance of developing post-partum depression (Di Florio et al., 2014; Wisner, Perel, Peindel, & Hanusa, 2004). Having this discussion can provide patients with similar information given to those receiving psychiatric genetic counseling and aid in identifying individuals who would benefit from referrals to mental health professionals. Unfortunately, many genetic counselors are uncomfortable discussing these topics, whether it be due to stigma or uncertainty (Peay et al., 2008). Should genetic counselors gain more comfort, individuals with a personal or family history of mental illness may welcome the opportunity to discuss mental illness when invited (Lautenbach, Hiraki, Campion, & Austin, 2012). This study aims to examine the patient interest in and comfort with discussing a personal and/or family history of mental illness with a prenatal genetic counselor during prenatal genetic counseling.

1.2 HERITABILITY OF MENTAL ILLNESS

Research into the field of psychiatric genetics dates to the years before the first World War in Germany. It is there that the current understanding started to unfold with the use of twin and family studies (Kendler & Neale, 2014). Twin studies operate under the assumption that monozygotic (identical) and dizygotic (fraternal) twins share the same environmental risk factors, at least within the womb. Since monozygotic twins
share 100% of their genetics and dizygotic approximately 50%, measuring the development of certain psychiatric conditions and their phenotypic variance within both takes into account genetic contribution. For this reason, concordance rates are commonly calculated. Gejman, Sanders, and Kendler (2011) describe concordance rates as “the probability that a second twin will develop a disorder if the proband (first-examined) twin has the disorder.” If the concordance rate is higher in the monozygotic twins than the dizygotic twins, this suggests that there is a greater genetic contribution. For example, bipolar disorder has an estimated concordance rate of 70% in monozygotic twins and 19% in dizygotic twins suggesting that the development of this psychiatric condition is largely in part to one’s genetics (Burmeister, McInnis, & Zollner, 2008). Furthermore, twin studies can be used to calculate heritability, or the proportion of phenotypic variance within a population that is caused by genetic contributions. These calculations range from 0% (no genetic contribution) to 100% (complete genetic contribution). Twin studies consistently show high heritability for many common psychiatric conditions. The low incidence disorder schizophrenia has one of the highest heritability estimates, ranging from 70-85% (Gejman et al., 2011; Burmeister et al., 2008). High incidence disorders such as major depressive disorder and anxiety disorders share a smaller, but still significant, heritability of approximately 40% (Burmeister et al., 2008).

Familial aggregation has also been observed in psychiatric conditions. Through family studies, current understanding supports that having a family member affected by a mental illness increases an individual’s risk of also developing a mental health condition over that of an individual in the general population (National Society of Genetic Counselors, n.d.). A positive family history of mental illness has also been correlated
with worse clinical outcomes, increased risk of suicide, and longer course of symptoms for the individual affected (Holma, Melartin, Holma, Paunio & Isometsa, 2011). These observations have led to the calculation of empirical recurrence risk data, which can be provided to families with diagnosed cases of mental illness (Inglis et al., 2017). In the case of schizophrenia, bipolar disorder, and schizoaffective disorder, an individual with a brother, sister, or parent affected with either condition has a 10-15% chance of developing one of those conditions as well, as opposed to about a 3% general population risk (National Society of Genetic Counselors, n.d.). As the number of affected family members increases, the risk to the proband increases beyond the quoted numbers above.

As useful as twin and family studies have been to advance the field of psychiatric genetics, they both come with limitations. These studies can only attest to the genetic correlation of mental illness. As Kendler comments, “showing heritability gives no insight into the molecular genetic mechanism involved” (2013). With the established correlation of the role of genetics in the development of psychiatric conditions, medical research has shifted its focus to determining these underlying genetic mechanisms.

1.3 GENETICS OF MENTAL ILLNESS

Searching for the underlying genetic mechanisms of psychiatric disorders is not a foreign concept to the medical community. Psychiatric conditions have been commonly associated with well-studied single gene and microdeletion conditions. Huntington’s disease (HD) is an autosomal dominant neurodegenerative disorder caused by 40 or more CAG repeats in the \textit{HTT} gene. Features include motor dysfunction and cognitive impairment. HD is also well known to be associated with psychiatric symptoms such as affective disorders, irritability, apathy, and psychosis (Julien et al., 2007). Evidence
suggests that these psychiatric symptoms are often the first signs of disease onset. Many have argued that these depressive symptoms can be attributed to one’s natural fears of disease progression; however, research has identified that these symptoms are an important feature of the preclinical stages of HD (Julien et al., 2007). 22q11.2 deletion syndrome (previously known as DiGeorge syndrome or velocardiofacial syndrome) is a microdeletion syndrome with features ranging from heart defects, cleft palate, immunodeficiency, hypocalcemia, and development delays (Genetics Home Reference, 2017). Neuropsychiatric features are the most common group of adult onset conditions in 22q11.2 deletion syndrome (22q11.2DS), comprised of cognitive impairment, intellectual disability, schizophrenia, non-psychotic psychiatric conditions (i.e. anxiety disorders), seizures, and early-onset Parkinson’s disease (Bassett, Costain, & Marshall, 2017). Of note, schizophrenia is the most important treatable neuropsychiatric feature. With an increased incidence 20-fold higher in individuals with 22q11.2DS than those in the general population, 1 in 4 individuals with the microdeletion will go on to develop schizophrenia (Bassett et al., 2017). These well-established incidences of psychiatric manifestations in conditions with known etiology provide further support that a genetic mechanism of psychiatric illness exists.

To investigate such claims, much research has been performed using linkage analysis and genome wide association studies (GWAS). These studies have led to the discovery of hundreds of loci associated with disease development. These loci have been found in the form of single nucleotide polymorphisms and copy number variants (Michaelson, 2017). For example, copy number variants in DISC1 have been implicated in the development of neuropsychiatric disorders, as the gene has detrimental
involvement in neurodevelopment and adult neuron function (Johnstone et al., 2015). While these discoveries further support genetics stake in the role of psychiatric disorder development, it is rare for mental illness to be entirely caused by inherited factors (National Society of Genetic Counselors, n.d.). This implicates that these identified loci increase an individual’s susceptibility to developing a mental illness but are not deterministic of disease manifestation.

Twin and family studies show a clear environmental role in the development of mental illness. Furthermore, epigenetic modifications, or genetic changes not attributed to changes in the DNA sequence, have emerging implications in the manifestation of psychiatric illness (Alhajji & Nemeroff, 2015). For these reasons, it is widely accepted that psychiatric disorders are of complex etiology and inheritance. They are not the sole product of genetic or environmental contributions, but the interaction between the two in an individual (Tsuang, Bar, Stone, & Faraone, 2004). Therefore, diagnostic genetic testing is not currently clinically available.

