EXAMINING THE ATTITUDES AND OPINIONS OF BIPOLAR DISORDER PRE- AND POST-EDUCATIONAL SESSION IN INDIVIDUALS AFFECTED WITH BIPOLAR DISORDER AND FIRST-DEGREE RELATIVES OF INDIVIDUALS AFFECTED WITH BIPOLAR DISORDER

by

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B.S., University of Pittsburgh, 2007

Submitted to the Graduate Faculty of

the Graduate School of Public Health in partial fulfillment

of the requirements for the degree of

Master of Science

University of Pittsburgh

2012

UNIVERSITY OF PITTSBURGH

GRADUATE SCHOOL OF PUBLIC HEALTH

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EXAMINING THE ATTITUDES AND OPINIONS OF BIPOLAR DISORDER PRE- AND POST-EDUCATIONAL SESSION IN INDIVIDUALS AFFECTED WITH BIPOLAR DISORDER AND FIRST-DEGREE RELATIVES OF INDIVIDUALS AFFECTED WITH BIPOLAR DISORDER

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Bipolar disorder (BPD) is a serious psychiatric condition that causes shifts in mood, energy levels, and the ability to complete daily activities. An estimated 1% of the United States' population is affected with BPD. In affected individuals, BPD can cause relationship problems, poor performance at work/school, substance abuse, and suicide. For these reasons, BPD is associated with a significant amount of morbidity and is a substantial public health concern.

Studies indicate that BPD is a multifactorial condition and although several candidate genes have been suggested, no single gene has been successfully identified. Recurrence risk for unaffected individuals that have one first-degree relative with BPD is 5-30%.

Research to identify the predisposing genes of BPD is ongoing. It is likely genetic counseling and testing for BPD will become routine in the future. This study is designed to analyze the knowledge, attitudes, and opinions regarding BPD and genetic testing for BPD. In order to capture those most likely to seek genetic testing and counseling for BPD, the target populations were individuals affected with BPD and first-degree relatives of individuals affected with BPD. The public health significance is that understanding the attitudes and opinions of these populations may help reduce the burden of the disease.

Participants were consented and took anonymous surveys over the telephone. They answered multiple choice knowledge questions and rated their level of agreement to statements,

based on the Health Belief Model (HBM), about bipolar disorder and genetic testing. By rating their level of agreement on a 5-point Likert scale, their health beliefs in the categories of perceived severity, susceptibility, benefits, and barriers were analyzed. Participants then participated in an educational session and took an identical survey.

Results indicate that the knowledge about BPD significantly increased following the educational session. The attitudes and opinions of primary affected individuals and first-degree relatives did not differ significantly pre-educational session in the HBM categories, however did differ significantly post-educational session in perceived severity. Neither population differed significantly among themselves pre- and post-educational session. When individual statements were analyzed, affected individuals were more moderate in concerns of having a child with BPD.

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ACKNOWLEGEMENTS

I would like to thank my thesis committee Elizabeth Gettig, MS, CGC, Daniel Normolle, PhD, and Vishwajit Nimgaonkar, MD, PhD for their guidance throughout this project. I would also like to thank the entire Department of Human Genetics Faculty and Staff for their dedication and commitment to their students.

1.0 INTRODUCTION

This study was designed to evaluate the knowledge, attitudes, and opinions of Bipolar Disorder (BPD) and genetic testing for BPD. In order to capture the populations most likely to seek genetic testing and/or genetic counseling, the target populations were individuals affected with BPD and first-degree relatives of individuals with BPD. This study also evaluated the impact of an educational session (similar to a genetic counseling session) on BPD.

An anonymous survey was completed over the telephone by participants (N=39). They answered multiple choice BPD knowledge questions and rated their level of agreement to statements, based on the Health Belief Model (HBM), about bipolar disorder and genetic testing (Janz & Backer, 1984). By rating their level of agreement on a 5-point Likert scale, their health beliefs in the categories of perceived severity, perceived susceptibility, perceived benefits, and perceived barriers were examined. The responses were analyzed using the Mann-Whitney test to assess if there were significant differences in BPD knowledge prior to and following a brief educational session on BPD. Additionally, the Mann-Whitney test was used to assess if there was a significant difference between the attitudes and opinions of affected individuals and first-degree relatives prior to and following an educational session on BPD. Lastly, the Mann-Whitney test was used to assess the differences between the attitudes and opinions of individuals affected with BPD pre- and post-educational session and of first-degree relatives pre- and post-educational session.

To date, thirteen individuals affected with BPD and twenty-six first-degree relatives of individuals affected with BPD have completed both pre- and post-educational session surveys.

1.1 SPECIFIC AIM 1

1.1.1 Specific Aim

Specific aim 1 was to assess and compare the attitudes and opinions of individuals affected with bipolar disorder and to the attitudes and opinions of first-degree relatives of individuals affected with bipolar disorder prior to an educational session on BPD.

1.1.2 Hypothesis

There will be no significant difference in the levels of perceived severity, perceived susceptibility, perceived benefits of genetic testing, and perceived barriers of genetic testing prior to an educational session on BPD between individuals affected with BPD and first-degree relatives of individuals affected with BPD.

1.1.3 Plan

Anonymous surveys were taken over the phone by primary affected individuals or by first-degree relatives of individuals with BPD. Using a Likert scale with ratings from 1-5, participants ranked their level of agreement with specific statements. The surveys were used to

assess participants' levels of perceived severity of BPD, perceived susceptibility to BPD, perceived benefits of genetic testing, and perceived barriers of genetic testing. There were three statements in each of the four HBM categories (Janz & Backer, 1984). The Mann-Whitney test was used to compare the affected population to the first-degree relatives to identify if there were any significant differences in attitudes and opinions between the two groups, prior to an educational session on BPD.

1.2 SPECIFIC AIM 2

1.2.1 Specific Aim

Assessment and comparison of attitudes and opinions of individuals affected with bipolar disorder against the attitudes and opinions of first-degree relatives of individuals affected with bipolar disorder following an educational session on BPD constituted specific aim 2.

1.2.2 Hypothesis

There will be no significant difference in the levels of perceived severity, perceived susceptibility, perceived benefits of genetic testing, and perceived barriers of genetic testing following an educational session on BPD between individuals affected with BPD and first-degree relatives of individuals affected with BPD.

1.2.3 **Plan**

Anonymous surveys were taken over the phone by primary affected individuals or by first-degree relatives of individuals with BPD. Using a Likert scale with ratings from 1-5, participants ranked their level of agreement with specific statements. The surveys were used to assess participants' levels of perceived severity of BPD, perceived susceptibility to BPD, perceived benefits of genetic testing, and perceived barriers of genetic testing. There were three statements in each of the four HBM categories. The Mann-Whitney test was used to compare the affected population to the first-degree relatives to identify if there were any significant differences in attitudes and opinions between the two groups, following an educational session on BPD.

1.3 SPECIFIC AIM 3

1.3.1 **Specific Aim**

Specific Aim 3 was to assess and compare the attitudes and opinions of individuals affected BPD prior to and following an educational session on BPD and compare the attitudes and opinions of first-degree relatives of individuals with BPD prior to and following an educational session on BPD.

1.3.2 **Hypothesis**

There will be no significant difference in the attitudes and opinions of primary affected individuals prior to and following an educational session on BPD. There will also be no significant difference in the attitudes and opinions of first-degree relatives prior to and following an educational session on BPD.

1.3.3 **Plan**

Anonymous surveys were taken over the phone by primary affected individuals or by first-degree relatives of individuals with BPD. Using a Likert scale with ratings from 1-5, participants ranked their level of agreement with specific statements. The surveys were used to assess participants' levels of perceived severity of BPD, perceived susceptibility to BPD, perceived benefits of genetic testing, and perceived barriers of genetic testing. There were three statements in each of the four HBM categories. The Mann-Whitney test was used to compare the affected population and relatives to identify if there were any significant differences prior to or following and educational session on BPD.

1.4 SPECIFIC AIM 4

1.4.1 Specific Aim

Specific aim 4 included assessing and comparing BPD knowledge of individuals affected with BPD and of first-degree relatives of individuals affected with BPD prior to and following an educational session on BPD.

1.4.2 Hypothesis

There will be no significant difference in the knowledge of BPD in primary affected individuals and first-degree relatives prior to and following an educational session on BPD.

1.4.3 Plan

Anonymous surveys were taken over the phone by primary affected individuals or by first-degree relatives of individuals with BPD. Using eight multiple choice questions, BPD knowledge of the participants was assessed prior to and following and educational session on BPD. The Mann-Whitney test was used to compare the level of knowledge of the affected population and of the first-degree relatives to identify if there were any significant differences between pre-educational session knowledge and post-educational session knowledge.

1.5 PARTICIPANT RATIONALE

The reason for the selection of participants based on being either affected with BPD or first-degree relatives to an affected individual is because this study was aimed at evaluating the population most likely to undergo genetic counseling and, once genetic testing for BPD becomes clinically available, would most likely undergo genetic testing.

2.0 BACKGROUND AND SIGNIFICANCE

This study was designed to examine the attitudes and opinions of BPD in individuals affected with BPD and first-degree relatives of individuals affected with BPD. BPD is one of the leading causes of disability in the United States (Müller-Oerlinghausen, Bergerhöfer, & Bauer, 2002). Annual public health cost (direct and indirect combined) of BPD have been estimated to be between 24 billion and 45 billion dollars (Wyatt & Henter, 1995; Begley C. , et al., 2001). BPD therefore is a significant public health concern and further studies on BPD and genetic testing are warranted. By understanding the prior knowledge, attitudes, and opinions of these two populations and by assessing how an educational session may affect the knowledge, attitudes, and opinions of BPD, it will help genetic counselors formulate and tailor appropriate genetic counseling for BPD in the future. Genetic counseling for BPD may help reduce the burden of the disease by providing education on the epidemiology and symptoms of BPD, treatment of BPD, and by providing psychosocial support. This could lead to early diagnosis and treatment of BPD, which helps improve outcome (Lish, Dime-Meenan, Whybrow, Price, & Hirschfeld, 1994).

2.1 BIPOLAR DISORDER EPIDEMIOLOGY

2.1.1 Incidence and Prevalence of BPD

Bipolar disorder affects approximately 1% of the U.S. population, although estimates are as high as 4.4% when the entire spectrum of BPD is considered (1.0% for BP1; 1.1% for BPII; and 2.4% for sub-threshold BPD, see natural history for explanation of BPD subtypes) (Torrey, Bowler, Taylor, & Gottesman, 1994; Merikangas, et al., 2007).

Unipolar depression has a higher prevalence in the U.S. than BPD; however, Begley, *et. al*. (2001) consider the negative public health consequences to be greater from BPD than from unipolar depression because of the significant morbidity associated with BPD. The mortality rate is also high. The lifetime risk of suicide in affected individuals approaches 20% (Goldberg & Harrow, 2004).

Men and women are equally likely to be affected by bipolar disorder and the typical age at onset is 15-24 years. Despite the early age at onset, there is typically a lapse of about 5-10 years from when symptoms begin to when treatment is sought or obtained (Müller-Oerlinghausen, Berghöfer and Bauer 2002).

2.1.2 Natural History of BPD

Bipolar disorder is characterized by cyclic episodes of depression and mania. Mania is the hallmark of BPD (Belmaker, 2004). Diagnosis of BPD relies strictly on clinical symptoms, because no validating diagnositic test exisits at this time (Craddock & Sklar, 2009). BPD is

currently diagnosed by using the Diagnostic and Statistical Manual of Mental Disorders 4th edition (DSM-IV) (American Psychiatric Association, 1994). This manual covers all mental illnesses and is published by the American Psychiatric Association.

Bipolar disorder comprises a spectrum of cyclic mood disorders, which includes bipolar I disorder (BP1), bipolar II disorder (BPII), cyclothymia, and bipolar disorder not otherwise specified (NOS) (Müller-Oerlinghausen, Bergerhöfer, & Bauer, 2002; American Psychiatric Association, 1994).

The DSM-IV criteria for BPI include at least one manic episode or mixed episode, usually with one or more episodes of major depression directly proceeding or following the manic or mixed episode (American Psychiatric Association, 1994). BPI was historically referred to as manic depression.

In depressive episodes, an individual can have a depressed mood, irrability, loss of interest in activites, insomnia or excessive tiredness, fatigue, decreased concentration, and frequent thoughts of death (American Psychiatric Association, 1994). These symptoms must continue for a period of 2 weeks or longer in order to be classified as a depressive episode. Depressive episodes typically occur more frequently and for longer periods of time than manic episodes (Belmaker, 2004).

In a manic episode, an individual can experience elevated mood or euphoria, lack of need for sleep, impaired judgment, reckless behaviors, rapid and excessive speech, distractibility, and delusions of grandeur (American Psychiatric Association, 2002; Belmaker, 2004). Mania causes significant impairment in an affected individual's life.

A mixed episode is an episode that meets the criteria for both a major depressive episode and a major manic episode for a period of at least one week (American Psychiatric Association, 1994). Mixed episodes also cause severe impairment in an affected individual's life.

BPII includes at least one hypomanic episode and recurrent episodes of major depression directly proceeding or following the hypomanic episode (American Psychiatric Association, 1994). Depressive episodes are the same as in BPI. Hypomanic episodes are episodes where manic-like symptoms occur, but without major impairment to daily functioning (American Psychiatric Association, 1994; Quaid, et al. 2001).

Cyclothymia is a mild form of BPD with fluctuations in moods involving numerous periods of mild depressive symptoms and mild hypomanic symptoms. It is considered chronic if it last for a period of 2 years or greater with symptom-free periods not exceeding 2 months of time (American Psychiatric Association, 1994).

Bipolar disorder- NOS are disorders that have features of bipolar disorder, but that do not meet any diagnostic criteria (American Psychiatric Association, 1994; Müller-Oerlinghausen, Bergerhöfer, & Bauer, 2002). It should be noted that for the purposes of this study, no distinctions were made between BPD subtypes.

Cycles of mania and depression vary from individual to individual. Some may have only one manic episode and many frequent depressive episodes, others may have frequent cycling between mania and depression, and yet others may have manic epidosdes every few years and rarely have depressive episodes (Belmaker, 2004). If an individual has four or more cycles between depression and mania annually, they are referred to as "rapid cyclers." (Belmaker, 2004)

BPD often occurs comborbidly with other DSM-IV disorders. These disorders most often include anxiety disorders, impulse control disorders, and substance abuse disorders. The comorbidity for BPI and BPII is 95.8% -97.7% and in sub-threshold BPD comorbitidy is 88.4% (Merikangas, et al., 2007).

2.1.3 **Treatment of BPD**

There is no cure for bipolar disorder but treatment is available. However, treatment can be complicated by misdiagnoses or if an affected individual does not seek treatment at the onset of symptoms. Studies show that bipolar disorder can be misdiagnosed, most commonly as unipolar depression, and it can take 10 or more years for some individuals to receive a correct diagnosis. Additionally, some individuals take the same amount of time to seek treatment for their symptoms (Hirschfeld, Lewis, & Vornik, 2003).

Another complication in treatment is that individuals who are being treated may choose to stop their treatment. This often occurs because an individual does not want to experience the negative side-effects of the mediation, misses the mania of BPD, or feel they do not need to medication any longer due to a symptom-free interval (Keck, et al., 2004).

Long-term treatment of BPD is typically focused on treating acute manic and depressive episodes, preventing manic and depressive episodes, preventing relapses, preventing suicide attempts, and to improve an affected individual's quality of life. (Geddes & Briess, 2007). Mood stabilizers are the typical pharmacological approach to treat BPD and can be used alone or in combination with other medications, like antidepressants.

In 1949, lithium was first discovered as a protectant against psychotic episodes and was introduced as a treatment to BPD in the 1970's (Schou, 1968; Quaid, Aschen, Smiley, &

Nurnberger, 2008). Lithium is often the first-choice of pharmacological treatment. It helps to prevent and treat acute episodes of mania. Despite treatment, approximately 20-40% of classical bipolar patients and up to 50% of patients across the entire bipolar spectrum will have some chronic symptoms (Calabrese, Fatemi, Kujawa, & Woyshville, 1996). Keck, et al. (2004) report that lithium is least effective in individuals that have mixed manic episodes and/or rapid-cycling. Individuals with frequent recurrences were less likely to be treated with mood-stabilizers and more likely to be treated with anti-depressants or antipsychotics (Lish, Dime-Meenan, Whybrow, Price, & Hirschfeld, 1994).

Anticonvulsants, like divalproex (Depakote) and carbamazepine (Tegretol) can also be used as mood stabilizers to treat BPD. Divalproex is effective for both classic mania, mixed mania, and can also be effective in BPD complicated by anxiety, drug abuse, and rapid-cycling. The effect of carbamazepine is similar to that of divalproex (Keck, et al., 2004). The anticonvulsants lamotrigine, gadapentin, and topiramate are being evaluated as possible treaments for BPD (Müller-Oerlinghausen, Bergerhöfer, & Bauer, 2002).