1.4 GENETIC COUNSELING AND MENTAL ILLNESS

Even without clinical genetic testing, the role of genetics in mental illness is publicly known. As little genetics education is provided during psychiatric training, mental health professionals feel that psychiatric genetic counseling services are useful and desirable to patients (Jenkins & Arribas-Ayllon, 2016). “Genetic counseling is the process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease,” as stated by the National Society of Genetic Counselor’s Definition Task Force (2006). Genetic counselors are
specially trained healthcare professionals who provide such services to patients for a variety of indications.

Skeptics exist in the utility of psychiatric genetic counseling services. A major criticism of the service is that too much uncertainty surrounds this group of conditions to give useful information, often citing the lack of diagnostic testing. Without these tests, there is much ambiguity in terms of phenotypic variability and severity, as well as recurrence risks (Peay et al., 2008). While these points are valid, most individuals diagnosed with a serious mental illness expected this uncertainty when entering psychiatric genetic counseling and still reported overall satisfaction with the genetic counseling they received (Hippman et al., 2013). On the opposite end of the spectrum, some feel that when diagnostic testing is clinically available for these conditions, negative patient reactions will outweigh the benefits of this information. Lebowitz and Ahn (2017) tested this hypothesis by administering fake genetic testing to determine a predisposition to developing major depressive disorder and offered it to individual’s currently experiencing depressive symptoms. While those who tested “positive” did express lower levels of confidence in their abilities to cope with this information, after receiving educational counseling these negative emotions dissipated. This suggests that with the prospect of genetic testing for psychiatric conditions on the horizon, genetic counseling is essential for accurate information and understanding of what these results would mean for a patient (Lebowitz & Ahn, 2017).

In 2012, the first psychiatric genetic counseling clinic was established in Vancouver, BC, Canada to provide adults and children with personal diagnoses or family history of mental illness information regarding the genetic contributions to these
conditions (Inglis et al., 2017). Several benefits have been identified from the development of such services. Patients perceived psychiatric genetic counseling to be useful and helpful, and self-reported that the session decreased their overall concerns about the condition (Austin & Honer, 2008). More recently, patients continue to mirror these opinions by scoring higher in knowledge of risk perception pertaining to mental illness post-counseling (Hippman et al., 2016), all while maintaining this gained knowledge over time (Moldovan, Pintea, & Austin, 2017). Importantly, patients report increased empowerment and self-efficacy post-counseling as well (Inglis et al., 2015).

1.5 POSTPARTUM DEPRESSION

A specific subset of major depressive disorder has been identified to affect as many as 1 in 9 women during the postpartum period (Ko, Rockhill, Tong, Morrow, & Farr, 2017). The American Psychiatric Association (2013) describes this group of women as having a depressive disorder with peripartum onset, further defining this diagnosis stating, “this specifier can be applied to the current or…most recent episode of major depression if onset of mood symptoms occurs during pregnancy or in the 4 weeks following delivery.” More commonly, this diagnosis gets termed post-partum depression (PPD). A PPD diagnosis has been associated with adverse maternal, infant, and childhood outcomes such as decreases in breastfeeding frequency and length, decreased maternal and infant bonding, and developmental disorders in the child (Kingston, Tough, & Whitfield, 2012; Stein et al., 1991; Wouk, Stuebe, & Meltzer-Brody, 2016). The etiology is unknown; however, established risk factors include depression and/or anxiety during pregnancy, stressful life events experienced during pregnancy, preterm birth, having an infant admitted to neonatal intensive care unit, and little social support
Research has also supported that previous maternal depression or a family history of mental illness increases a woman’s chance of developing PPD (Di Florio et al., 2013; Wisner et al., 2004). For those women who have had or are having symptoms of a mood and/or anxiety disorder, the risk to develop PPD is even greater in primiparous women (Di Florio et al., 2014).

Postpartum psychosis is the most serious mental health condition that can occur after pregnancy, characterized by delusions, hallucinations, and conceptual disorganization (Mighton et al., 2016), with an incidence of 1 in 500 to 1 in 1,000 deliveries (American Psychiatric Association, 2013). These episodes of postpartum psychosis are considered a psychiatric emergency and can onset as early as 2-3 days after delivery. Women at increased risk to experience postpartum psychosis include women with a personal history of mood disorders, especially women in their first pregnancy (Di Florio et al., 2014; Inglis, Hippman, Carrion, Honer, & Ausitn, 2014; Mighton et al., 2016). For example, women diagnosed with bipolar disorder have a 20% chance of experiencing a postpartum episode of mania or psychotic depression (Di Florio et al., 2013).

Because the incidence of PPD is so high, The American College of Obstetricians and Gynecologists released a committee opinion detailing recommendations about screening for depression during the perinatal period. The Committee on Obstetric Practice (2015) recommend the following:

- Clinicians should screen patients at least once during the perinatal period using a validated, standardized tool for mood and anxiety disorders
• Patients with established risk factors for perinatal mood disorders should be monitored closely.

• Follow-up and treatment options should be available and well understood for those who screen positive.

• Systems should be in place to initiate follow-up to diagnose and treat those who screen positive.

One such validated screening tool is the Edinburgh Postnatal Depression Scale (EPDS) (Cox, Holden, & Sagovsky, 1987). This short 10 item questionnaire takes approximately 5 minutes to complete, allowing this to be administered during a prenatal appointment to aid in identifying individuals experiencing depressive symptoms. Each item consists of a statement and participants are asked to pick the answer that comes closest to how they have felt in the past 7 days. Each answer is given a score of 0-3 based on the seriousness of how they are feeling, with 0 being the least serious and 3 being the most serious. The sum of the scores is tallied for a total out of 30. Those that score a 15 or greater should be followed up on by their healthcare provider to further assess their mental health.

1.6 RATIONALE FOR CURRENT RESEARCH

Although more psychiatric genetic counseling clinics are in the works, psychiatric conditions remain uncommon as a referral indication to genetic counseling services. This is despite the fact that mental illness is very common in the general population, with 1 in 4 adults experiencing symptoms of a mental illness at some point in their lifetime (Center for Behavioral Statistics and Quality, 2016). Therefore, it is common for mental illness to be revealed in the context of the family history during other genetic counseling
specialties, like prenatal genetic counseling (Inglis et al., 2017). Prenatal genetic counselors have the unique opportunity of being able to help provide education regarding topics such as recurrence risk, inheritance of mental illness, and chance to develop PPD. However, this requires both the genetic counselor to feel comfortable discussing these topics and the patient willing to disclose a personal and/or family history of mental illness.

Due to the stigma surrounding mental illness, family members may be reluctant to discuss a diagnosis within the family, or to spontaneously volunteer information about psychiatric diagnoses to a genetic counselor without prompting as patients generally do not know what to expect during a genetic counseling appointment (Bernhardt, Biesecker, & Mastromarino, 2000). Despite this, individuals with a personal or family history of mental illness may welcome the opportunity to discuss this topic when disclosure is invited (Lautenbach et al., 2012). Research suggests that a strong family history of a psychiatric disorder can affect individual’s attitudes towards having children (Austin, Smith, & Honer, 2006; Meiser et al., 2007) as mothers of children diagnosed with mental illness perceive their child’s diagnosis to be more severe than other similarly inherited conditions (Lautenbach et al., 2012). Therefore, these individuals report having high interest in receiving education toward reproductive decision making (Quinn et al., 2014) and do not perceive stigma in obtaining mental health services for their child (Polaha, Williams, Heflinger, & Studts, 2015).

Regarding PPD, even with the recommendations to screen at least once in the prenatal period, approximately 65% of pregnant women go undiagnosed. Of those that are diagnosed, only 50% go on to receive treatment due to barriers such as cost,
opposition to treatment, and stigma (Ko, Farr, Dietz, & Robbins, 2012). Untreated maternal depression has been associated with adverse fetal outcomes including slower rates of fetal body and head growth (Marroun et al., 2012). These findings contribute to one of the leading causes of maternal death within the first-year post-partum, suicide (Esscher et al., 2016; Oates, 2003). Discussing the possibility of developing depression during and after pregnancy earlier in the reproductive decision-making process allows women ample time to understand their risk, explore protective factors, obtain resources, and create a plan for treatment should they develop symptoms (Inglis et al., 2017). Since prenatal genetic counselors interact with women in both the preconception and prenatal period, they are primed to aid in identifying and providing referrals to mental health professionals to women at an increased risk.

For these opportunities to be taken advantage of, genetic counselors must begin asking and feeling comfortable with providing genetic counseling about mental illness. A survey of pediatric genetic counselors revealed that they felt the increased risk of psychiatric illness is important to disclose when discussing features of 22q11.2 deletion syndrome, but they were less likely to discuss this feature at diagnosis when compared to other adult onset features such as hypothyroidism due to stigma and limited knowledge of psychiatric illness (Martin et al., 2012). With the extensive research to support that providing genetic counseling about mental illness is useful to patients, solutions to remedy this have been introduced. Genetic counselors and genetic counseling students reported feeling more comfortable asking about a personal or family history of mental illness after watching a documentary film based on the lives of individuals diagnosed with a psychiatric condition (Anderson & Austin, 2012). Genetic counseling students also
identified an interest in more psychiatric genetic counseling training during their schooling to prepare them to provide information to patients after graduation (Low, Dixon, Higgs, Joines, & Hippman, 2017). Still, prenatal genetic counselors do not routinely ask about a personal and/or family history of mental illness while taking the family history.

Other complex disorders are more commonly addressed in the family history during a prenatal genetic counseling session. For example, Alzheimer disease is a neurodegenerative disorder that has a similar inheritance and recurrence risk to mental illness. This disease has rare instances of solely genetic etiologies, while the vast majority of diagnoses are attributed to the contribution of both genetics and environment. Thus, the greatest risk of recurrence is those who have a first-degree relative affected (Goldman et al., 2011). The two conditions differ in that the stigma surrounding discussing Alzheimer disease is less than what is thought to be around mental illness. Perhaps then, the missing piece needed for prenatal genetic counselors to initiate a conversation about a personal and/or family history of mental illness lies in discovering the level of interest and comfort with discussing this topic in the population they serve.

1.7 PURPOSE AND HYPOTHESIS

This study aimed to explore patient interest in and comfort with discussing a personal and/or family history of mental illness with a genetic counselor during a prenatal genetic counseling session. Guidance has been published outlining how to manage patient concerns regarding psychiatric conditions and post-partum depression during a prenatal genetic counseling session (Inglis et al., 2017); however, a lack of knowledge exists as to whether patients are interested in discussing these issues. There is also a gap in terms of
knowledge about patient comfort levels pertaining to mental illness discussion with a prenatal genetic counselor. The purpose of the present study was to investigate these levels by administering questionnaires to patients receiving prenatal genetic counseling by asking them to rank their level of interest in discussing mental illness, their level of comfort on being asked or the thought of being asked about a personal and/or family history of mental illness, and topics that patients would like to discuss pertaining to mental illness and post-partum depression within the scope of a prenatal genetic counselor.

Specifically, the goals of this study were to:

• Describe the degree of self-reported comfort with being asked about and the level of interest in discussing mental illness in a prenatal genetic counseling session

• Test the hypothesis that individuals with a personal and/or family history of mental illness will be more interested in discussing their family’s history of mental illness with a prenatal genetic counselor than individuals who have no such family history

• Test the hypothesis that women who expressed interest in discussing mental illness with a prenatal genetic counselor would have higher scores on the Edinburgh Postnatal Depression Scale (EPDS) than those who were not interested in discussing mental illness.

The information gathered from this study may provide supporting evidence of whether patients are interested and comfortable with discussing mental illness.
CHAPTER II: MANUSCRIPT

DISCUSSING HISTORY OF MENTAL ILLNESS DURING PRENATAL GENETIC COUNSELING: PATIENT INTEREST AND COMFORT ¹

¹ Nimrichter, S., Austin, J., & Jones, A., & Vincent, V. To be submitted to Journal of Genetic Counseling.
2.1 ABSTRACT

Purpose: This study aimed to explore patient interest in and comfort with discussing a personal and/or family history of mental illness with a genetic counselor during a prenatal genetic counseling session.

Methods: Participants included pregnant women who met with a genetic counselor for routine prenatal screening/testing counseling at Palmetto Health USC Medical Group Department of OB/GYN. Following their appointment, they were given a copy of the invitation to participate, questionnaire, and mental health resource page by the genetic counselor who performed their genetic counseling.

Results: Forty participants completed questionnaires. 70% of participants indicated some level of interest in discussing mental illness with a genetic counselor. There was no significant difference in level of interest in discussing mental illness with a genetic counselor between those who did and did not have a personal or family history of mental illness (p=.220). Similarly, there was no significant difference in Edinburgh Postnatal Depression Scale score between those who were interested and those who were not interested in discussing mental illness with a genetic counselor (p = 0.14). Of the participants who were directly asked by the genetic counselor about a personal and/or family history of mental illness, 90% reported some level of comfort with being asked. Of the participants who were not directly asked, 90% reported they would have felt comfortable if asked about a personal and/or family history of mental illness. No participants indicated they were or would have been very uncomfortable being asked about mental illness.
Conclusion: These results suggest that patients are interested in and comfortable with discussing a personal and/or family history of mental illness with a genetic counselor during prenatal genetic counseling. Overall, participants were as interested in discussing mental illness as they were about chromosome conditions, single gene conditions, and isolated birth defects. Prenatal genetic counselors should routinely ask about mental illness while taking the family history and be prepared to discuss information regarding the genetic components of mental illness.