Atypical antipsychotics are also considered mood stabilizers as some have been found to help treat mania in BPD. The atypical antipsychotics approved by the Food and Drug Administration (FDA) to treat BPD mania are aripiprazole (Abilify), olanzapine (Zyprexa), quetiapine (Seroquel), risperidone (Risperdal), ziprasidone (Geodon) (Geddes & Briess, 2007; Keck, et al., 2004). Clozapine (Clozaril) can also be used, but because it poses a risk for a serious blood side effect, it is typically only used if patients that do not respond to any other antipsychotics (Keck, et al., 2004)

Antidepressants, such as lamotrigine (Lamictal), bupropion (Wellbutrin), citalopram (Celexa), escitalopram (Lexapro), fluoxetine (Prozac), fluvoxamine, (Luvox), paroxetine

(Paxil), sertraline (Zoloft), venlafaxine (Effexor), duloxetine (Cymbalta), and olanzapine/fluoxetine combination (Symbyax), are frequently used as adjunct therapy to mood stabilizers (Geddes & Briess, 2007; Keck, et al., 2004).

Electroconvulsive therapy (ECT) can be used to treat depressive episodes as well (Müller-Oerlinghausen, Berghöfer and Bauer 2002). And while ECT is sometimes viewed negatively, it can be a more immediate way to help those who are severly ill or suicidal (Keck, et al., 2004). ECT is done under close medical surveillance and is done under anesthesia

Education can help individuals and families learn the signs and symptoms of BPD, which can lead to earlier treatment and diagnosis as well as recognition of relapse. It can also help them learn how to better manage BPD. For this reason, education is considered an important aspect of treatment as well (Keck, et al., 2004).

Psychotherapy can be used as adjunct treatment in BPD and is almost always used along with medication. Psychotherapy can help individuals learn how to manage stress, deal with thoughts and feelings, and deal with behaviors in a constructive manner. It can also increase problem-solving skills. Psychotherapy can also be very helpful for other problems people with bipolar disorder may have, such as anxiety, eating disorders, or substance abuse (Geddes & Briess, 2007).

Alcohol and drug abuse frequently complicate the clinical course of BPD as well as the treatment of individuals with BPD. Affected individuals in the depressive phase may use alcohol or drugs as self-medication and in the manic phase may use them recreationally due to reckless behavior. Not every individual with BPD will abuse drugs or alcohol and the extent of abuse varies between patients. There is no way to predict which affected individuals will suffer drug or alcohol abuse (Belmaker, 2004).

2.1.4 **Risk Factors for Bipolar Disorder**

Risk factors for bipolar disorder include both genetic and environmental factors, and genetic factors explain approximately 70% of bipolar disorder (Edvardeen, et al., 2008). Qualitatively, Craddock and Jones (2001) report that at least 20 studies report in increase in the prevalence of BPD among first-degree relatives; however, the quantitative data between studies varies. One study found that if one parent is affected with BPD, the recurrence risk for his or her children is approximately 10 times higher than the population risk (Craddock & Jones2001). The Psychiatric Special Interest Group (SIG) of the National Society of Genetic Counselors (NSGC) report that the recurrence risk for first-degree relative to be 5-30% (NSGC, 2007).

Factors that have been associated with poor prognosis are older age at onset, frequent sub-threshold BPD symptoms, longer duration of the illness, and poor psychological support (Zis, Grof, Webster, & Goodwin, 1980; Keller, et al., 1992; O'Connell, Mayo, Eug, Jones, & Gabel, 1985). Other factors affecting prognosis include male gender, marital status, having a personality disorder, having BP1 vs. having BPII, and having stable episode frequencies; however there factors are less validated (Gaviria, Flaherty, & Val, 1982; Peselow, Dunner, Dieve, & Lautin, 1982; Prien, Caffey, & Kiett, 1974; Tohen, Waternaux, & Tsuang, 1990).

As mentioned earlier, BPD affects men and women equally and the average age at onset is between 15-24 years of age. Having a family history also increases the recurrence risk in unaffected indidivuals (which is explained in more detail in the following section).

Tsuchiya, Byrne, & Mortensen (2003) analyzed approxiamtely 100 studies that examined environmental factors and BPD. Their analysis established that there has been inconsistent findings between studies. There have been suggestive findings that prenancy

complications, winter and spring births, brain injury, multiple sclerosis, and stressful life events may be antecedens of BPD (Tsuchiya, Byrne, & Mortensen, 2003).

Drug abuse is a known risk factor for BPD. A 3-year study that followed 4,4045 participants determined that cannabis smokers are 3 times more likely to develop psychotic symptoms, including manic depression (van OS, et al., 2002). Methamphetamine or crystal meth may also trigger psychiatic illnesses in vulnerable individuals (Degenhardt, Hall, & Lynskey, 2003; Henquet, et al., 2005).

2.1.5 **Molecular Genetics of BPD**

Twin studies suggest a genetic link to BPD. The concordance rate of BPD among monozygotic twins ranges from 40 to 80%, while the rate is only about 10-20% in dizygotic twins (Plomin, DeFries, & McClearn, 1997). Fifty percent of individuals affected with bipolar disorder report having a family history of the disorder. Risk is increased in families with many affected members, and families with multiple members across several generations with BPD are called multiplex families (Finn & Smoller, 2006). Additionally, families that have an earlier average age at onset are also at higher risks (Finn & Smoller, 2006).

The Psychiatric Special Interest Group of the National Society of Genetic Counselors (NSGC) provided empiric BPD recurrence risks in 2007 based on which relative(s) is affected. They composed these risks after a review of empiric risk literature. For any first -degree relative of an affected individual the risk is 5-30%. Having an affected child has the lowest risk of 10% while having two affected parents carries the highest risk of 50-60%. Siblings have a 13% risk, children of one affected parent have a 15-30% risk, and individuals with both have a 20% risk.

Individuals with a second-degree relative with BPD, have about a 5% chance to develop the condition.

Despite the support for a genetic cause, no single locus has been replicated consistently and statistical analysis suggests polygenic inheritance (Lenox, Gould, & Manji, 2002; Belmaker, 2004). Genetic heterogeneity is further complicated by phenotypic overlap with other psychiatric illnesses and makes discovering the genetic factors challenging (Barnett & Smoller, 2009).

Linkage and association studies have implicated several signaling pathway involved in BPD, which suggests that BPD is likely controlled by an interaction of different biological processes (Serretti & Mandelli, 2008; Escamilla & Zavala, 2008)

The and leading candidate genes associated with bipolar disorder include BDNF, DAOA, DISC1, SLC6A4, and TPH2. (Serretti & Mandelli, 2008; Kato, 2007; Escamilla & Zavala, 2008; Barnett & Smoller, 2009)

Positional gene candidate studies show assocations of TRPM2, GPR50, Citron, CHMP1.5, GCHI, MLCI, GABRA5, BCR, CUX2, FLJ32356, and NAPG with BPD (Kato, 2007). The cytogenetic regions of 22q11 and 3q13 have also been implicated (Kato, 2007; Nimgaonkar, 1998).

Genome-wide association studies (GWAS) are continuing to identify new possible candidate genes for BPD, however larger and more robust studies are needed (Burmeister, McInnis, & Zollner, 2008). Some genes that have been implicated so far by GWAS include DGKH, CACNA1C, ANK3. (Barnett & Smoller, 2009),

2.1.6 **Psychiatric Genetic Counseling**

Mental disorders have a high prevalence in the US, and there has been an increase in public awareness and knowledge about genetics and heredity. For these reasons, it is logical to believe that genetic counseling for mental illnesses will likely be a regularity in the future (Austin & Honer, 2004; Finn & Smoller, 2006).

The American Society of Human Genetics defines genetic counseling as:

> "Genetic counseling is a communication process that deals with the human problems associated with the occurrence or risk of occurrence of a genetic disorder in a family. This process involves an attempt by one or more appropriately trained person to help the individual or family to (i) comprehend the medical facts including the diagnosis, probable course of the disorder, and the available management, (ii) appreciate the way heredity contributes to the disorder and the risk of the disorder in specified relatives, (iii) understand the alternatives for dealing with the risk of recurrence, (iv) choose a course of action which seems to them appropriate in view of their risk, family goals, and their ethical and religious standards and act in accordance with that decision, and (v) to make the best possible adjustments to the disorder in than affected family member and/or to the risk of recurrence of that disorder." (Fraser, 1974)

Genetic counseling for bipolar disorder is a relatively new area for genetic counselors. The causes of BPD are still unknown and genes have yet to be identitfied. There are currently no clincal tests for bipolar disorder and no clear-cut recurrence risks. This makes genetic counseling for BPD challenging (Austin & Honer, 2004; Peay, et al., 2008)

And while genetic counseling for bipolar disorder is relatively new, there appears to be a demand for it. Finn and Smoller (2006) concluded that patients, family memebers, and mental health clinicaians are interested in genetic counseling and testing for psychiatric disorders. Quaid, Aschen, Smiley, & Nurnberger (2008) report that up to 75% of affected indidivuals would have genetic counseling if it was available and offered to them.

Another study by Trippitelli et. al. (1998) survey 45 individuals and their spouces and found that 100% of affected individuals would definiately or probably take a genetic test for bipolar disortder if it was available.

Autin and Honer (2004), Peay et al. (2008), and Austin et al. (2008) suggest considering the following issues when conducting a genetic counseling session on mental illness:

1) Understand the motivations for why the patient is seeking genetic counseling. Are they looking for recurrence risks (qualitative or quanitative?) or do they want to understand the etiology of the disorder? Are they coming out of fear? Do they want reassurance they can have unaffected children?
2) Understand the patient's beliefs about why mental illness occurred in their family and how it is viewed in the family.
3) Understand the patient's view of the burden BPD
4) Understand the patients perception of recurrence risks for BPD
5) Normalize genetic variations to avoid with-in family stigmatizations.
6) Stress the positive side of increased knowledge and awareness of mental illness.
7) Emphasize environmental contributions, lifestyles choices, and hope for recovery to avoid a deterministic view.

It is the goal of the genetic counseling session to increase the patient's understanding of multifactorial conditions, the importance of correct diagnosis, the limitations of recurrence risk estimates, and the symptoms, course of illness, and treatment of BPD (Finn & Smoller, 2006).

The American Psychiatric association guidelines for the treament of bipolar disorder make the suggestion that genetic counseling for BPD can be helpful to affected individuals who are

considering having children (The American Psychiatric Association, 2003). Awarness of the genetic factors fo BPD can be help for diagnosis and patient care (Finn & Smoller, 2006).

2.1.7 **Health Belief Model**

The Health Belief Model (HBM) is a theory of health behavior that is used to understand and predict health behaviors by examining target populations' attitudes and opinions on certain health conditions. It was developed in the 1950's to try and understand the failure of ceratin health initatives (Janz & Backer, 1984). How an individual perceives a certain disease, like bipolar disorder, may influence how he or she interpretations new health information about that disease (Wang, et al., 2009).

The health belief model theorizes that several "classes" of factors influence health-related actions (Rosenstock, Strecher, & Becker, 1988). These factors include perceived severity, perceived susceptibility, perceived benefits, perceived barriers, and self efficacy (Rosenstock, Strecher, & Becker, 1988).

Perceived severity is how an individual views the consequences of having a specific health condition. Consequences can be both medical consequences and/or social consqeunces. It can also include how severe an individual believes a condition to be if left untreated.

Perceived susceptibility is how vulnerable an invidual feels to developing a specific health condition. Even if an individual believes a health condition is serious, if they do not believe that are susceptible to that condition, they are unlikely to take action.

Perceived benefit is how much an individual believes that a certain health behavior will reduce his or her susceptibility to a health condition or lessen the severity of a health condition.

If one does not feel like there is a benefit to a health behavior her or she will be unlikely to take action.

Perceived barriers include any negative consequences an individual might endure if a given health behavior is taken. These negative consequences can include physical, psychological, financial, and social consequences as well as discomfort experienced and time consumed (Janz & Backer, 1984). Janz and Backer (1984) compare perceived benefits and perceived barriers to a "cost-benefit analysis." Self-efficacy is the belief in one's self to be able to successfully perform a health behavior to produce the benefits from that behavior.

Anything that influences a person's perceptions, including demographics (age, sex, race, ethnicity), can affect his or her perception and therefore indirectly influence the likelihood of carrying out a health related behavior. (Janz & Backer, 1984)

3.0 MATERIALS AND METHODS

3.1 DESIGN AND RATIONALE

The purpose of this project was to learn more about the knowledge, attitudes, and opinions about bipolar disorder and about the potential benefits and barriers to genetic testing for BPD. BPD is a serious public health issue and research is being conducted to try to determine the causes of BPD. Because genetics play a role in this condition, it is likely that in the future genetic counseling for BPD and other psychiatric conditions will become routine. In order to best serve the BPD community and their family members, it is necessary to evaluate their thoughts about the condition and the implications of genetic testing.

3.2 PARTICIPANTS

Participants were recruited publically via physical and online (Craigslist) posting of a flyer approved by the University of Pittsburgh's Institutional Review Board (IRB) (Appendix F). Participants were from Pennsylvania, Ohio, Illinois, Maryland, and Washington DC. Informed consent was obtained via telephone script.

Inclusion criteria included: age of 18 years or above and a self-reported diagnosis of BPD age 18 years or above and have a first-degree relative with self-reported BPD. These populations

were targeted because they would be the most likely to seek genetic testing, once the susceptibility genes are confirmed and genetic testing becomes available. The demographic information obtained from the participants is reflected in the demographic section of the results.

3.3 EXPERIMENTAL DESIGN

This study was approved by the University of Pittsburgh Institutional Review Board (IRB) under IRB number 0610128 in 2010-2012 (Appendix B). Participants who volunteered for the study were consented over the telephone via an informed consent script. Demographic information, including sex, race, age, marital status, number of children, and education level were collected before the survey was administered. Participants completed the survey over the telephone. Once the survey was completed, participants partook in an educational session, also completed over the telephone, and then an identical survey was administered.

This study focuses on the knowledge questions and the Health Belief Model portion of the survey. Eight multiple choice knowledge questions and twelve Health Belief Model statements were provided to participants before and after the educational session. Participants ranked their level of agreement to each Health Belief Model statement on a 5-point Likert scale.

3.3.1 **Perceived Severity**

Perceived severity was measured on a 5-point Likert scale (1 = strongly disagree to 5 = strongly agree) by use of three statements. The statements were (1) Bipolar disorder is a serious

condition. (2) Having a child with bipolar disorder would be very scary. (3) My life would change if my child had bipolar disorder.

Perceived severity was measured in order to assess how individuals with BPD and first-degree relatives of individuals with BPD view the burden of the disease.

3.3.2 **Perceived Susceptibility**

Perceived susceptibility was measured on a 5-point Likert scale (1 = strongly disagree to 5 = strongly agree) by use of three statements. These statements were (1) My children are at risk for bipolar disorder. (2) Bipolar disorder could happen in my family. (3) My partner may be a carrier of genes for bipolar disorder.

Perceived susceptibility was measured to assess how individuals with BPD and first-degree relatives of individuals with BPD view the vulnerability of their family to the disease.

3.3.3 **Perceived Benefits**

Perceived benefits were measured on a 5-point Likert scale (1 = strongly disagree to 5 = strongly agree) by use of three statements. These statements were (1) It is useful to know if I have genes that make bipolar disorder more likely. (2) It is useful to know if my partner has genes that make bipolar disorder more likely. (3) Knowing the risk of having a child with bipolar disorder would change my plans about a future pregnancy.

Perceived benefits were measured to assess how individuals with BPD and first-degree relatives of individuals with BPD viewed the benefits of knowing the genetic predisposition to bipolar disorder.

3.3.4 **Perceived Barriers**

Perceived barriers were measured on a 5-point Likert scale (1 = strongly disagree to 5 = strongly agree) by use of three statements. These statements were (1) Genetic testing for bipolar disorder is painful and difficult. (2) My partner would be hard to convince to have genetic testing. (3) I would not want to pay for genetic testing.

Perceived barriers were measured to assess what individuals with BPD and first-degree relatives of individuals with BPD felt the potential obstacles were to genetic testing.

3.3.5 **Knowledge Questions**

Knowledge of bipolar disorder was assessed prior to and following an educational session on BPD using eight multiple choice questions addressing the etiology, epidemiology, symptoms, treatment, and genetic testing of BPD. Every correct answer was scored "1" while every incorrect answer was scored "0". The highest score participants could receive, pre- and post-educational session, was eight and the lowest score they could receive was zero.

3.4 DATA ANALYSIS

3.4.1 **Health Belief Model Statements**

The HBM data were analyzed to determine if there was a significant difference between how individuals affected with BPD and first-degree relatives of individuals affected with BPD

responded to each statement. The data was also group to analyze if there was a significant difference between perceived severity, perceived susceptibility, perceived benefits, and perceived barriers. These analyses were done prior to and following and educational session on BPD.

In addition, the effect of the educational session was analyzed by comparing the surveys of individuals with bipolar disorder prior to the educational session on BPD and following the educational session. This was also done with the surveys completed by the first-degree relatives of individuals with bipolar disorder.

Statements were ranked by level of agreement on a Likert scale of 1-5. One represented strongly disagree and five represented strongly agree. All significance calculations were done using the Mann-Whitney test. A confidence level of 95% was used. Any p-values less than .05 were considered statistically significant.