2.2 INTRODUCTION

In 2015, 43.4 million adult Americans (17.9% of the adult population) were estimated to be diagnosed with a mental illness (Center for Behavioral Health Statistics and Quality, 2016). Mental illness is common; as many as 1 in 4 individuals will experience symptoms of a psychiatric condition within their lifetime (Kessler et al., 2005). Twin studies have consistently revealed high heritability for such conditions, ranging from 60-85% for low incidence disorders like schizophrenia and bipolar disorder to closer to 40% for more common conditions like major depressive disorder and panic disorders (Burmeister et al., 2008). Therefore, family members of individuals with psychiatric disorders have an increased risk of developing similar conditions compared to the general population. Mental illnesses are complex and heterogeneous in etiology, that is, they arise as a result of the effects of varying combinations of genes and environmental factors in different individuals (Tsuang et al., 2004). Despite this complexity, advances in technology have allowed hundreds of susceptibility loci to be identified (e.g. through the use of genome wide association studies). These loci are associated with increasing an individual’s risk of developing a psychiatric condition.
Still, there are currently no available clinical tests to determine a genetic susceptibility to mental illness.

Individuals with a mental illness who have received genetic counseling exhibit greater knowledge and more accurate understanding of risk perception after counseling (Hippman et al., 2016) as well as increased empowerment and self-efficacy (Inglis et al., 2014). Genetic counselors are specially trained healthcare professionals who engage in “the process of helping people understand and adapt to the medical, psychological, and familial implications of the genetic contributions to disease” (National Society of Genetic Counselor’s Definition Task Force, 2006). Though psychiatric conditions are not a common indication for referral to genetic counseling, they can frequently be uncovered within the context of the family history in a prenatal genetic counseling session given the prevalence in the population (Inglis et al., 2017). However, due to the stigma surrounding mental illness, family members may be reluctant to discuss a diagnosis within the family, or to spontaneously volunteer information about psychiatric diagnoses to a genetic counselor without prompting. Despite this, individuals with a personal or family history of mental illness may welcome the opportunity to discuss this topic when disclosure is invited (Lautenbach et al., 2012).

Furthermore, maternal history of mental illness increases the chance of developing post-partum depression (Di Florio et al., 2014; Wisner et al., 2004). One in nine women will experience post-partum depression (PPD) symptoms in their lifetime (Ko et al., 2017). PPD is associated with adverse maternal, infant, and childhood outcomes such as decreases in breastfeeding frequency and length, decreased maternal and infant bonding, and developmental disorders in the child. (Kingston et al., 2012;
Stein et al., 1991; Wouk et al., 2016). The etiology is unknown; however, established risk factors include depression and/or anxiety during pregnancy, stressful life events experienced during pregnancy, preterm birth, having an infant admitted to neonatal intensive care unit, and little social support (Committee on Obstetric Practice, 2016). Research has also supported that previous maternal depression or a family history of mental illness increases a woman’s chance of developing PPD (Di Florio et al., 2014; Wisner et al., 2004). A staggering 50% of women who develop PPD go untreated (Ko et al., 2012), contributing to one of the leading causes of maternal death within the first-year post-partum, suicide (Esscher et al., 2016; Oates, 2003). Furthermore, women with a personal history of mental illness are at an increased risk of post-partum psychosis, a psychiatric emergency (Oates, 2003). Due to the commonality, undertreatment, and potential for a medical emergency, prenatal genetic counselors interacting with pregnant women are primed to aid in identifying and providing resources to mental health professionals to women at an increased risk.

Guidance has been published outlining how to manage patient concerns regarding psychiatric conditions and post-partum depression during a prenatal genetic counseling session (Inglis et al., 2017); however, a lack of knowledge exists as to whether patients are interested in discussing these issues. There is also a gap in terms of knowledge about patient comfort levels pertaining to mental illness discussion with a prenatal genetic counselor. This study aims to explore the self-reported patient interest in and comfort with discussing a personal and/or family history of mental illness with a genetic counselor during prenatal genetic counseling.
2.3 MATERIALS AND METHODS

2.3.1 Participants and Study Design

The Institutional Review Board at Palmetto Health approved this study in July 2017. Data collection occurred August 2017 through December 2017. Study participants consisted of women who met with a prenatal genetic counselor at Palmetto Health USC Medical Group Department of OB/GYN. Subjects were referred for routine prenatal screening or testing counseling, like first trimester screening. In this clinic, patients referred for first trimester screening all meet with a genetic counselor. In this appointment, a genetic counselor takes a personal and family history, provides counseling regarding first trimester screening and other genetic screening/testing options, and obtains informed consent for any testing. Eligibility requirements for this study were as follows:

- participants must be over the age of 18,
- participants must be English-speaking,
- participants must be pregnant,
- participants must have received prenatal genetic counseling for routine prenatal screening or testing, during which a detailed family history was obtained.

Exclusion criteria were as follows:

- participants with an indication for genetic counseling other than routine prenatal screening or testing, such as a documented family history of a genetic condition or an abnormal prenatal screen.
To recruit participants for this study, potential subjects were given a paper copy of the invitation to participate, questionnaire, and mental health resource page by the genetic counselor who performed their genetic counseling (materials can be found in Appendix A). The invitation had the option to complete the questionnaire online or by the provided copy. Upon completion of the paper copy, the questionnaire was returned to the front desk of the ultrasound suite, either in the provided lock box or to the front desk staff. Online questionnaires were submitted through surveymonkey.com. Participation in this study was completely voluntary and anonymous.

2.3.2 Instrumentation

The purpose designed questionnaire consisted of 26 total items and was followed by five demographic questions. The complete questionnaire can be found in Appendix A. Questions were designed to assess participants comfort felt with being asked about mental illness in prenatal genetic counseling, and if they had interest in discussing these conditions.

The Edinburgh Postnatal Depression scale (EPDS) was administered as part of the 26-item questionnaire. This validated 10-item screening tool asks participants to check the answer that comes closest to how they have felt in the past 7 days. Answers are scored 0-3, with 0 being the least serious and 3 being the most serious. Scores are tallied for a total score out of 30. Scores greater than or equal to 15 are classified as experiencing significant depressive symptoms.

The questionnaire ended with five demographic questions to establish age and race of the participants, the number of times they had been pregnant, the number of living children they had, and the level of schooling they had completed.
2.3.3 Data Analysis

Quantitative data analysis was performed using SPSS statistical analysis software. Fisher’s exact test was used to identify any significant association between the level of interest in discussing a personal and/or family history of mental illness with a genetic counselor between participants who indicated a positive family history and those who indicated a negative family history of mental illness. An independent-samples t-test was performed to identify any significant association between the level of interest in discussing mental illness and EPDS score. A probability value of 0.05 (p = 0.05) was used for all tests.

2.4 RESULTS

A total of 40 participants completed or partially completed the questionnaire either online or by paper copy. Three participants completed the questionnaire online and 37 by paper copy. All 40 participant’s questionnaires were considered in reporting the results. The number of participants varied per question. Thirty-five participants were considered in the data analysis.

2.4.1 Demographics

A summary of the participant’s demographics can be found in Table 2.1. Thirty-nine participants provided their age. The age of the participants ranged from 19 to 39 years, with most participants being between the ages of 25 and 30 (41%). All 40 participants indicated their race. Seventeen participants indicated they were white (42%), 21 indicated they identified as a race other than white (52%), and 2 indicated a mixed race (5%). Thirty-eight participants indicated how many times they had been pregnant including this pregnancy, with the majority indicating this was their second (n = 13) or
Table 2.1 Demographic characteristics of participants

<table>
<thead>
<tr>
<th>Participant Characteristics</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>39</td>
<td></td>
</tr>
<tr>
<td>18-24</td>
<td>10</td>
<td>26</td>
</tr>
<tr>
<td>25-30</td>
<td>16</td>
<td>41</td>
</tr>
<tr>
<td>31-35</td>
<td>11</td>
<td>28</td>
</tr>
<tr>
<td>36-40</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>40+</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td>40</td>
<td></td>
</tr>
<tr>
<td>American Indian or Alaska Native</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Asian</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>Black or African American</td>
<td>14</td>
<td>35</td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>7</td>
<td>18</td>
</tr>
<tr>
<td>Native Hawaiian or Other Pacific Islander</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>White</td>
<td>19</td>
<td>46</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Gravida</td>
<td>38</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>10</td>
<td>26</td>
</tr>
<tr>
<td>2</td>
<td>13</td>
<td>34</td>
</tr>
<tr>
<td>3</td>
<td>12</td>
<td>32</td>
</tr>
<tr>
<td>4</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>5</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Living Children</td>
<td>40</td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>19</td>
<td>48</td>
</tr>
<tr>
<td>1</td>
<td>15</td>
<td>38</td>
</tr>
<tr>
<td>2</td>
<td>5</td>
<td>13</td>
</tr>
<tr>
<td>3</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Highest Degree or Level of Education Completed</td>
<td>40</td>
<td></td>
</tr>
<tr>
<td>Less than High School</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>High School Graduate or GED</td>
<td>8</td>
<td>20</td>
</tr>
<tr>
<td>Some college, no degree</td>
<td>9</td>
<td>23</td>
</tr>
<tr>
<td>Associate's Degree</td>
<td>6</td>
<td>15</td>
</tr>
<tr>
<td>Bachelor's Degree</td>
<td>11</td>
<td>28</td>
</tr>
<tr>
<td>Master's Degree</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>Other Advanced Degree beyond a Master's degree</td>
<td>3</td>
<td>8</td>
</tr>
</tbody>
</table>
third pregnancy (n = 12). Forty respondents indicated how many living children they had, with the most common being 0 living children (n = 19). Forty participants indicated their highest degree or level of education completed. The most common response was a bachelor’s degree (n = 11) followed by some college, no degree (n = 9).

2.4.2 Interest in Discussing Mental Illness

Participants were asked questions regarding their level of interest in discussing mental illness with a genetic counselor during prenatal genetic counseling. The majority of participants indicated interest in discussing mental illness (n = 28, 70%). When compared to other common prenatal genetic counseling indications, mental illness (n = 21) had high interest levels similar to those of single gene conditions (n = 21) and isolated birth defects (n = 20) (Figure 2.1). The majority were very interested in discussing chromosome conditions (n = 27).

![Figure 2.1 Interest Level in Discussing Various Conditions with a Genetic Counselor during Prenatal Genetic Counseling](image)
Participants were later asked if there was a history of mental illness in their or the father of the baby’s family. Figure 2.2 illustrates the level of interest in discussing mental illness with a genetic counselor in those with a positive family history compared to those with a negative family history. Fifteen out of 40 participants indicated a positive family history of mental illness. Within this group, 12 out of the 15 (80%) indicated interest in discussing mental illness. No participants with a positive family history indicated they were not at all interested in discussing with a genetic counselor.

![Figure 2.2 Interest Level of Participants with a Positive and Negative Family History of Mental Illness](image)

Of the 25 participants who reported no family history, 16 (64%) indicated interest in discussing mental illness. Table 2.2 gives the average interest level score for both groups of participants with a positive family history and negative family history using a 5 point Likert scale (5 = very interested, 1 = not at all interested). There was no significant difference in level of interest in discussing mental illness with a genetic counselor.
between those who did and did not have a personal or family history of mental illness as assessed by Fisher's exact test, \( p = .220 \) (Laerd Statistics, 2016).

Table 2.2 Average Interest in Discussing Mental Illness in Participants with a Positive Family History and Negative Family History of Mental Illness

<table>
<thead>
<tr>
<th>Family History of Mental Illness</th>
<th>N</th>
<th>Average Interest Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive</td>
<td>15</td>
<td>4.2</td>
</tr>
<tr>
<td>Negative</td>
<td>25</td>
<td>3.8</td>
</tr>
</tbody>
</table>

Interest levels in discussing mental illness and EPDS scores were analyzed. One participant scored a 15 or higher on the EPDS (score of 17). Six out of 40 participants scored an 11 or higher on the EPDS, including the participant who scored a 17. Of these 6 participants, all 6 indicated they were very interested in discussing mental illness. Table 2.3 summarizes the average EPDS score for those with interest and those without interest in discussing mental illness. Participants that indicated they were neutral (\( n = 5 \)) to discussion were omitted from the data analysis. There was no significant difference in EPDS score between those who were interested and those who were not interested in discussing mental illness with a genetic counselor as assessed by an independent-samples t-test, t-value = 1.51, p-value = 0.14 (Laerd Statistics, 2015).

Table 2.3 Average EPDS Score in Participants who had Interest and in those who did not have Interest in Discussing Mental Illness

<table>
<thead>
<tr>
<th>Interest Level in Discussing Mental Illness</th>
<th>N</th>
<th>Average EPDS Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Interested/Somewhat Interested</td>
<td>28</td>
<td>5.79</td>
</tr>
<tr>
<td>Somewhat Not Interested/Not at all Interested</td>
<td>7</td>
<td>3.00</td>
</tr>
</tbody>
</table>
2.4.3 Comfort with Discussing Mental Illness

Thirty-eight participants designated whether the genetic counselor asked them directly about a personal and/or family history of mental illness. Thirty out of 38 (79%) indicated that the genetic counselor asked about a personal and/or family history of mental illness. Of these participants, the majority (90%) reported some level of comfort with being asked. No participants indicated that they were very uncomfortable. Figure 2.3 summarizes the comfort levels expressed in this group.