3.4.2 **Knowledge Questions**

Knowledge of bipolar disorder was assessed prior to and following and educational session on BPD using eight multiple choice questions addressing the etiology, epidemiology, symptoms, treatment, and genetic testing of BPD. Every correct answer was scored "1" while every incorrect answer was scored "0". The highest score participants could receive, pre- and post-educational session, was eight and the lowest score they could receive was zero. The averages of the answers pre- and post-educational session were compared with-in each group and then the two groups were combined to increase sample size.

All significance calculations were done using the Mann-Whitney test. A confidence level of 95% was used. Any p-values less than .05 were considered statistically significant.

4.0 RESULTS

4.1 DEMOGRAPHICS

Thirty-nine individuals have completed both pre-educational session and post-educational session surveys to date. Thirteen of these individuals reported themselves to be affected with bipolar disorder and twenty-six participants reported having at least one first-degree relative with bipolar disorder.

Of the individuals with bipolar disorder, 69% (N=9) were females and 31% (N=4) were male (figure 1).

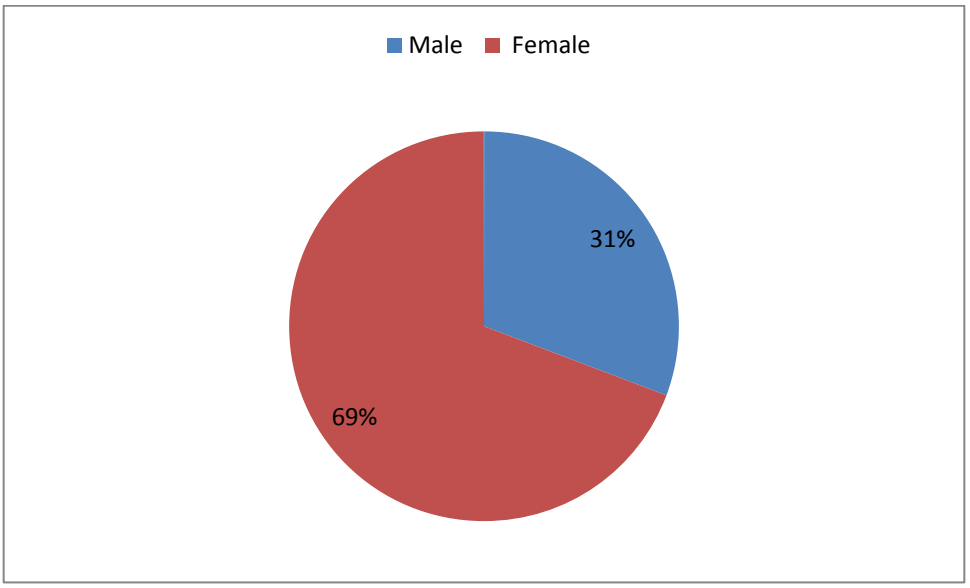

Figure 1: Sex distribution of participants with BPD
Males N=4, Females N=9

Education level among the participants with BPD varied among the group, with 8% (N=1) having less than a high school education, 15% (N=2) having a high school education or equivalent, 39% (N=5) having some college, 15% (N=2) completing college, and 23% (N=3) with a graduate degree or higher (figure 2).

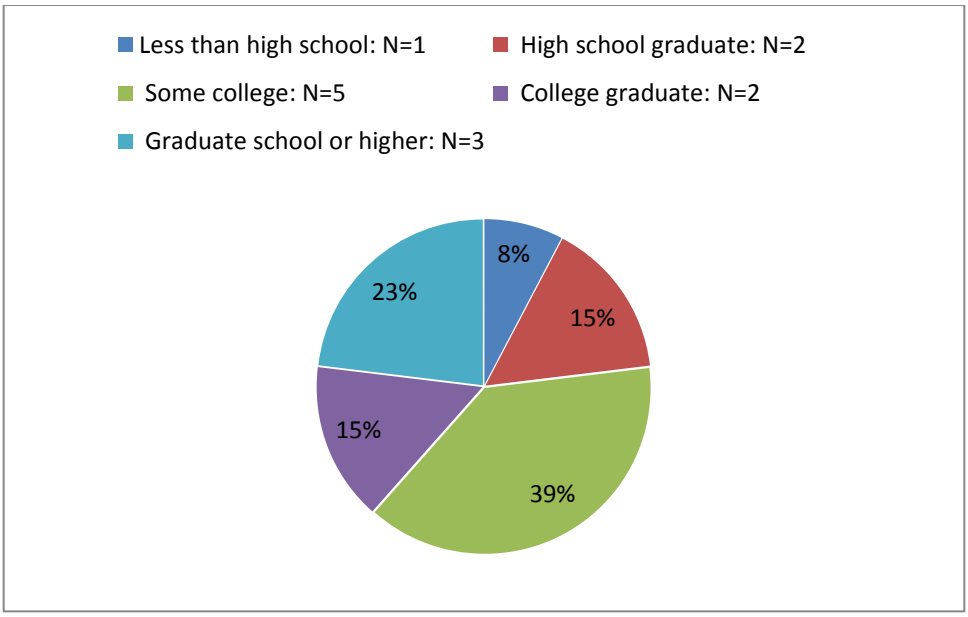

Figure 2: Education levels of particpants with BPD

Ages of participants with BPD ranged from 18 years-60 years. The full distribution of ages can been seen in figure 3.

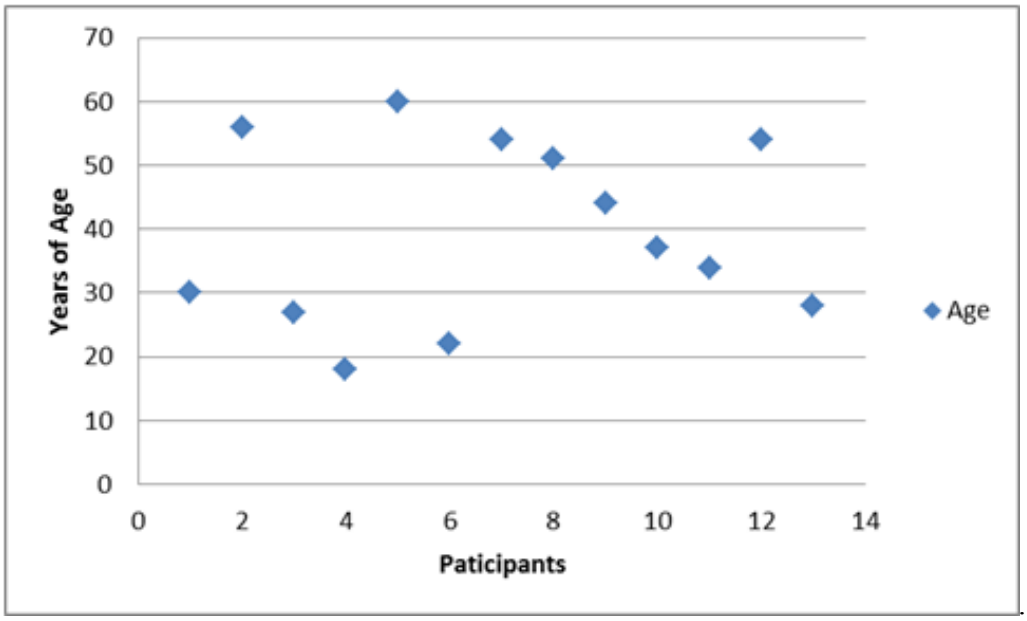

Figure 3: Age distribution of participants with BPD
N=13

Of the first-degree relatives of individuals with bipolar disorder, 85% (N=22) were female and 15% (N=4) were male (figure 4).

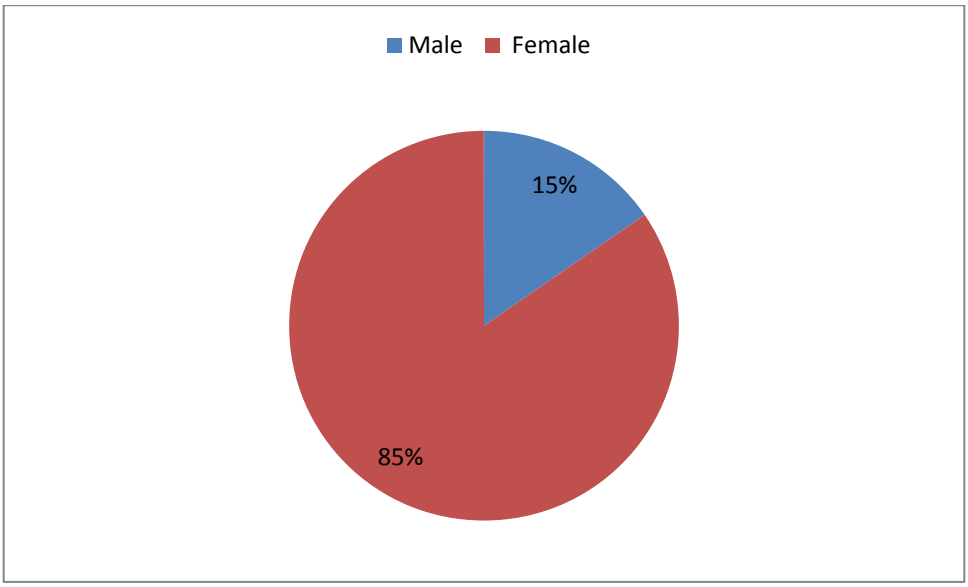

Figure 4: Sex distribution of first-degree relatives
Males N=4, Females N=22

Education level among the first-degree relatives varied among this group, with 4% (N=1) having less than a high school education, 11% (N=3) having a high school education or equivalent, and 42% (N=11) having some college, 31% (N=8) completing college, and 12% (N=3) with a graduate degree or higher (figure 5).

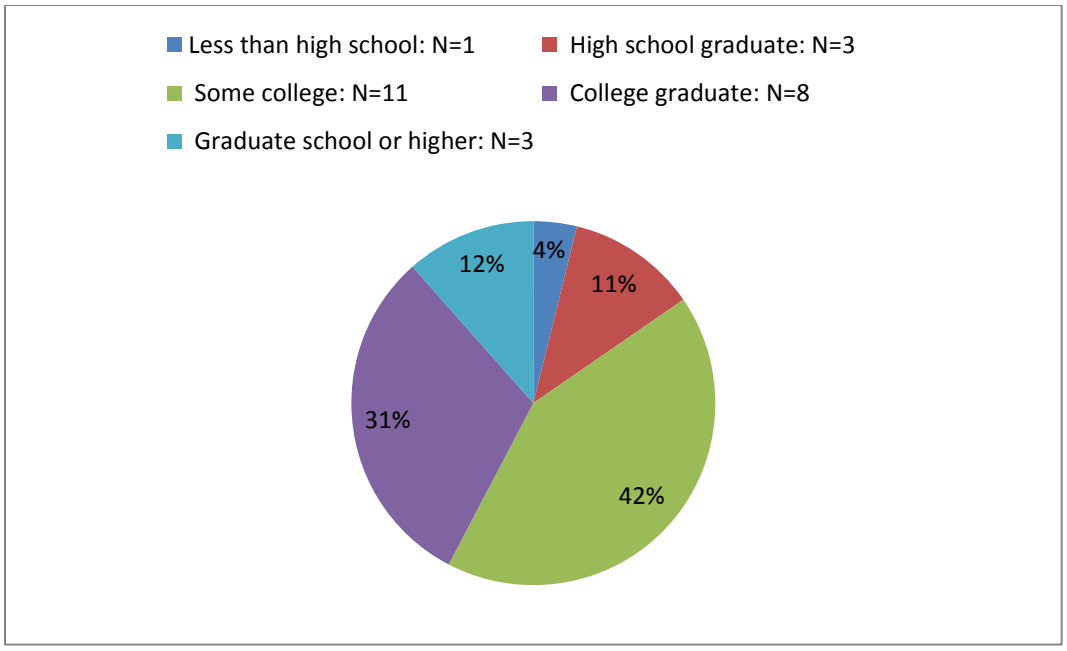

Figure 5: Education levels of first-degree relatives

In the first-degree relative group (N=26) ages ranged from 18 years -66 years. The full distribution of ages can be seen in figure 6.

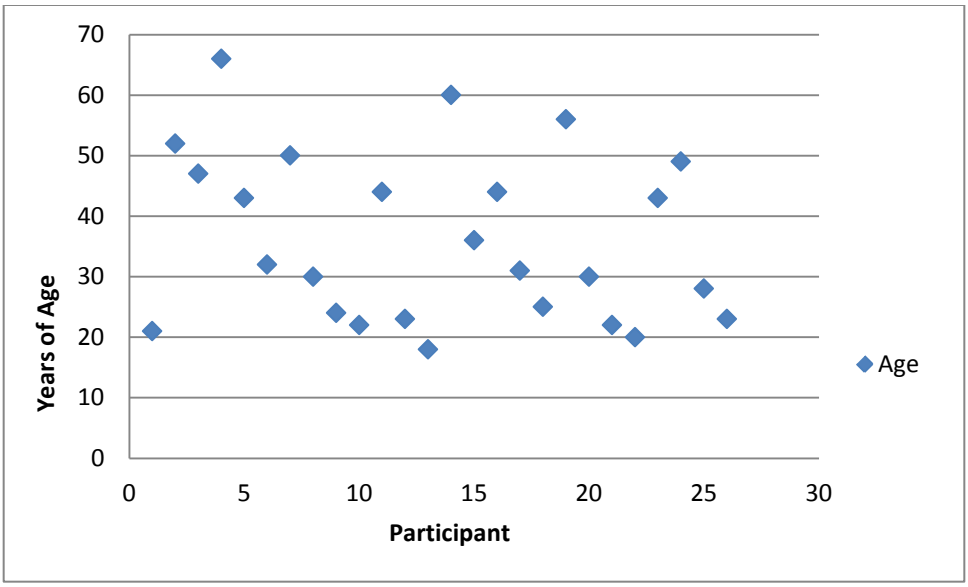

Figure 6: Age distirbution of first-degree relatives

Out of the 13 individuals affected with bipolar disorder, 9 individuals had relatives also diagnosed with bipolar disorder and 4 individuals had no first-degree relatives diagnosed with bipolar disorder. Of the 26 unaffected individuals who had first-degree relatives with BPD, 1 participant had only one affected parent, no participants had only child with the condition, 11 had only one affected sibling, and 14 had two or more first-degree relatives with the condition or had a first-degree relative and a second- or third-degree relative with the condition. Table 1 shows the distribution of the affected relatives for both the affected individuals and the unaffected individuals.

Table 1. Affected relatives of both primary affected and first-degree relatives

Participants	Parent	Sibling	Child	SDR	TDR
Individuals with BPD					
1	-	-	-	-	-
2	1	-	-	-	-
3	-	-	-	-	-
4	1	1	-	-	-
5	-	1	1	-	-
6	-	1	-	-	1
7	-	1	-	-	-
8	-	1	-	-	-
9	1	1		1	-
10	-	-	2	-	1
11	-	-	-	-	-
12	-	-	-	1	-
13	-	-	-	-	-
Relatives					
1	1	-	-	-	-
2	-	1	-	1	1
3	-	1	-	-	-
4	-	2	-	-	-
5	1	-	-	-	1
6	1	-	-	1	-
7	1	-	1	1	-
8	-	1	-	-	1
9	1	1	-	-	-
10	-	1	-	1	-
11	-	1	-	-	-
12	1	1	-	-	-
13	1	1	-	-	-
14	-	1	-	-	-
15	1	3	1	2	-
16	-	1	-	-	-
17	-	1	-	1	-
18	-	1	-	-	-
19	-	1	-	-	-
20	-	1	-	-	-
21	-	1	-	1	-
22	-	1	-	-	-
23	-	1		-	-
24	-	1	1	-	1
25	-	1	-	-	-
26	-	1	-	-	-

4.2 DATA

The raw data collected from the study can be seen in Appendix A (figures 17-40 and Table 20).

4.3 SPECIFIC AIM 1

Thirteen individuals with BPD and twenty-six first-degree relatives of individuals with BPD completed the pre-educational session survey. The average responses per statement for both the affected and first-degree relatives are shown in Table 2 and in figure 3.

Table 2: The pre-educational session, average responses and standard deviations per statements 1-12 of affected individuals and of first-degree relatives.