![Figure 2.3 Comfort Level Associated with being Directly Asked about a Personal and/or Family History of Mental Illness by a Genetic Counselor](image)

Of the participants who indicated the genetic counselor did not ask directly about a personal and/or family history of mental illness (n=9), the majority (90%) indicated they would have been comfortable if the genetic counselor had asked. No participants indicated they would have had any level of discomfort. Figure 2.4 summarizes the reported comfort levels of this described group.
Next, comfort level associated with discussing mental illness with a genetic counselor was assessed. Thirteen of the 30 (43%) participants who indicated the genetic counselor directly asked about mental illness had a follow up discussion. Of these 13 respondents, the majority (85%) were comfortable having a discussion. No participants indicated they were very uncomfortable. Figure 2.5 summarizes these results.

2.4.4 Discussion of Mental Illness during Prenatal Genetic Counseling

Figure 2.6 shows the mental health topics participants discussed or would have liked to discuss with a genetic counselor during their prenatal genetic counseling appointment. Thirteen out of 30 participants who were directly asked about a personal and/or family history of mental illness indicated they had a follow-up discussion regarding mental health topics with a genetic counselor. Some participants had a positive family history while others had a negative family history.
Of the 11 who had a positive family history and were directly asked by the genetic counselor, 6 indicated they had a discussion (55%). In these discussions, genetic testing, factors that contribute to the development of mental illness, chance for family members to develop mental illness, and resources were most commonly discussed. Three participants who had a positive family history were not asked by the genetic counselor about mental illness in themselves or their family.

The participants that were directly asked but did not have a discussion and participants who were not asked about a personal and/or family history of mental illness indicated which mental health topics they would have liked to discuss with the genetic counselor. Eleven out of the 23 participants indicated a discussion was not applicable (i.e. no family history). The most common topics participants would have liked to discuss were factors contributing to mental illness development, genetic testing, postpartum depression, and chance for family members to develop mental illness.
Figure 2.6 Mental Health Topics Participants Discussed or would have liked to Discuss with a Genetic Counselor during their Prenatal Genetic Counseling Appointment.

2.5 DISCUSSION

We used survey methodology to explore patient reported interest in and comfort with discussing a personal and/or family history of mental illness with a genetic counselor during prenatal genetic counseling. To our knowledge, this is the first study to investigate this topic. Overall, our results indicate that a majority of participants expressed interest in discussing mental illness during their genetic counseling appointment. These levels of interest are comparable to those of discussing single gene conditions (i.e. sickle cell disease, cystic fibrosis), chromosome conditions (i.e. Down syndrome, trisomy 18), and isolated birth defects (i.e. spina bifida, heart defects).

We hypothesized that participants with a positive family history of mental illness would more likely be interested in discussing psychiatric conditions with the genetic counselor than those without a family history. Our analyses did not yield significant results across these two groups, which suggests that interest level in discussing mental
illness is not dependent on the presence of a family history. However, it was observed that in the 4 participants who indicated they were not at all interested in discussing mental illness, all 4 did not report having a family history of psychiatric conditions. A similar theme emerged when analyzing the EPDS scores between participants who had interest and those who did not have interest. The nonsignificant results suggest that experiencing depressive symptoms during the prenatal period does not influence level of interest in discussing mental illness. It should be noted that the 5 participants who scored between an 11-14, a cut-off commonly used in clinic to identify those experiencing depressive symptoms, and for the 1 participant who scored a 17, all indicated they were very interested in discussing mental illness.

Overall, participants were comfortable or would have been comfortable with the genetic counselor asking explicitly about a personal and/or family history of mental illness. Similarly, participants who had a discussion about mental illness were overall comfortable with the discussion. Importantly, no participants out of the 40 indicated they would be very uncomfortable being asked about mental illness or discussing it.

Studies have shown that a number of genetic counselors rarely or never ask about psychiatric conditions when taking a family history (Monaco, Conway, Valverde, & Austin, 2010). This may be attributed to the fact that genetic counselors feel uncertain about how helpful they may be in providing information regarding mental illness or previously held stigmatized views of individuals and their families affected by these conditions (Feret, Conway, & Austin, 2011; Peay et al., 2008). However, the combined expressed interest level and comfort from participants across comparably sized white and nonwhite ethnicities in this study supports previous claims that genetic counselors should
routinely incorporate asking about mental illness when taking a family history (Inglis et al., 2017). This suggests that research should continue to be done in finding ways to decrease genetic counselor discomfort and increase preparedness to discuss mental health topics within the scope of practice (Anderson & Austin, 2012; Low et al., 2017).

Approximately one third of participants indicated they discussed mental illness with the genetic counselor. These participants consisted of individuals with a positive family history and those with a negative family history in comparable numbers. The topic of genetic testing was most commonly discussed, which is consistent with previously described interest level regarding this topic (Laegsgaard & Mors, 2008; Mitchell et al., 2010). Factors that contribute to development of mental illness, chance for family members to develop mental illness, and resources were also commonly discussed and are frequently cited as appropriate topics for genetic counselors to talk about with their patients (Inglis et al., 2017; Peay et al., 2008; National Society of Genetic Counselors, n.d.). It was not the intention of this study to analyze how and what exact information was presented to patients during these discussions.

Factors that contribute to the development of mental illness, chance for family members to develop mental illness, and genetic testing were commonly indicated by participants as topics they would have liked to discuss with a genetic counselor. This suggests that a larger number of participants would like to have had a conversation regarding the same topics as those in this study who had a discussion with the genetic counselor. Importantly, postpartum depression (PPD) was frequently indicated as a topic participants would have liked to discuss with a genetic counselor. This conversation becomes more essential when the patient has a personal and/or family history of mental
illness or is currently experiencing depressive symptoms, as they are at an increased chance of developing PPD (Di Florio et al., 2014; Inglis et al., 2014; Mighton et al., 2016).

Approximately half of participants with a reported family history of mental illness and one third of the participants who scored above a 10 on the EPDS (including the participant who scored a 17) did not have a discussion regarding this history with the genetic counselor even though they indicated they were explicitly asked about mental illness. The Practice-Based Competencies for genetic counselors states that they should “assess probability of conditions with a genetic component…using relevant knowledge and data based on pedigree analysis, inheritance patterns, [and] genetic epidemiology” (Accreditation Council for Genetic Counseling, 2015). Since the genetic basis of mental illness is known, genetic counselors should be discussing these conditions with their patients when it appears in the personal or family history. It is also important to discuss recurrence risk within this population, as studies have found individuals often overestimate risk to their family members (Austin et al., 2006; Kalb, Vincent, Herzog, & Austin, 2017). With that being said, this study was not intended to investigate how participants were asked about a personal and/or family history of mental illness by the genetic counselor. This could have influenced how participants answered the question and subsequently affected if the genetic counselor decided a discussion was warranted.