Statement	Mean Affected Scores (1-5)	Affected SD	Mean relative scores (1-5)	Relative SD
1	4.61	0.76	4.76	0.42
2	3.07	1.49	4.53	0.81
3	2.46	1.61	4.38	1.02
4	3.84	1.57	3.57	1.17
5	4.69	0.85	4.69	0.54
6	3.84	1.46	3.03	1.37
7	4.23	1.48	4.61	0.69
8	4.46	1.19	4.34	0.97
9	2.76	1.83	2.61	1.55
10	1.46	0.77	2.61	0.89
11	2.84	1.67	2.23	1.42
12	3.07	1.80	2.84	1.31

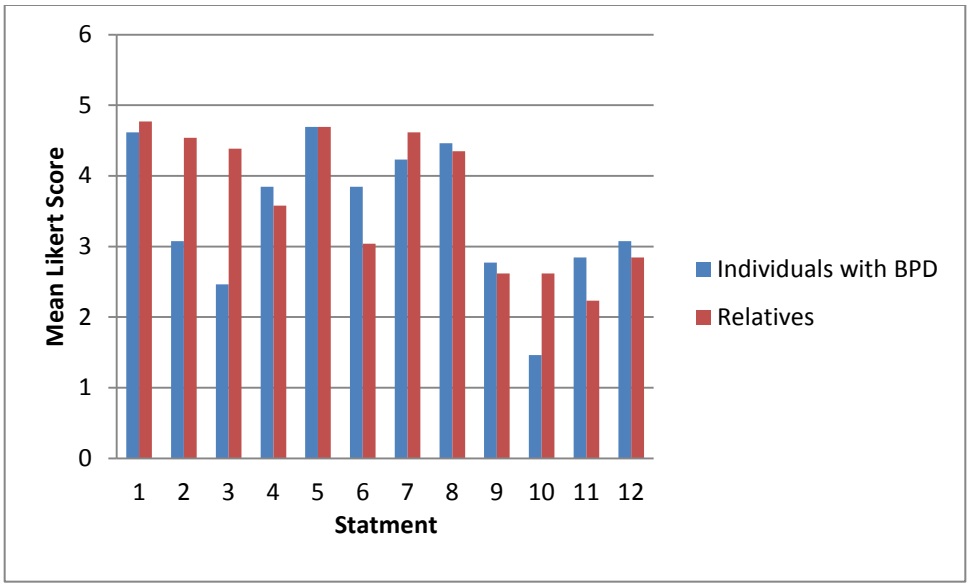

Figure 7: The pre-educational session, mean responses per statements 1-12 of affected individuals and of first-degree relatives

When each statement was compared based on average responses, statements 2 and 3 were statistically significant based on the Mann-Whitney test. Statement 2 corresponds to the statement: Having a child with bipolar disorder would be very scary (p-value of .002) Statement 3 corresponds to the statement: My life would change if my child had bipolar disorder (p-value of .0008). All other average responses between the affected inviduals and the first-degree relatives were not statistically significant based on the Mann-Whitney test. Table 3 shows the Z-score and p-values for the average responses to statements 1-12.

Table 3. Mann-Whitney Test of pre-educational session average responses per statement for affected individuals compared to first-degree relatives.

Statement	Mann-Whitney Z-score	Mann-Whitney P-value
1	0.32	0.74
2	2.97	0.002
3	3.32	0.0008
4	1.14	0.25
5	0.32	0.74
6	1.71	0.08
7	0.44	0.65
8	0.89	0.37
9	0.17	0.85
10	1.47	0.14
11	0.99	0.31
12	0.44	0.65

The pre-educational session averages of statements 1-3, 4-6, 7-9, and 10-12 were averaged to comprise the pre-educational session responses of the perceived severity, susceptibility, benefits, and barrier categories, respectively. The average score for severity pre-educational session was 3.38 ± 1.11 for affected individuals and 4.56 ± 0.19 for first-degree relatives. The average score for susceptibility pre-educational session was 4.13 ± 0.49 for affected individuals and 3.77 ± 0.71 for first-degree relatives. The average score for benefits pre-educational session was 3.82 ± 0.92 for affected individuals and 3.86 ± 1.08 for first-degree relatives. The average score for barriers pre-educational session was 2.46 ± 0.87 for affected individuals and 2.56 ± 0.31 for first-degree relatives. Table 4 shows the average responses per HBM category and the standard deviations of that category for both affected individuals and first-degree relatives.

Table 4. The pre-educational session, mean response per category of affected individuals and of first-degree relatives

	Severity	Susceptibility	Benefits	Barriers
Affected Mean	3.38	4.13	3.82	2.46
Affected SD	1.11	0.49	0.92	0.87
Relative Mean	4.56	3.77	3.86	2.56
Relative SD	0.19	0.71	1.08	0.31

Figure 8 represents the average responses per HBM category in graphical form for both the affected individuals and first-degree relatives, pre-educational session.

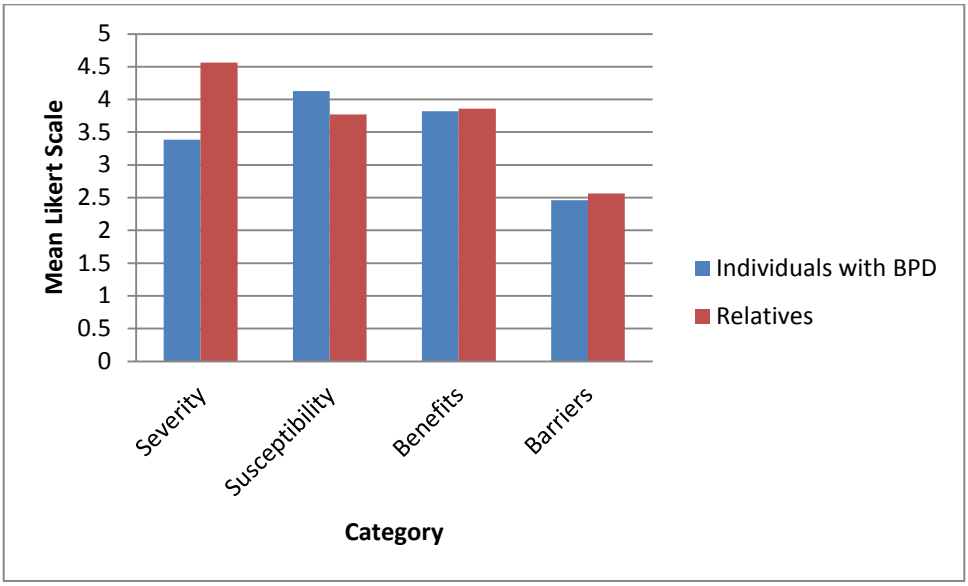

Figure 8: Average response per category for affected individuals and first-degree relatives: pre-educational session

These differences of the averages responses per HBM category of severity, susceptibility, benefits, and barriers were not significant based on the Mann-Whitney test (p-values of 0.27, 0.27, 0.82, and 0.66, respectively). Table 5 shows the Z-score of the Mann-Whitney test and the p-value for each of the HBM categories tested.

Table 5. Mann-Whitney test of average responses per category, pre-educational session

Category	Mann-Whitney Z-score	Mann-Whitney P-value
Severity	1.09	0.27
Susceptibility	1.09	0.27
Benefits	0.21	0.82
Barriers	0.43	0.66

4.4 SPECIFIC AIM 2

Thirteen individuals with BPD and twenty-six first-degree relatives of individuals with BPD completed the post-educational session survey. The average responses per statement for both the affected and first-degree relatives are shown in Table 6 and in figure 9.

Table 6: The post-educational session, average responses and standard deviations per statements 1-12 of affected individuals and of first-degree relatives

Statement	Affected scores	Affected SD	Relative scores	Relative SD
1	4.23	1.23	4.80	0.49
2	3.30	1.75	4.46	0.85
3	2.38	1.55	4.34	1.01
4	4.30	0.85	3.73	1.04
5	4.07	1.18	4.5	0.76
6	3.76	1.23	3.38	1.32
7	4.15	1.34	4.30	0.88
8	3.84	1.40	4.26	0.96
9	1.84	1.46	2.88	1.68
10	1.38	0.86	1.76	1.10
11	2.30	1.65	1.96	1.18
12	2.84	1.81	2.76	1.33

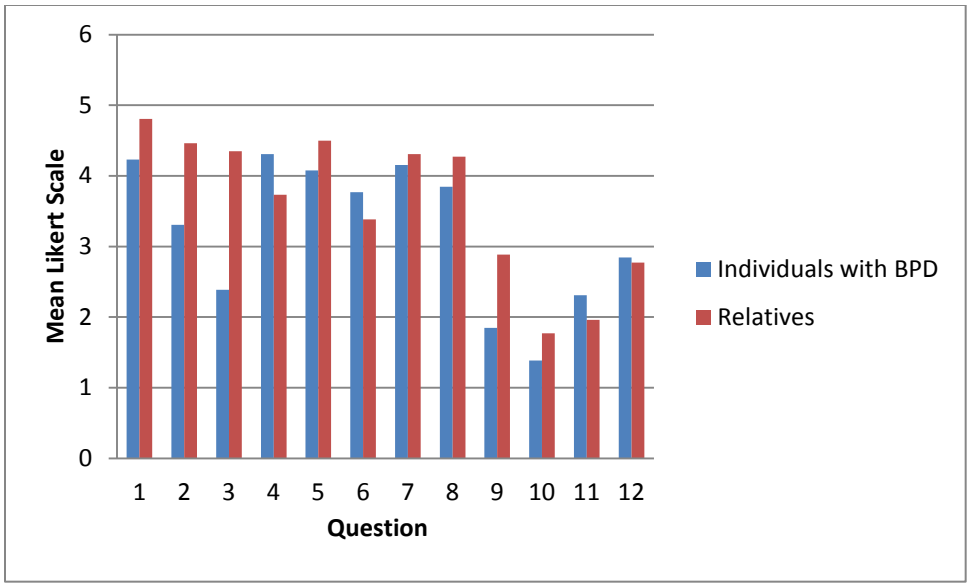

Figure 9: The post-educational session, mean responses per statements 1-12 of affected individuals and of first-degree relatives

When each statement was compared based on average responses, statements 2 and 3 were statistically significant based on the Mann-Whitney test. Statement 2 corresponds to the statement: Having a child with bipolar disorder would be very scary (p-value of .049) Statement 3 corresponds to the statement: My life would change if my child had bipolar disorder (p-value of .0007). All other average responses between affected individuals and relatives were not statistically significant based on the Mann-Whitney test. Table 7 shows the Z-score and p-values for the average responses to statements 1-12

Table 7. Mann-Whitney Test of post-educational session average responses per statement for affected individuals compared to first-degree relatives

Question	Mann-Whitney Z-score	Mann-Whitney P-value
1	1.40	0.16
2	1.96	0.049
3	3.38	0.0007
4	1.47	0.14
5	1.10	0.27
6	0.70	0.48
7	0.10	0.91
8	0.86	0.38
9	1.71	0.08
10	0.89	0.37
11	0.26	0.78
12	0	1

The post-educational session averages of statements 1-3, 4-6, 7-9, and 10-12 were averaged to comprise the post-educational session responses of the perceived severity, susceptibility, benefits, and barrier categories, respectively. The average score for severity post-educational session was 3.30 ± 0.92 for affected individuals and 4.53 ± 0.24 for first-degree relatives. The average score for susceptibility post-educational session was 4.05 ± 0.27 for affected individuals and 3.87 ± 0.57 for first-degree relatives. The average score for benefits post-educational session was 3.28 ± 1.25 for affected individuals and 3.82 ± 0.81 for first-degree relatives. The average score for barriers post-educational session was 2.17 ± 0.73 for affected individuals and 2.16 ± 0.53 for first-degree relatives. Table 8 shows the average responses per HBM category and the standard deviations of that category for both affected individuals and first-degree relatives.

Table 8. The post-educational session, mean response per category of affected individuals and of first-degree relatives

Column1	Severity	Susceptibility	Benefits	Barriers
Affected Mean	3.30	4.05	3.28	2.17
Affected SD	0.92	0.27	1.25	0.73
Relative Mean	4.53	3.87	3.82	2.16
Relative SD	0.24	0.57	0.81	0.53

Figure 10 represents the average responses per HBM category in graphical form for both the affected individuals and first-degree relatives, post-educational session.

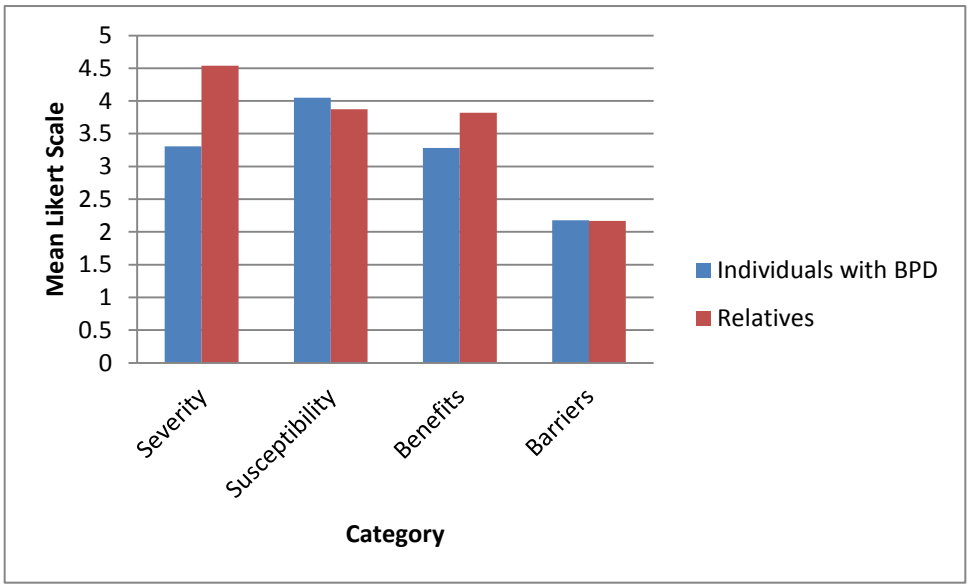

Figure 10: Average response per category for affected individuals and first-degree relatives: post-educational session

The differences of the averages responses in the HBM categories of susceptibility, benefits, and barriers were not significant based on the Mann-Whitney test (p-value of 0.51, 0.27, 0.82; respectively). Although it should be noted that in the category of susceptibility the p-value was very close to the p-value cut off of 0.05. The category of perceived severity was statistically

significant between the affected and first-degree relatives (p-value of 0.049). Table 9 shows the Z-score of the Mann-Whitney test and the p-value for each of the HBM categories tested.

Table 9. Mann-Whitney test of average responses per category, post-educational session

Category	Mann-Whitney Z-score	Mann-Whitney P-value
Severity	1.96	0.049
Susceptibility	0.65	0.51
Benefits	1.09	0.27
Barriers	0.21	0.82

4.5 SPECIFIC AIM 3

4.5.1 Affected Individuals

Thirteen individuals with BPD completed both the pre- and post-educational session surveys. The average perceived severity was 3.38 ± 1.1 pre-educational session and 3.30 ± 0.92 post-educational session. The average perceived susceptibility pre-educational session was 4.12 ± 0.48 and 4.05 ± 0.27 post-educational session. The average perceived benefit was 3.82 ± 0.91 pre-educational session and 3.28 ± 1.25 post-educational session. The average perceived barriers was 2.46 ± 0.87 pre-educational session and 2.17 ± 0.73 post-educational session. Table 10 shows the average responses and standard deviations per HBM category for the affected individuals both pre- and post-educational session.

Table 10. Affected individuals average response per category pre- and post-educational session

	Severity	Susceptibility	Benefits	Barriers
Pre-mean	3.38	4.12	3.82	2.46
SD	1.10	0.48	0.91	0.87
Post-mean	3.30	4.05	3.28	2.17
Standard Deviation	0.92	0.27	1.25	0.73

None of these differences between pre- and post-educational session responses per HBM category were significant based on the Mann-Whitney test (p-values of 0.82, 0.82, 0.51, and 0.27). Table 11 shows the Z-score and p-value of the Mann-Whitney test for affected individuals' average responses per HBM category pre- and post -educational session.

Table 11. Mann-Whitney test of the categories for affected individuals pre- vs. post-educational session

Category	Mann-Whitney Z-score	Mann-Whitney P-value
Severity	0.21	0.82
Susceptibility	0.21	0.82
Benefits	0.65	0.51
Barriers	1.09	0.27

Figure 11 shows the average responses per HBM category in graphic form for affected individuals, pre- and post- educational session.

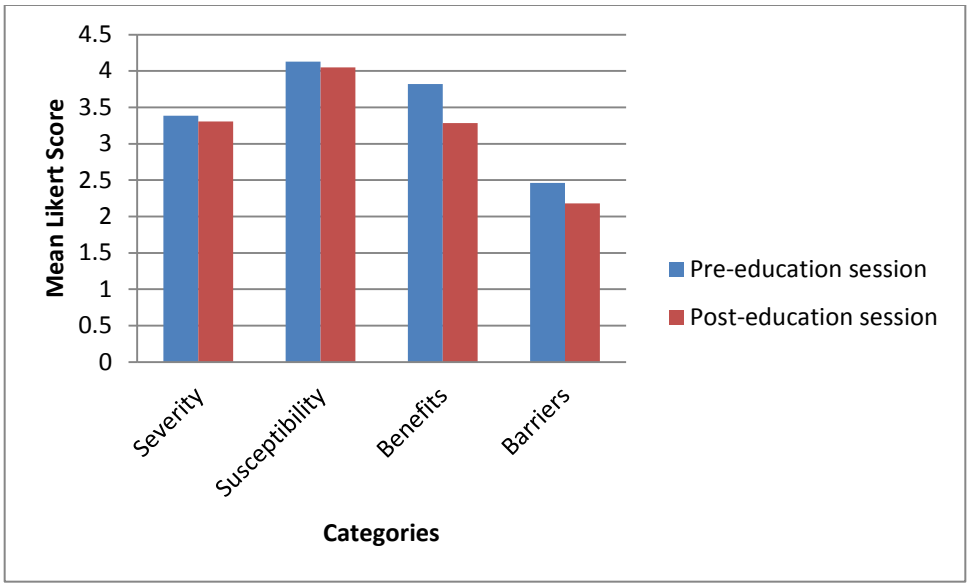

Figure 11. Average responses per category in individuals with BPD pre- and post-educational session.

When each response was compared per statement pre- and post-educational session there were no statistically significant differences based on the Mann-Whitney test. Table 12 shows the average responses and standard deviation per statement for affected individuals pre-and post-educational session.

Table 12. Average response per statement for affected individuals pre- and post-educational session

Question	Pre-education Session	SD	Post-education Session	SD
1	4.615384615	0.767947648	4.230769231	1.23516842
2	3.076923077	1.497861724	3.307692308	1.750457816
3	2.461538462	1.613246448	2.384615385	1.556623565
4	3.846153846	1.573009528	4.307692308	0.854850414
5	4.692307692	0.854850414	4.076923077	1.187542172
6	3.846153846	1.463224399	3.769230769	1.23516842
7	4.230769231	1.48064435	4.153846154	1.344504484
8	4.461538462	1.198289379	3.846153846	1.405118847
9	2.769230769	1.83275049	1.846153846	1.463224399
10	1.461538462	0.776250026	1.384615385	0.869718493
11	2.846153846	1.675616993	2.307692308	1.652503928
12	3.076923077	1.800996875	2.846153846	1.818706218

Figure 12 shows the average responses per statement of the affected individuals pre- and post-educational session in graphical form.

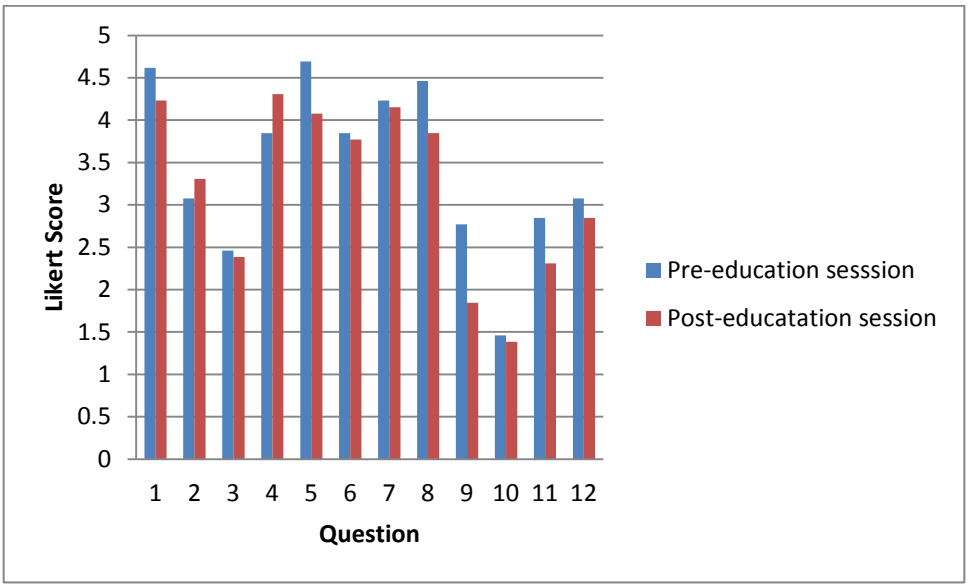

Figure 12. Average responses per statement for affected individuals pre- and post-educational session

Table 13 shows the Mann-Whitney Z-scores and p-values of the 12 responses per statement for affected individuals pre- and post-educational session.

Table 13. Mann-Whitney Test of affected individuals average responses pre- and post-educational session

Statement	Mann-Whitney Z-score	P-value
1	0.89	0.36
2	0.53	0.59
3	0.15	0.87
4	0.20	0.83
5	1.76	0.07
6	0.10	0.91
7	0.48	0.62
8	1.43	0.15
9	1.10	0.27
10	0.33	0.73
11	0.79	0.42
12	0.25	0.79

When the average responses per statement pre- and post-edcuational session were graphed on a scatter plot, the trend appears that following the educational session, the repsonses were more moderate for the statements, despite them not being significantly different (figure 13).

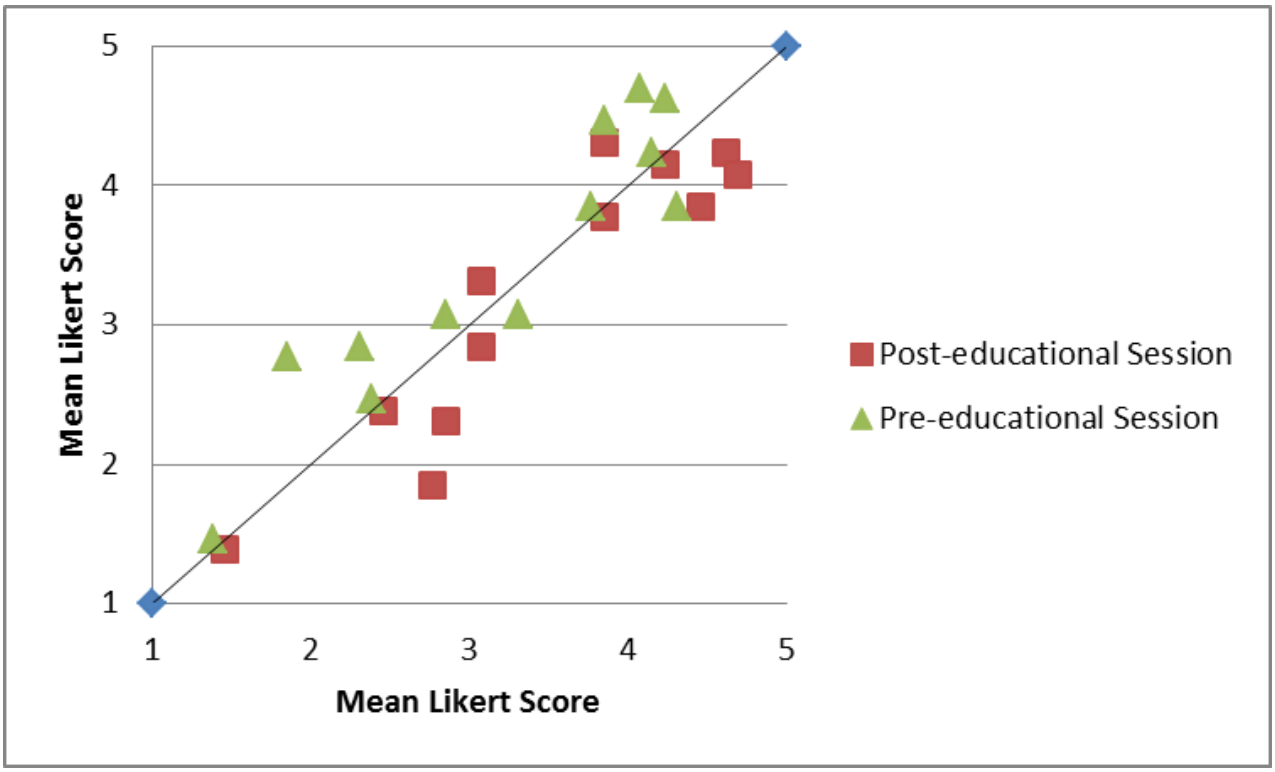

Figure 13: Scatter plot of average responses of affected individuals pre- and post-educational session

4.5.2 First-degree Relatives

Twenty-six first-degree relatives of individuals with BPD completed the pre- and post-educational session survey. The average perceived severity was 4.56 ± 0.19 pre-educational session and 4.53 ± 0.24 post-educational session. The average perceived susceptibility was 3.76 ± 0.71 pre-educational session and 3.87 ± 0.57 post-educational session. The average perceived benefits was 3.85 ± 1.08 pre-educational session and 3.82 ± 0.81 post-educational session. The average perceived barriers was 2.56 ± 0.31 pre-educational session and 2.16 ± 0.53 post-educational session. Table 14 shows the average responses and standard deviation per HBM category for the first-degree relatives, pre- and post-educational session.

Table 14. Relatives avearge response per HBM category pre- and post-educational session

	Severity	Susceptibility	Benefits	Barriers
Pre-mean	4.56	3.76	3.85	2.56
SD	0.19	0.71	1.08	0.31
Post-mean	4.53	3.87	3.82	2.16
SD	0.24	0.57	0.81	0.53

None of these differences in responses pre- and post-educational session for first-degree relatives were significant based on the Mann-Whitney test. Table 15 shows the Mann-Whitney test Z-scores and p-values per category for first-degree relatives average responses.

Table 15. Mann Whitney Test of relatives' avearges reponses pre- and post-educational session

Category	Mann-Whitney Z-score	Mann-Whitney P-value
Severity	0.21	0.82
Susceptibility	0.21	0.82
Benefits	0.65	0.51
Barriers	1.09	0.27

Figure 14 shows the average responses per HBM category in graphic form for first-degree relatives, pre- and post- educational session.

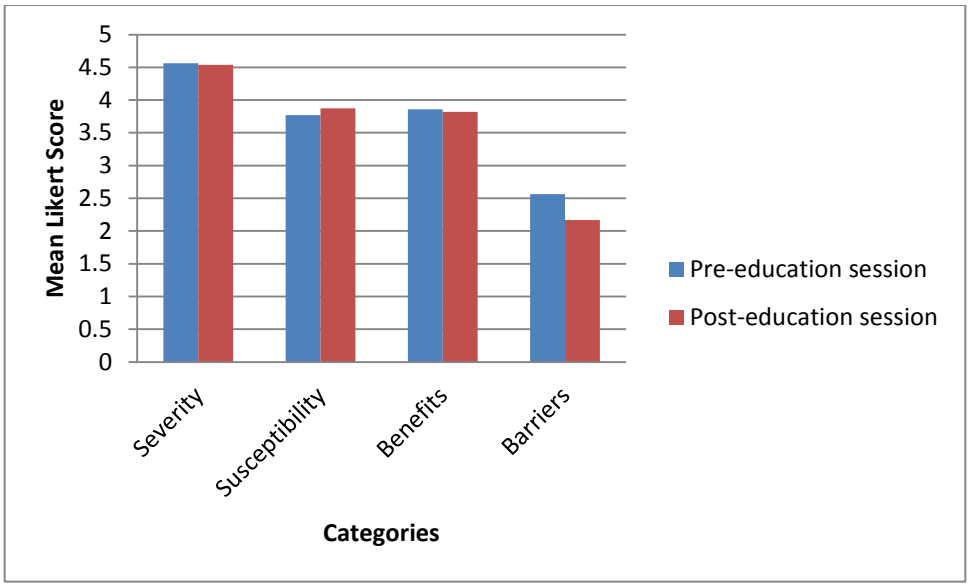

Figure 14: Average responses per HBM category in relatives pre- and post-educational session

When each response was compared per statement pre- and post-educational session there were no statistically significant differences based on the Mann-Whitney test. Table 16 shows the average responses and standard deviation per statement for first-degree relatives pre-and post-educational session.

Table 16. Average responses per statement of relatives pre- and post-educational session

Statement	Pre-educational session	SD	Post-educational session	SD
1	4.76	0.42	4.80	0.49
2	4.53	0.81	4.46	0.85
3	4.38	1.02	4.34	1.01
4	3.57	1.17	3.73	1.04
5	4.69	0.54	4.5	0.76
6	3.03	1.37	3.38	1.32
7	4.61	0.69	4.30	0.88
8	4.34	0.97	4.26	0.96
9	2.61	1.55	2.88	1.68
10	2.61	0.89	1.76	1.10
11	2.23	1.42	1.96	1.18
12	2.84	1.31	2.76	1.33

Figure 15 shows the average responses per statement of the first-degree relatives pre- and post-educational session in graphical form.

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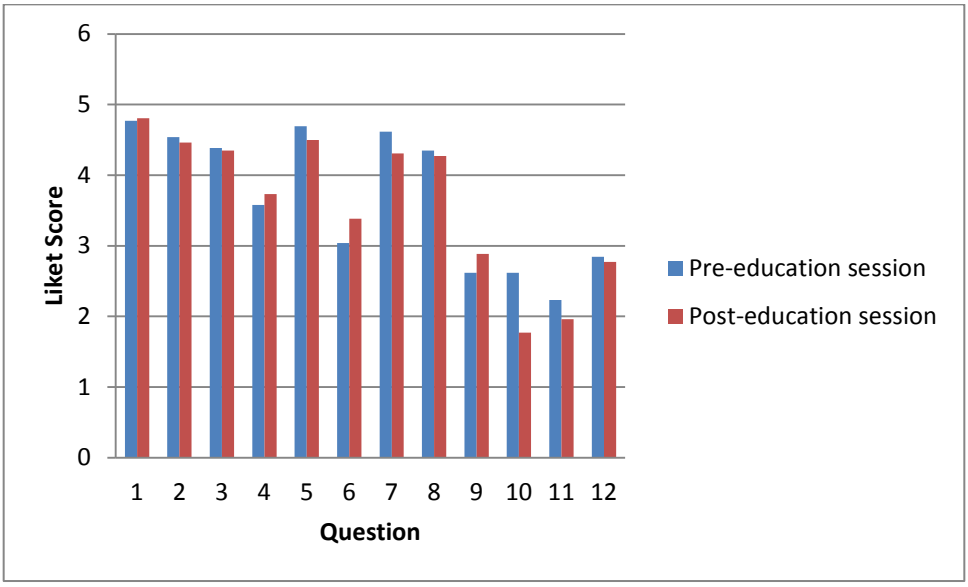


Figure 15:Average responses per statement for relatives pre-and post-educational session

Table 17 shows the Mann-Whitney Z-scores and p-values of the 12 responses per statement for first-degree relatives pre- and post-educational session.

Table 17. Mann-Whitney test of relatives average responses pre- and post-educational session

Statement	Mann-Whitney Z-score	P-value
1	0.21	0.82
2	0.43	0.66
3	0.27	0.78
4	0.39	0.69
5	0.90	0.36
6	1.00	0.31
7	1.23	0.21
8	0.14	0.88
9	0.43	0.66
10	0.83	0.40
11	0.46	0.64
12	0.23	0.81

When the responses were graphed on a scatter plot, it did not appear that there was a trend of reponses to be more moderate or severe pre- or post- educational session (figure 16).

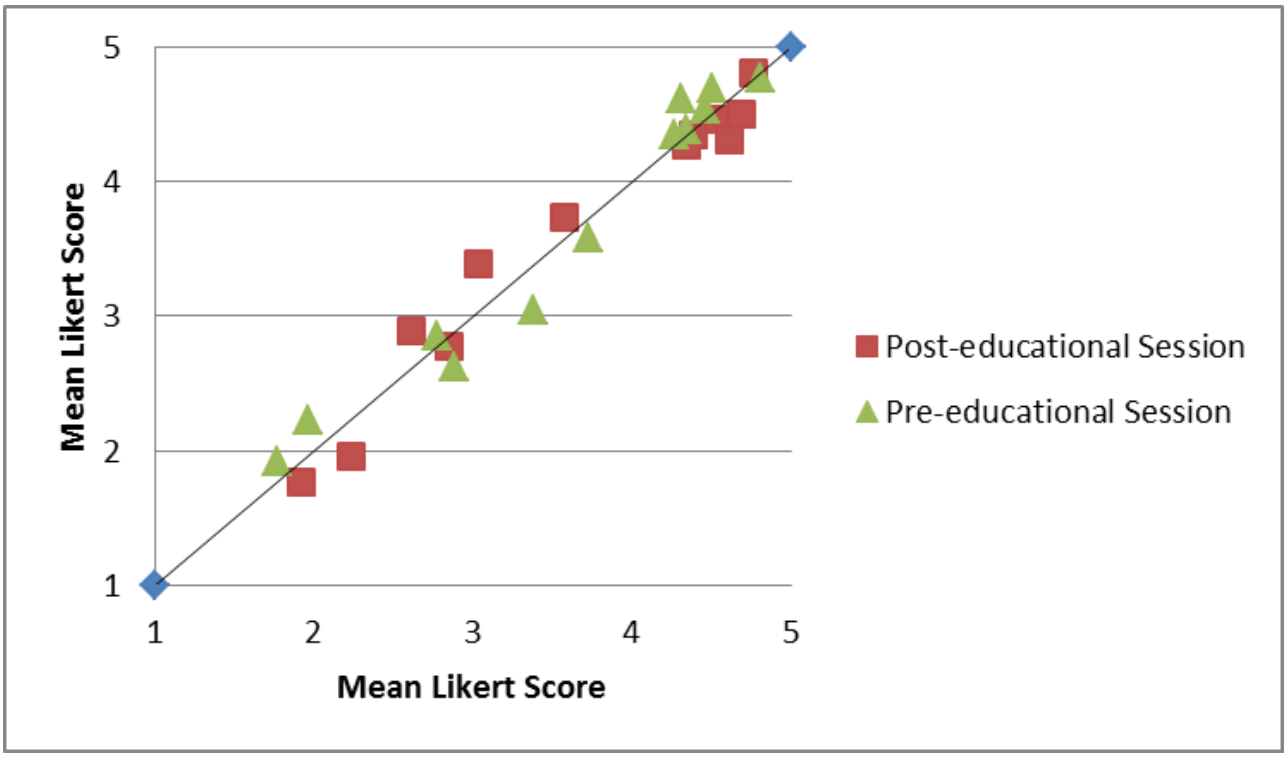


Figure 16. Scatter plot of responses of first-degree relatives pre and post-educational session

4.6 SPECIFIC AIM 4

The average knowledge of the affected individuals was 5.61 ± 1.55 and 6.3 ± 2.09 pre- and post-educational sessions, respectively. The first-degree relatives' knowledge average was 6.07 ± 1.32 pre-educational session and 6.61 ± 1.23 post-educational session. When affected individuals and first-degree relatives were considered as one group, the knowledge average was 5.92 5.92 ±1.40 pre-educational session, and 6.51 ± 1.55 post-educational session. Table 18 shows the average knowledge score and standard deviations pre- and post-educational session for affected individuals, relatives, and the entire study population,

Table 18. Knowledge scores pre- and post-educational session

	Pre-educational session	Post-educational session
Affected Average	5.61 ± 1.55	6.3 ± 2.09
Relative Average	6.07 ± 1.32	6.61 ± 1.23
Combined Average	5.92 ±1.40	6.51 ± 1.55

When the affected individuals' knowledge scores were tested for significance using the Mann-Whitney test, there was no significant difference between the pre- and post-educational scores (p-value = 0.20). This was also true for the first-degree relatives' knowledge scores (p-value = 0.12). When the participants were observed as a group however, the scores were significantly different (p-value 0.03). The post-educational knowledge scores were significantly higher than the pre-educational scores for the combined group. (Table 19)

Table 19. Mann-Whitney test of Knowledge score pre- and post-educational session

	Mann-Whitney Z-Score	p-value
Affected	1.256410256	0.208967265
Relatives	1.537299997	0.124219862
Combined	2.073626677	0.038113996

5.0 DISCUSSION

This study analyzed the knowledge, attitudes, and opinions of bipolar disorder and genetic testing for bipolar disorder. With continued research into the genetic causes of psychiatric conditions, like bipolar disorder, the demand for genetic counseling for such disorders will increase. In order to best serve the bipolar disorder community and their family members, it is crucial for genetic counselors to have insight on the scope of knowledge affected individuals and first-degree relatives have on BPD and how affected and at-risk individuals feel about the severity of bipolar disorder, personal and/or familial susceptibility to bipolar disorder, the believed advantages of genetic testing, and the believed barriers to genetic testing.