This study is not without limitations. Our research was conducted within one prenatal genetic counseling clinic in South Carolina with a limited number of participants. It is possible that pregnant women in different prenatal genetic counseling clinics, states, or regions within the United States have differing interest and comfort
levels discussing mental illness than those described. We only surveyed women of reproductive age; therefore, it is possible women outside of reproductive age and men have differing feelings regarding discussing mental illness with a genetic counselor as well. However, it should be noted that the population surveyed came from varying racial backgrounds, with comparable white and nonwhite participants surveyed. Because it was at the discretion of the genetic counselor who met with the participant to invite them to take the survey, there may have been unintentional bias as to who was given the survey. For example, if a potential participant disclosed a family history of mental illness, the genetic counselor may have been more likely to invite them to participate than if no such history was disclosed. Lastly, because the prenatal genetic counselors were aware this study was being conducted, they may have been more likely to ask potential participants about a personal and/or family of mental illness and could potentially have skewed this data.

Future larger scale studies could provide further support that interest in and comfort with discussing mental illness is observed in other prenatal genetic counseling clinics or regions within the United States. This study could potentially be replicated in different genetic counseling settings, such as pediatric or adult, to see if similar themes emerge across specialties. A survey of how genetic counselors ask about mental illness during the family history may elucidate how patients with a personal or family history respond, so that the most effective way of asking about psychiatric conditions may be revealed. Finally, because this study had comparable sizes of nonwhite and white participants, future research may be warranted to see if there are differences between
ethnic backgrounds regarding interest and comfort discussing psychiatric conditions during prenatal genetic counseling.
CHAPTER III: CONCLUSION

To our knowledge, this is the first study to explore patient interest in and comfort with discussing a personal and/or family history of mental illness with a genetic counselor during prenatal genetic counseling. The majority of participants expressed interest in and comfort with discussing mental illness with a genetic counselor regardless of the presence of a family history. The absence or presence of depressive symptoms in the prenatal period did not dictate interest level either. Genetic counselors who practice in prenatal genetic counseling should routinely incorporate asking about mental illness while taking the family history and be prepared to discuss mental health topics (i.e. etiology, recurrence risk, postpartum depression) to those who have a personal and/or family history or with those who express interest. Replication of this study in other prenatal genetic counseling clinics or other genetic counseling specialties is warranted to provide further support to these claims.
REFERENCES


Kendler, K.S. (2013). What psychiatric genetics has taught us about the nature of psychiatric illness and what is left to learn. *Molecular Psychiatry*, 18, 1058-1066. doi:10.1038/mp.2013.50


APPENDIX A: QUESTIONNAIRE MATERIALS

UNIVERSITY OF SOUTH CAROLINA
SCHOOL OF MEDICINE

My name is Sarah Nimrichter and I am a genetic counseling student in the University of South Carolina’s Genetic Counseling Graduate Program. You are being invited to participate in a study of what information you would be interested in receiving from a genetic counselor in a prenatal visit.

Today, you met with a prenatal genetic counselor to discuss First Trimester Screening, a screen offered to all pregnant women. During your appointment, the genetic counselor took a family history, asking detailed questions about medical diagnoses and healthcare conditions in your family. This information guides the genetic counselor as to what medical conditions you may benefit from discussing more as it relates to genetics.

If you decide to participate, this brief survey will take 5-10 minutes of your time. Most of the survey revolves around your interest and comfort level in talking about mental health conditions with a genetic counselor. You may be uncomfortable answering some of the questions. You do not have to answer any of the questions that make you feel uncomfortable. By beginning and submitting this survey, you are agreeing to be a participant.

All responses gathered from the questionnaire will be kept anonymous and confidential. The results of this study may be published or presented at academic meetings; however, participants will not be identified. Your participation in this research is voluntary.

We will be happy to answer any questions you have about the study. You may contact me at (803) 545-5775 and sarah.nimrichter@uscmed.sc.edu or my faculty advisor, Vicki Vincent at (803) 545-5727 and victoria.vincent@uscmed.sc.edu if you have study related questions or problems. If you have any questions about your rights as a research participant, you may contact the Office of Research Compliance at Palmetto Health at 803-434-2884.

Thank you for your consideration. If you would like to participate, please type the following link to complete the questionnaire online (https:// surveymonkey.com/r/USCGcsurvey) or fill out the provided paper copy. When you are done, submit the online questionnaire or return the completed paper copy to the box located at the checkout window in the USC OB/GYN suite 106 (ultrasound suite).

Best Wishes,

Sarah Nimrichter
(803) 545-5775
Sarah.nimrichter@uscmed.sc.edu
For questions 1 to 4, rank your level of interest in discussing the following conditions with a genetic counselor, with 5 being very interested and 1 being not at all interested.

<table>
<thead>
<tr>
<th>Condition</th>
<th>5 – Very Interested</th>
<th>4 – Somewhat Interested</th>
<th>3 – Neutral</th>
<th>2 – Somewhat Not Interested</th>
<th>1 – Not at all interested</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Single Gene Conditions (cystic fibrosis, spinal muscular atrophy, sickle cell disease)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2) Chromosome Conditions (Down syndrome, trisomy 18, trisomy 13)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3) Isolated Birth defects (Neural tube defects, cleft lip/palate, heart defects)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4) Mental Illness (schizophrenia, bipolar disorder, anxiety disorders, depression)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

For questions 5 to 8, is there a history of the following conditions in either the father of the baby’s family or your family?

5) Single Gene Conditions (e.g. Cystic fibrosis, spinal muscular atrophy, sickle cell disease, etc.) Y or N

6) Chromosome Conditions (e.g. Down syndrome, Trisomy 18, Trisomy 13) Y or N

7) Isolated Birth Defects (Neural tube defects, cleft lip/palate, heart defects) Y or N

8) Mental Illness (schizophrenia, bipolar disorder, anxiety disorders, depression) Y or N

9) Did your genetic counselor ask you directly about a personal or family history of mental illness?  
   Y or N (If no, please skip to question 15)
10) If you answered yes to question 9, how did you feel about being asked about a personal or family history of mental illness?
   5 – very comfortable
   4 – somewhat comfortable
   3 – neutral
   2 – somewhat uncomfortable
   1 – very uncomfortable

11) If you answered yes to question 9, did you have a discussion about mental illness with the genetic counselor? Y or N (If no, skip to question 16)

If you answered yes to the question 11 “did you have a discussion about mental illness with the genetic counselor” please answer questions 12 to 14:

12) What mental health topic(s) did the genetic counselor discuss? (Select all that apply)
   a) Factors that contribute to the development of mental illness
   b) Chance for family members to develop mental illness
   c) Things you can do to protect your mental health (e.g. exercise, adequate sleep, etc.)
   d) Post-partum depression (depression after having a baby)
   e) Resources (e.g. information about mental health professionals)
   f) Genetic Testing
   g) Other: ____________________________________________

13) Were there topics regarding mental health conditions you wish the genetic counselor would have covered? (Select all that apply)
   a) Factors that contribute to the development of mental illness
   b) Chance for family members to develop mental illness
   c) Things you can do to protect your mental health (e.g. exercise, adequate sleep, etc.)
   d) Post-partum depression (depression after having a baby)
   e) Resources (e.g. information about mental health professionals)
   f) Genetic Testing
   g) Other: ____________________________________________
   h) No, there were no other topics I would have liked covered

14) How comfortable were you discussing these mental health topics with your genetic counselor?
   5 – very comfortable
   4 – somewhat comfortable
   3 – neutral
   2 – somewhat uncomfortable
   1 – very uncomfortable

Please skip questions 15 and 16 and move to question 17.
If you answered NO to question 9 “did your genetic counselor ask you directly about personal or family history of mental illness” please answer questions 15 and 16:

15) How would you have felt if your genetic counselor asked you directly about a personal or family history of mental illness?
   - 5 – very comfortable
   - 4 – somewhat comfortable
   - 3 – neither comfortable or uncomfortable
   - 2 – somewhat uncomfortable
   - 1 – very uncomfortable

16) Please select the topics related to mental illness that you would have liked to have discussed with your genetic counselor (select all that apply):
   a) Factors that contribute to the development of mental illness
   b) Chance for family members to develop mental illness
   c) Things you can do to protect your mental health (e.g. exercise, adequate sleep, etc.)
   d) Post-partum depression (depression after having a baby)
   e) Resources (e.g. information about mental health professionals)
   f) Genetic Testing
   g) Not applicable (e.g. no family or personal history of mental illness)

Please complete the following ten items by checking the answer that comes closest to how you have felt in the past 7 days, not just today.

17) I have been able to laugh and see the funny side of things.
   - □ As much as I always could
   - □ Not quite so much now
   - □ Definitely not so much now
   - □ Not at all

18) I have looked forward with enjoyment to things.
   - □ As much as I ever did
   - □ Rather less than I used to
   - □ Definitely less than I used to
   - □ Hardly at all

19) I have blamed myself unnecessarily when things went wrong.
   - □ Yes, most of the time
   - □ Yes, some of the time
   - □ Not very often
   - □ No, not at all

20) I have been anxious or worried for no good reason.
   - □ No, not at all
   - □ Hardly ever
   - □ Yes, sometimes
   - □ Yes, very often

21) I have felt scared or panicky for no very good reason.
   - □ Yes, quite a lot
   - □ Yes, sometimes
   - □ No, not much
   - □ No, not at all
22) Things have been getting on top of me.
   □ Yes, most of the time I haven’t been able to cope at all
   □ Yes, sometimes I haven’t been coping as well as usual
   □ No, most of the time I have coped quite well
   □ No, I have been coping as well as ever
23) I have been so unhappy that I have had difficulty sleeping.
   □ Yes, most of the time
   □ Yes, sometimes
   □ Not very often
   □ No, not at all
24) I have felt sad or miserable.
   □ Yes, most of the time
   □ Yes, quite often
   □ Not very often
   □ No, not at all
25) I have been so unhappy that I have been crying.
   □ Yes, most of the time
   □ Yes, quite often
   □ Only occasionally
   □ No, never
26) The thought of harming myself has occurred to me.
   □ Yes, quite often
   □ Yes, sometimes
   □ Hardly ever
   □ No, never

Demographics:

Age: __________

Race (Choose all that apply)
   □ American Indian or Alaska Native
   □ Asian
   □ Black or African American
   □ Hispanic or Latino
   □ Native Hawaiian or Other Pacific Islander
   □ White
   □ Other

How many times have you been pregnant including this pregnancy: ______

Number of living children: ______

Highest Degree or Level of Education Completed (select one):
   □ Less than high school
   □ High school graduate or equivalent (e.g. GED)
   □ Some college, no degree
   □ Associate’s degree
   □ Bachelor’s degree
   □ Master’s degree
   □ Other advanced degree beyond a Master’s degree
Thank you for your participation! Please return your completed survey to the box at the check out window in USC OB/GYN office Suite 106 (ultrasound office).
If you or someone you know has a mental illness, there are ways to get help. These resources can be used to find help for you, a friend, or family member.

**Get Immediate Help**

National Suicide Prevention Lifeline (1-800-273-8255)

Veterans, Military, & Families Crisis Line (1-800-273-8255 Press 1)

**Finding Health Care Providers and Treatment in Your Area**

South Carolina Mental Health Centers by County
(http://www.state.sc.us/dmh/cmhc.htm)

- Columbia Area Mental Health Center (803) 898-4800/ (803) 898-8888
- Lexington County Mental Health Center (803) 996-1500/(803) 395-3545
- Orangeburg Area Mental Health Center (803) 536-1463
- Beckman Center for Mental Health Services (864) 229-7120

Palmetto Health Day Treatment Program (Columbia, SC) (803) 296-8765

Substance Abuse and Mental Health Services Administration Referral Helpline (1-800-662-4357)

Substance Abuse and Mental Health Services Administration Behavioral Health Treatment Locator (https://findtreatment.samhsa.gov/)

Local Therapists (www.psychologytoday.com)

*Contact your insurance company for a list of providers*
**National Agencies, Advocacy Groups, and Professional Organizations**

Anxiety and Depression Association of America (https://www.adaa.org)

Depression and Bipolar Support Alliance (www.dbsalliance.org / (800) 826-3632 toll free)

Mental Health America (http://www.mentalhealthamerica.net / (800) 969-6642 toll free)

National Alliance on Mental Illness (www.nami.org / (800) 950-6264)

Postpartum Support International (http://www.postpartum.net / (800) 944-4773 toll free helpline)

**Help for Service Members and Their Families**

Current service members, veterans, and their families may face different mental health issues than the general population. Please visit https://www.mentalhealth.gov/get-help/veterans/index.html for a list of resources.

**More Information about Mental Health Conditions**

National Institute of Mental Health (https://www.nimh.nih.gov/health/topics/index.shtml)

National Society of Genetic Counselors: Mental Health and Genetics (http://aboutgeneticcounselors.com/Genetic-Conditions/Mental-Health-Conditions)

Women’s Mental Health (www.womensmentalhealth.org)