By comparing primary affected individuals with first-degree relatives of affected individuals, it can help genetic counselors understand if there is a difference in attitudes and opinions of bipolar disorder in those affected and those at an increased risk to develop the condition. This can help genetic counselors tailor counseling session for these individuals and understand the family dynamics in families with members affected with BPD. By assessing the knowledge of BPD, it can help genetic counselors understand patients understanding of BPD and if there are any educational areas that made need emphasis during a session.

5.1 SPECIFIC AIM 1

The first aim was to analyze the attitudes and opinions of bipolar disorder and genetic testing prior to an educational session on BPD in both individuals affected with BPD and first-degree relatives of individuals affected with BPD. The attitudes and opinions of both groups were compared to see if there was a significant difference between the two groups.

It was hypothesized that primary affected individuals and first-degree relatives would not have significantly different attitudes and opinions about BPD and genetic testing for BPD prior to the educational session on BPD. The data did not refute the hypothesis

The data did indicate that affected individuals felt differently about their level of concern over having a child with bipolar disorder and if they thought their life would change if they had a child with bipolar disorder. Affected individuals were moderately concerned, while first-degree relatives were highly concerned. Without explanation from participants, one cannot conclude as to why primary affected individuals had less concern over having a child with BPD. One can hypothesize that because primary affected individuals already deal with BPD and its effects that they would better understand how to help and take care of a child that developed the condition.

Possible implications of affected individuals having less concern over having a child with the condition is that as a whole, if genetic testing for bipolar condition is available in the future, primary affected individuals as a group may be less inclined to pursue prenatal or even presymptomatic testing on their children compared to at-risk first-degree relatives.

5.2 SPECIFIC AIM 2

The second aim was to analyze the attitudes and opinions of bipolar disorder and genetic testing following an educational session on BPD in both individuals affected with BPD and first-degree relatives of individuals affected with BPD. The attitudes and opinions of both groups were compared to see if there was a significant difference between the two groups.

It was hypothesized that primary affected individuals and first-degree relatives would not have significantly different attitudes and opinions about BPD and genetic testing for BPD following the educational session on BPD. The data did not refute the hypothesis in the combined categories of perceived susceptibility, perceived benefits, and perceived barriers. However, the data showed a significant difference in perceived severity following the educational session between affected individuals and first-degree relatives.

While the educational session on BPD did not significant change primary affected individuals opinions on the level of severity of BPD (See AIM 3 below), each group differed enough in their responses post-educational session that comparatively their responses is significant. If affected individuals view bipolar disorder as moderately severe, while first-degree relatives view it as highly severe, it may indicate that first-degree relatives would be more inclined to pursue genetic counseling and/or genetic testing for the condition. The motivation for this may be fear of developing the condition themselves or fear of having a child with the condition.

The data also indicated that affected individuals again had a lower level of concern over having a child with bipolar disorder compared to first-degree relatives.

As stated above, possible implications of affected individuals having less concern over having a child with the condition is that as a whole, if genetic testing for bipolar condition is

becomes available, primary affected individuals as a group may be less inclined to pursue prenatal or presymptomatic testing on their children compared to at-risk first-degree relatives.

5.3 SPECIFIC AIM 3

Specific aim 3 was to analyze the attitude and opinions of bipolar disorder and genetic testing prior to and following and educational session on BPD in both primary affected individuals and first-degree relatives.

It was hypothesized that an educational session on bipolar disorder, while possibly increasing the knowledge of the participants, would not significantly change how participants perceived bipolar disorder. The data did not refute the hypothesis. In addition, a significance difference was not found in the level of agreement for any one statement in either group prior to and following the educational session.

The educational session was created similar to a genetic counseling session. The session included factual information on BPD. Factual information is typically focused on improving accurate information about a particular topic. While factual information is one aspect of genetic counseling, the other aspect, psychosocial counseling, was not addressed in the information session (due to constraints of the study). Psychosocial counseling is aimed at targeting emotional and personal experiences.

While factual information may be sufficient in shaping an individual's attitudes and beliefs, often it is a combined effect of information and personal experience. Because bipolar disorder is such a significant health concern, it is hypothesized that participants' personal experience and prior knowledge played a larger role in shaping their attitudes and opinions and

that the educational session provided in the study did not provoke significant changes in participants' responses within each group. No comment can be made on if a larger, more interactive education session or genetic counseling session would impact responses.

5.4 SPECIFIC AIM 4

The last aim was to assess and compare affected individuals BPD knowledge pre-and post-educational session and to also asses and compare first-degree relatives BPD knowledge pre- and post-educational session.

It was hypothesized that there would be no difference in the knowledge scores for either group pre-or post-educational session. The data did not refute the hypothesis. Further evaluation showed that as a group, the average of all participants BPD knowledge scores did have a significant increase from the pre-educational session score to the pot-educational session scores. The reason for this is most likely due to the lower number of participants when each group was considered alone.

The data show that overall, an educational session on factual BPD information may increase the BPD knowledge of individuals with BPD and first-degree relatives of individuals with BPD as a group. Further studies with a larger sample size would be needed to better assess the effect of the educational session intervention on BPD knowledge.

5.5 LIMITATIONS

Limitations of this study include self-selection bias, as participants all volunteered for the study. In addition, all participants were self-reported to have BPD or to have a relative with BPD. These diagnoses were not confirmed by the investigator.

Due to the method of advertising, only larger cities were targeted and so the rural population was not captured in this study. Much of the advertising was done over the internet, and so those without a computer or without internet access were not captured in the study.

This survey was done completely over the phone, so it did not capture those that do not have telephone access. In addition, because the survey was done completely over the telephone, it complicated the administration of the surveys and educational session. The investigator had no way of knowing the level of attentiveness of the participant to the questions being asked or to the educational session. The effect of the education session would likely be improved by face-to-face administration, or by teleconference administration (video conferencing/Skyping).

Another limitation is that there were no groups in this study that did not receive the intervention (educational session). Because of this, it was not observed how individual's responses and answers may have changed just by being asked the questions or by being read the statements again. Ideally, with more participants, this would be implemented as an internal control for the study and should be considered in future studies.

Lastly, the study was complicated by the fact that some individuals affected with BPD were also first- degree relatives of individuals affected BPD. This complicates the study because the groups are not independent of each other.

5.6 FUTURE STUDIES

Future studies would include looking and assessing the qualitative data collected from the study by analyzing the open-ended questions. In addition, a larger scale study would be useful help increase the power of this study and to determine significance with more robustness. This is true for both the HBM portion of the study and of the knowledge of BPD section of the study.

6.0 CONCLUSION

Bipolar disorder is a serious psychiatric condition. Studies indicate that there are genetic factors that can cause a predisposition to developing BPD; however these factors are currently not well understood. This study was aimed at understanding the perceived severity of BPD, perceived susceptibility to BPD, perceived benefits of genetic testing, and perceived barriers of genetic testing of primary affected individuals and first-degree relatives of affected individuals.

The results of Aim 1 did not refute the hypothesis that there would be no significant difference in the pre-educational session responses of primary affected individuals and first-degree relatives. The results of Aim 2 did not support the hypothesis and showed that in the category of perceived severity of BPD, the primary affected individuals differed significantly from the first-degree relatives, post-educational session. The affected individuals were more moderate in their responses of BPD severity post-educational session. There was not a significant difference in the other HBM categories of perceived susceptibility, benefits, and barriers following the educational session.

Both prior to and following an educational session on BPD, affected individuals significantly differed in their responses related to having concern about having a children with bipolar disorder. The affected individuals' responses more moderate..

The results from Aim 3 did not refute the hypothesis and found that the affected individuals' responses did not differ significantly between pre- and post-educational session and

that the responses of first degree relatives did not differ significantly between pre- and post-educational session.

The results form aim 4 showed that there was no significant difference in pre- and post-educational session knowledge scores when each group was consider separately. These results do not refute they hypothesis. However, when the participants were considered as one population, there was a significant increase in BPD knowledge score from pre-educational session to post-educational session. This is most likely due to the low number of participants in each group separately and having a higher number of total participants when considered as one population

By understand the knowledge, attitudes, and opinions of affected individuals and first-degree relatives of individuals affected with BPD, it can help genetic counselors create and tailor more effective genetic counseling sessions for these patients. By comparing these two groups, it will also help genetic counselors understand the family dynamics of families affected with BPD, which can help genetic counselor be prepared in dealing with these families. Optimizing genetic counseling sessions will theoretically optimize the benefit BPD patients will receive form these sessions.

If genetic testing for BPD becomes available, it is possible that that prenatal and/or presymptomatic testing in children will also be available. Theoretically, if primary affected individuals are less concerned over having a child with BPD, they may be less likely to pursue prenatal or presymptatic genetic testing in child than first-degree relatives of individuals with bipolar disorder.

APPENDIX A

DATA

A.1 PRE-EDUCATIONAL SESSION RAW DATA

Each figure represents the statements 1-12 pre-educational session and statements 1-12 post-educational session. For each statement the total number of responses per Likert choice (1-5) is graphed for both the primary affected individuals and the fist-degree relatives.

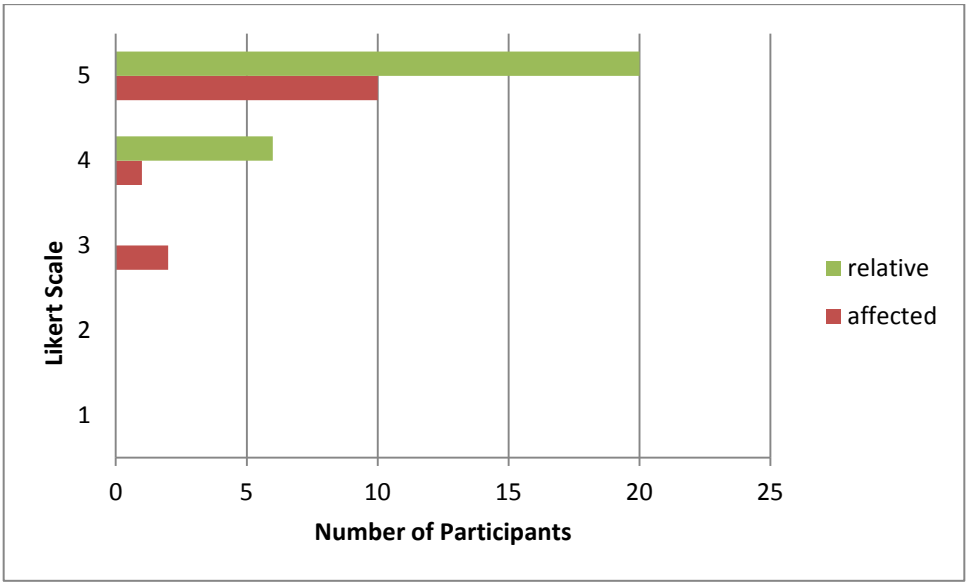


Figure 17: Agreement to "Bipolar disorder is a serious disease:" pre-educational session

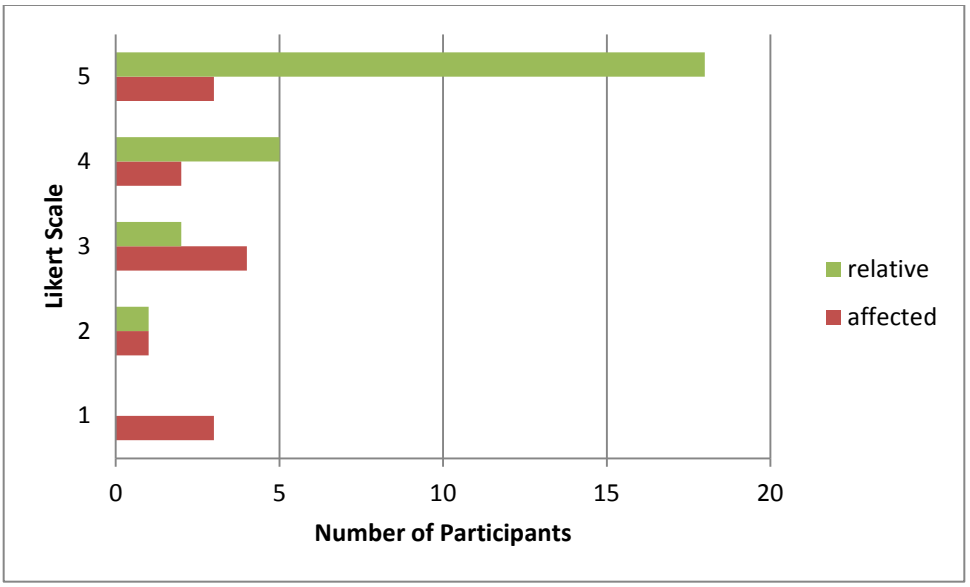


Figure 18: Agreement to "Having a child with bioplar disorder would be very scary:" pre-educational session

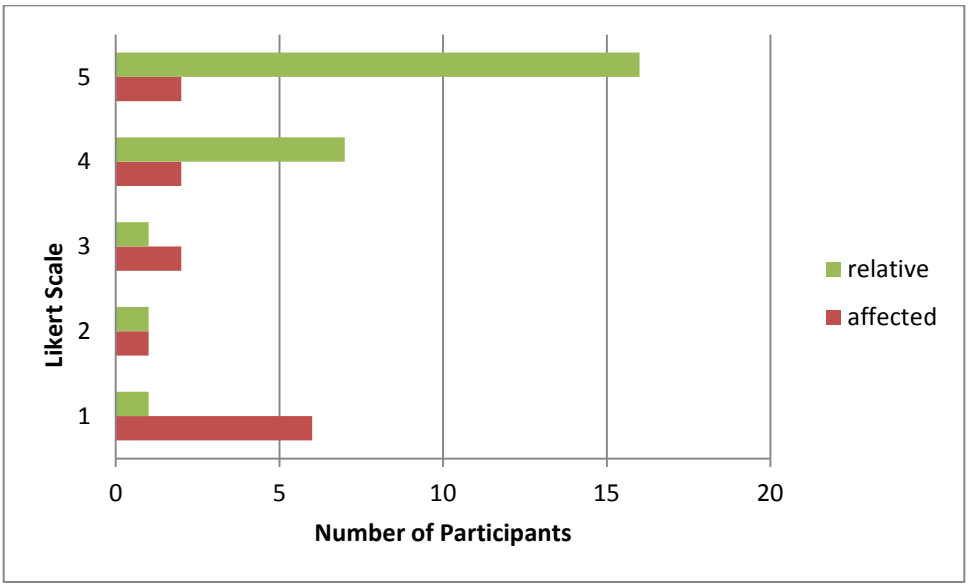


Figure 19: Agreement to "My life would change if my child had bioplar disorder:" pre-educational session

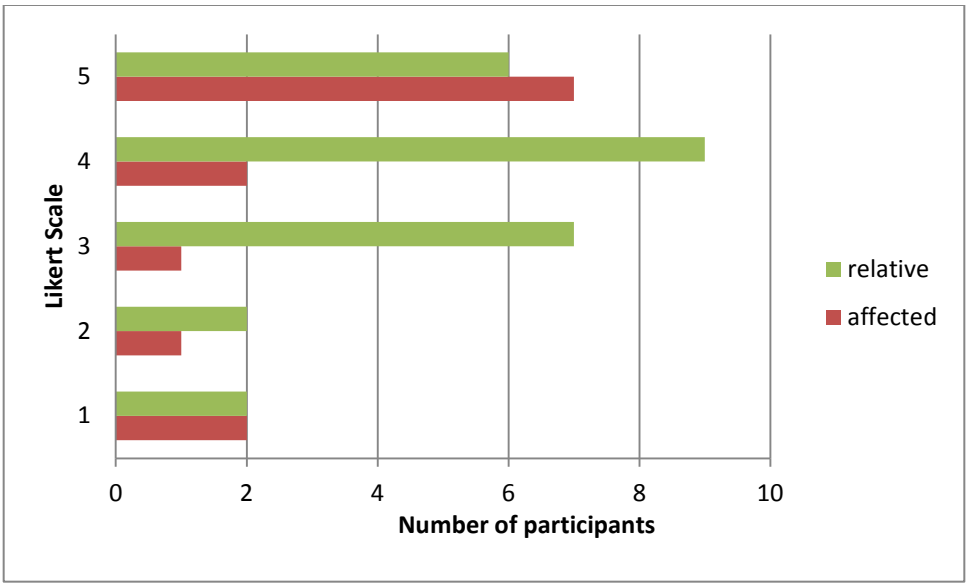


Figure 20: Agreement to "My children are at risk for bipolar disorder:" pre-educational session

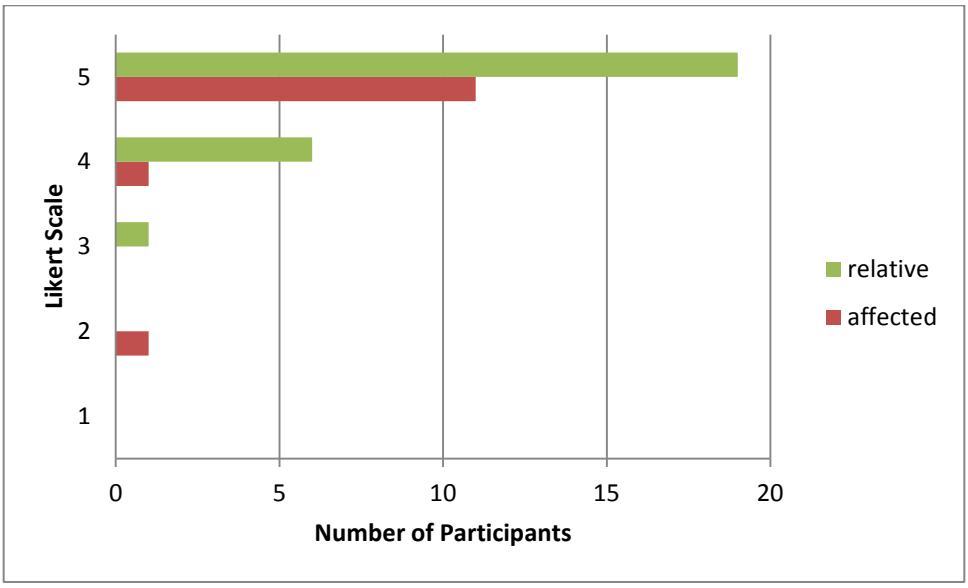


Figure 21: Agreement to "Bipolar disorder could happen in my family:" pre-educational session

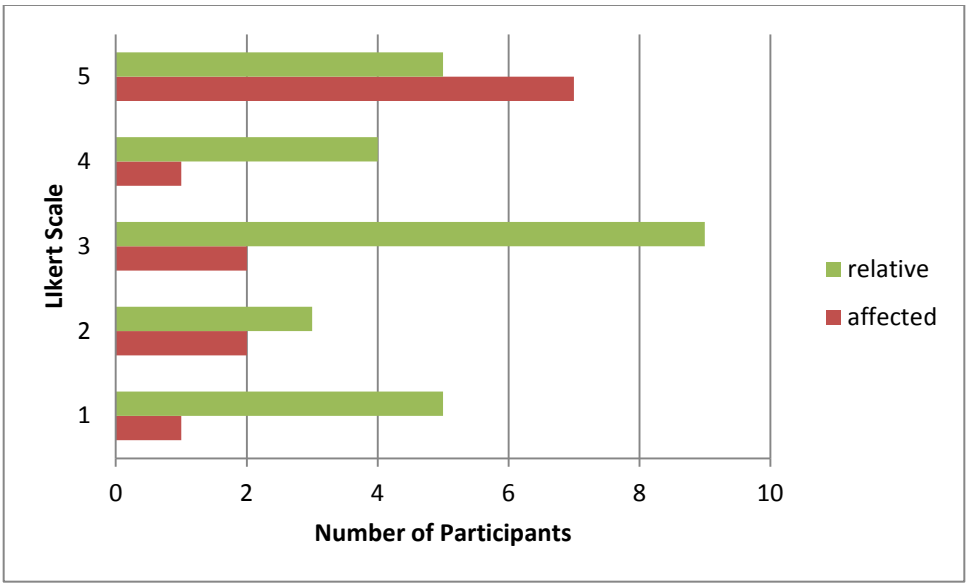


Figure 22: Agreement to "My partner may be a carrier of genes for bipolar disorder:" pre-educational session

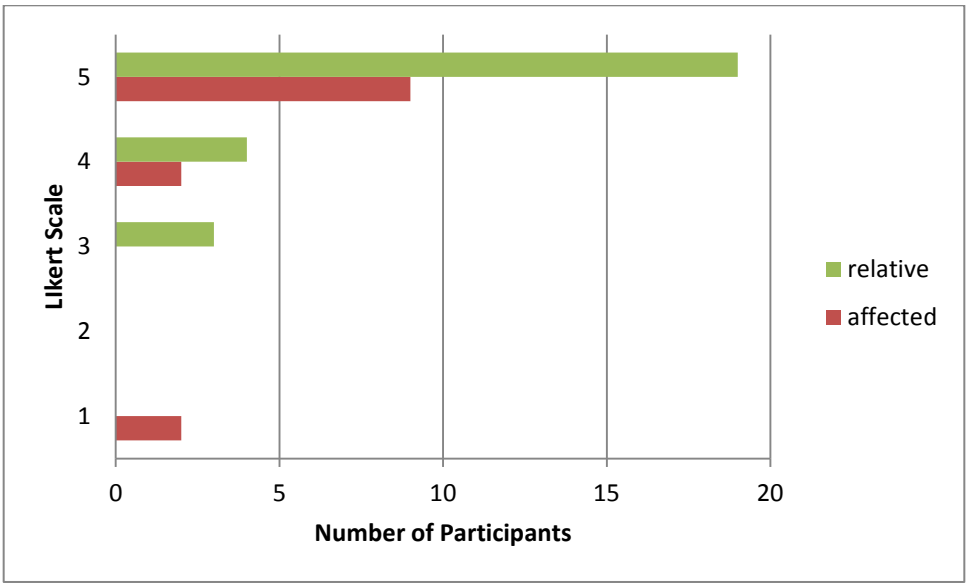


Figure 23: Agreement to "It is useful to know if I have genes that make bipolar disorder more likely:" pre-educational session

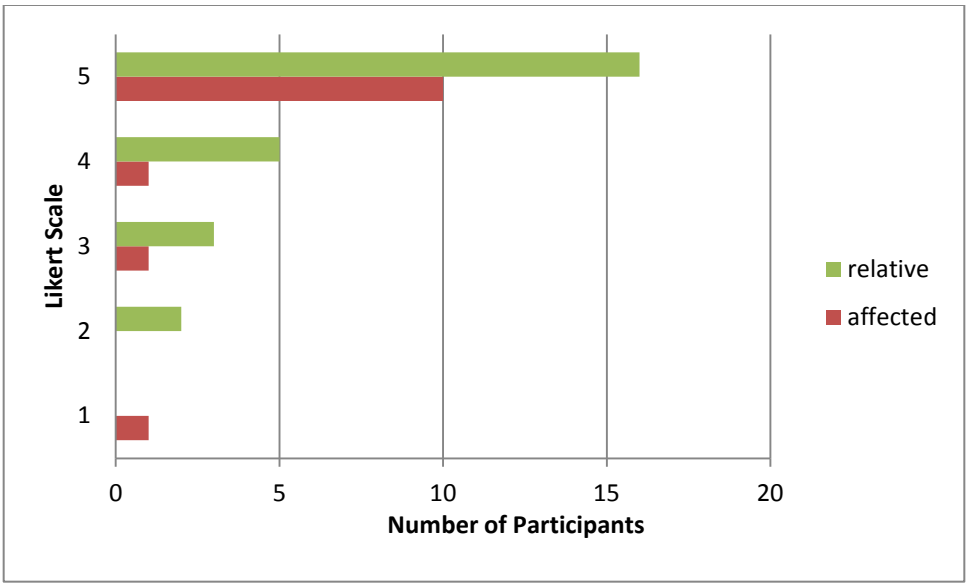


Figure 24: Agreement to "It is useful to know if my partner has genes that make bipolar disorder more likely:" pre-educational session

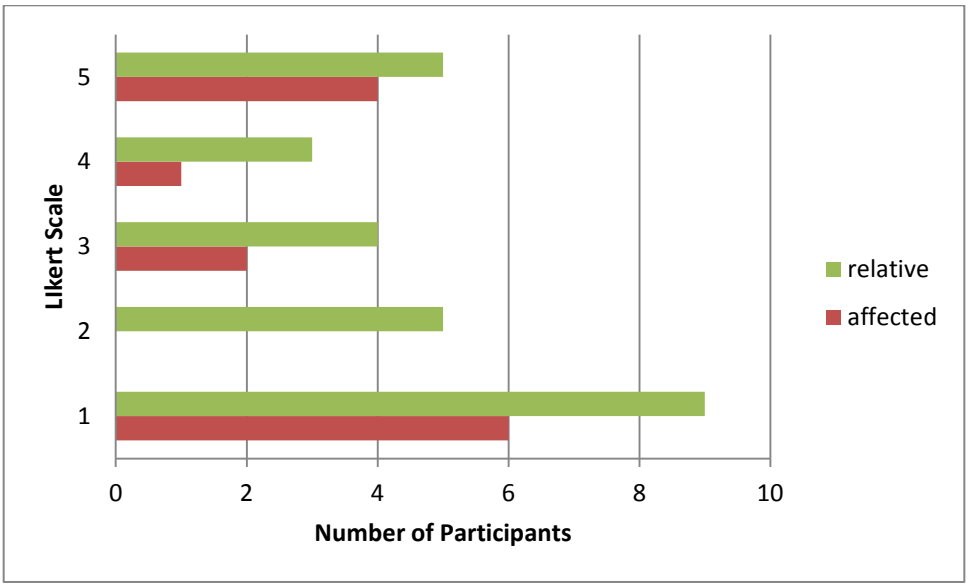


Figure 25: Agreement to "Knowing the risk of having a child with bipolar disorder would change my plans about a future pregnancy:" pre-educational session

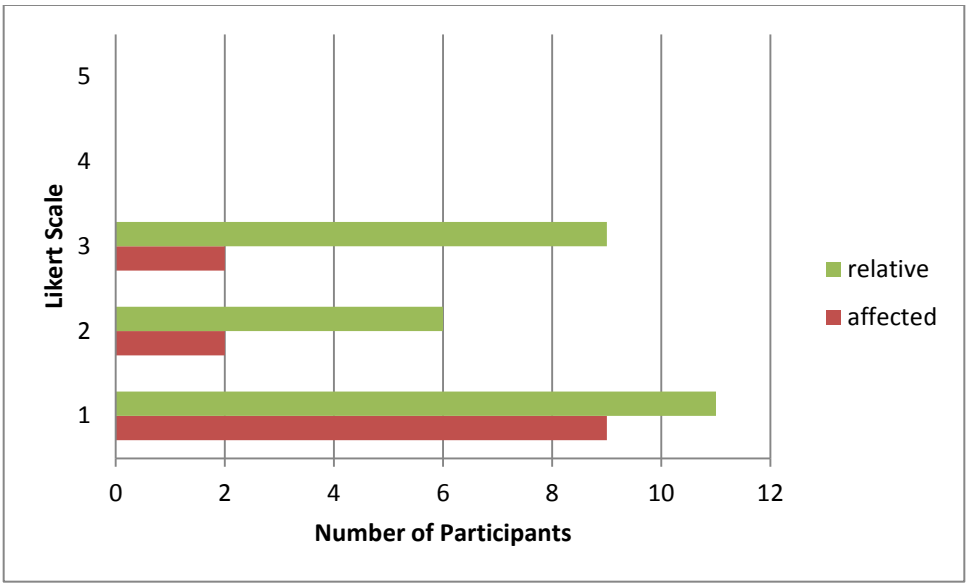


Figure 26: Agreement to "Genetic testing is painful and difficult:" pre-educational session

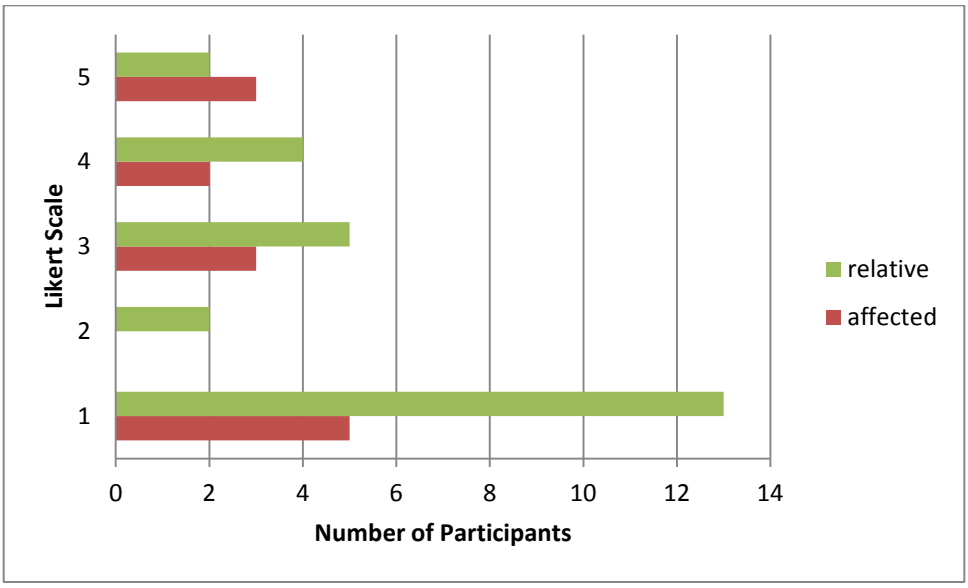


Figure 27: Agreement to "My partner would be hard to convince to have genetic testing:" pre-educational session

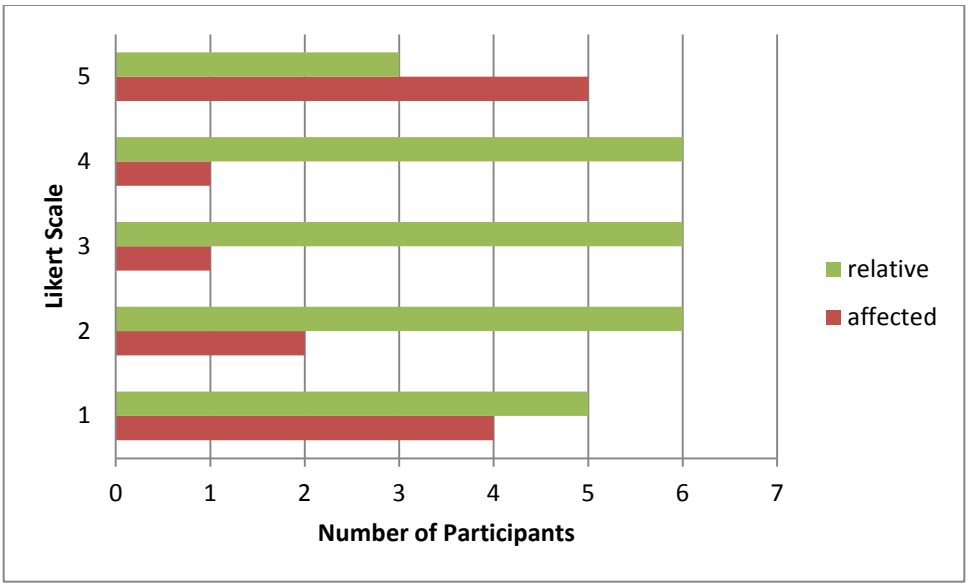


Figure 28: Agreement to "I would not want to pay for genetic testing:" pre-educational session

A.2 POST-EDUCATIONAL SESSION RAW DATA

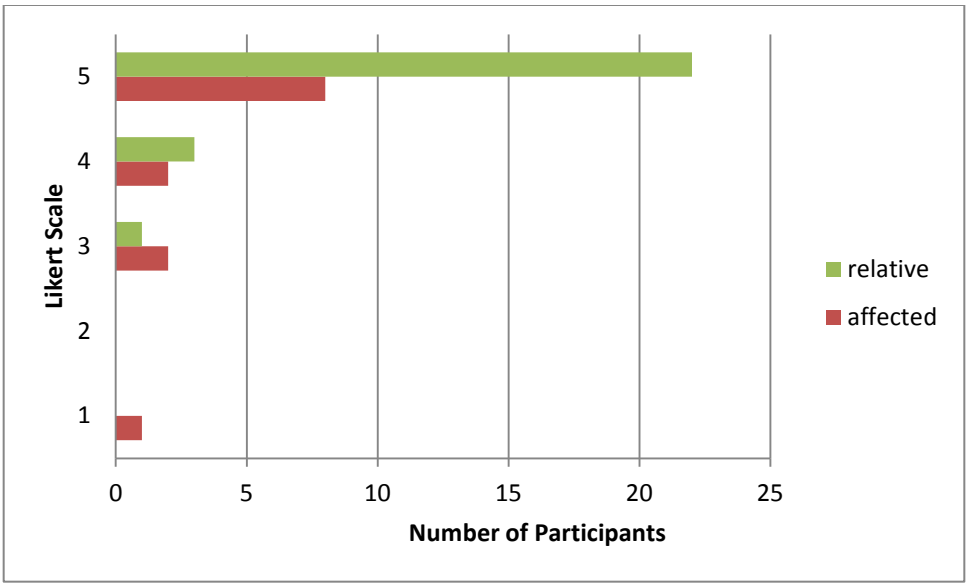


Figure 29: Agreement to "Bipolar disorder is a serious disease:" post-educational session

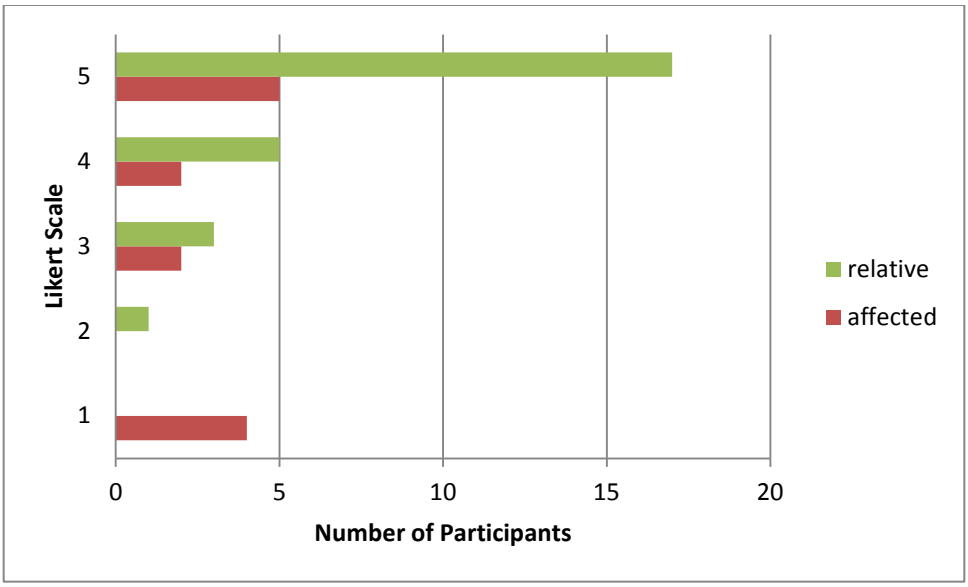


Figure 30: Agreement to "Having a child with bipolar disorder would be very scary:" post-educational session

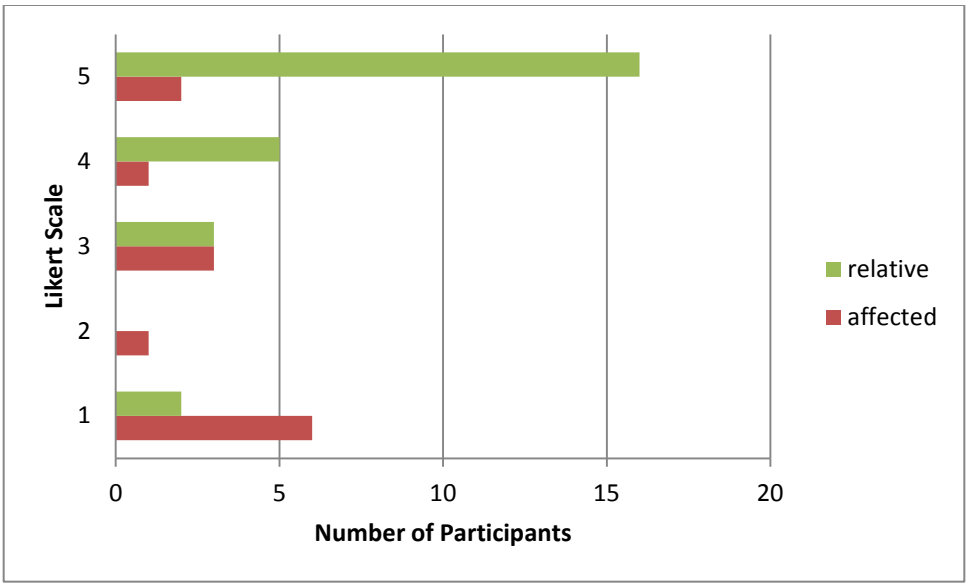


Figure 31: Agreement to "My life would change if my child had bipolar disorder" post-educational session

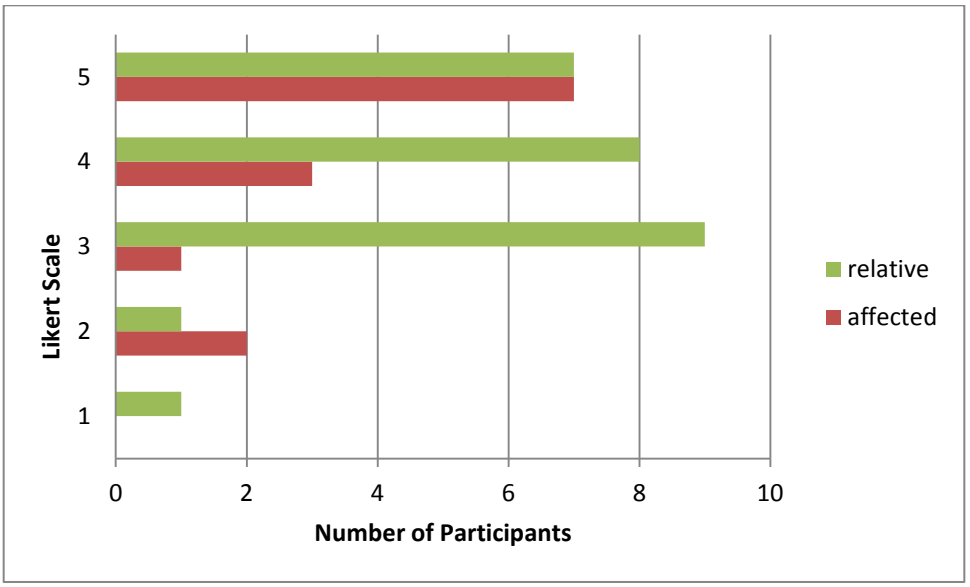


Figure 32: Agreement to "My children are at risk for bipolar disorder:" post-educational session

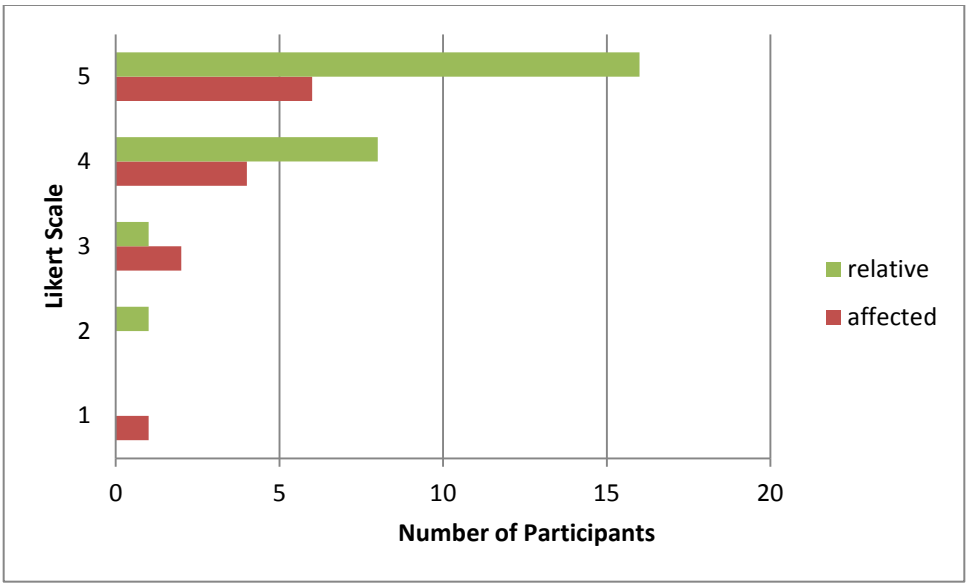


Figure 33: Agreement to "Bipolar disorder could happen in my family:" post-educational session

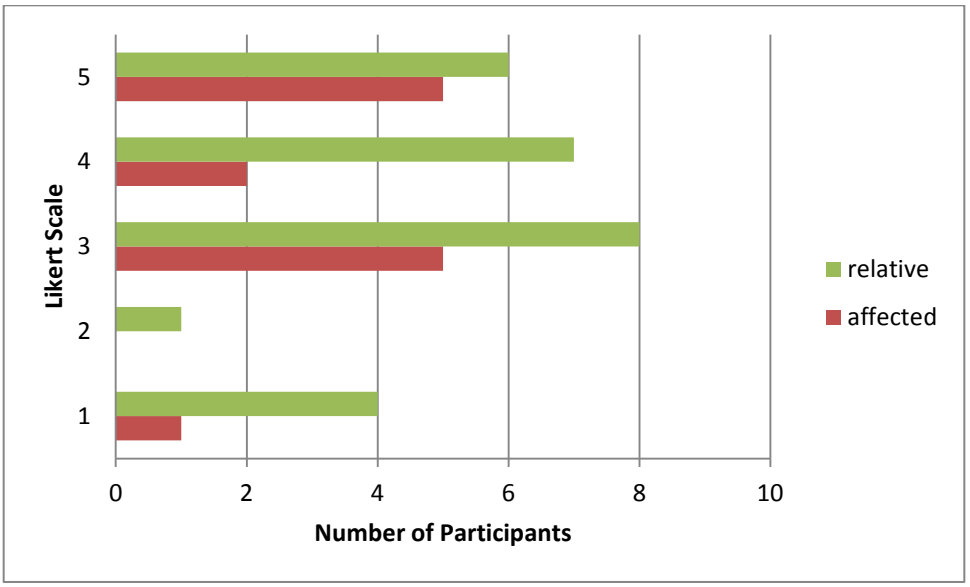


Figure 34: Agreement to "My partner may be a carrier of genes for bipolar disorder:" post-educational session

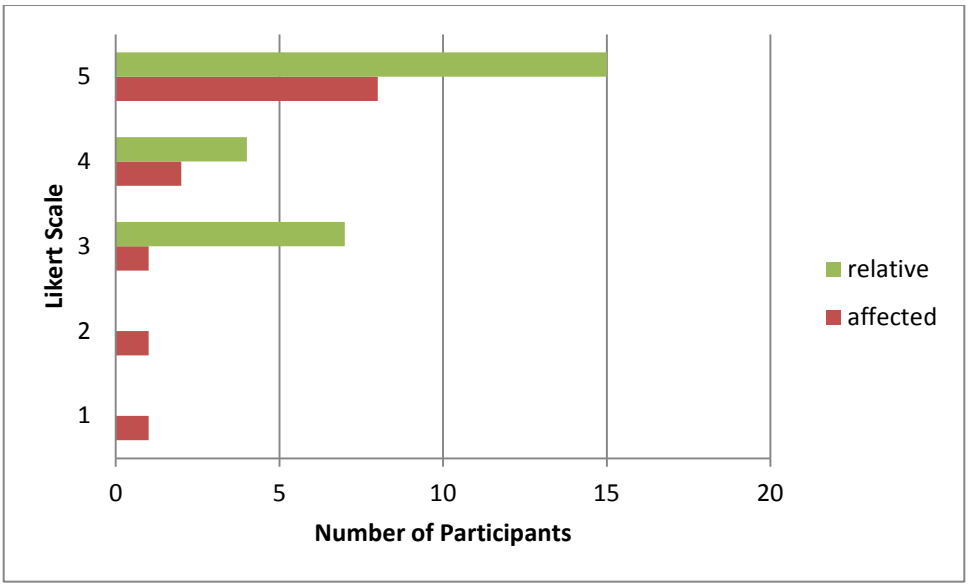


Figure 35: Agreement to "It is useful to know if I have genes that make bipolar disorder more likely:" post-educational session

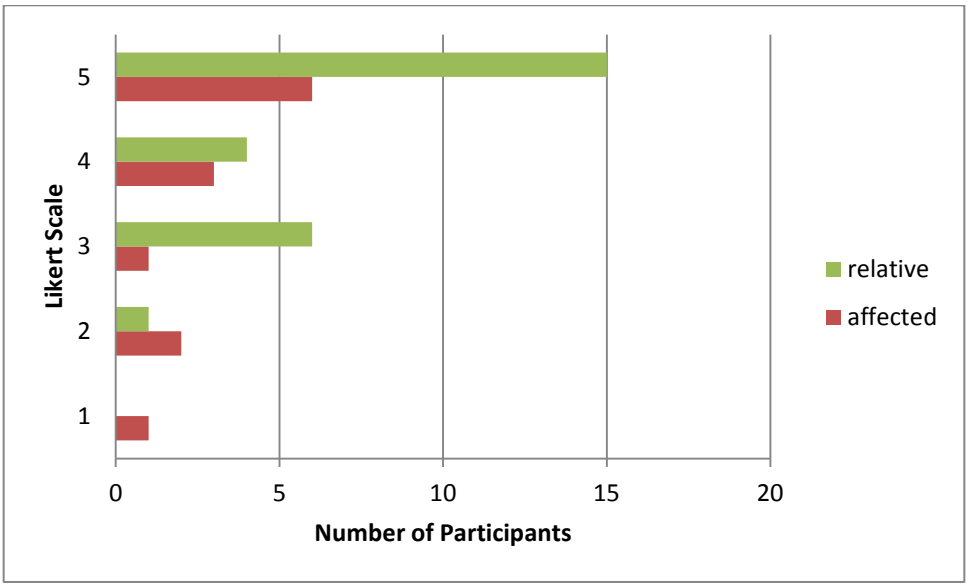


Figure 36: Agreement to "It is useful to know if my partner has genes that make bipolar disorder more likely:" post-educational session

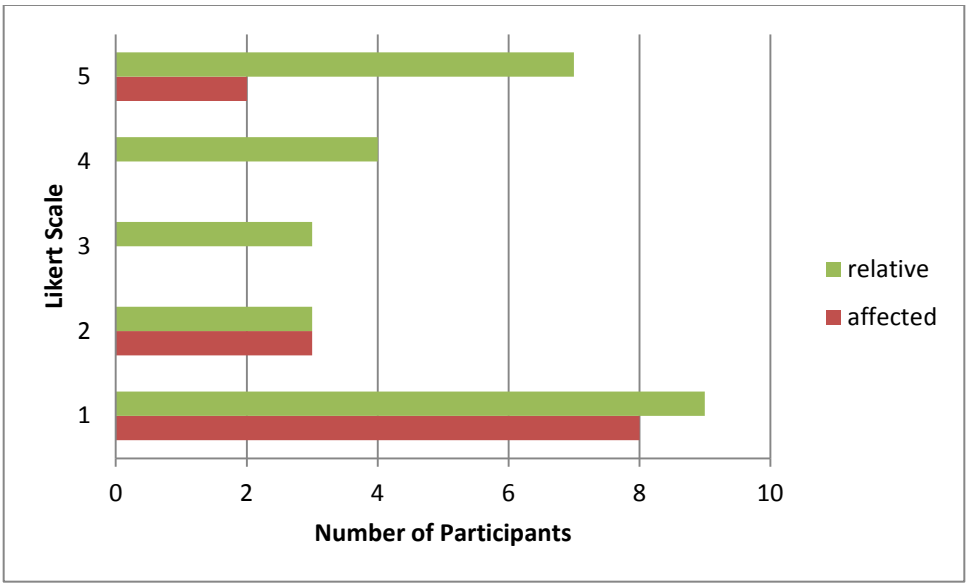


Figure 37: Agreement to "Knowing the risk of having a child with bipolar disoder would change my plans about a future pregnancy:" post-educational session

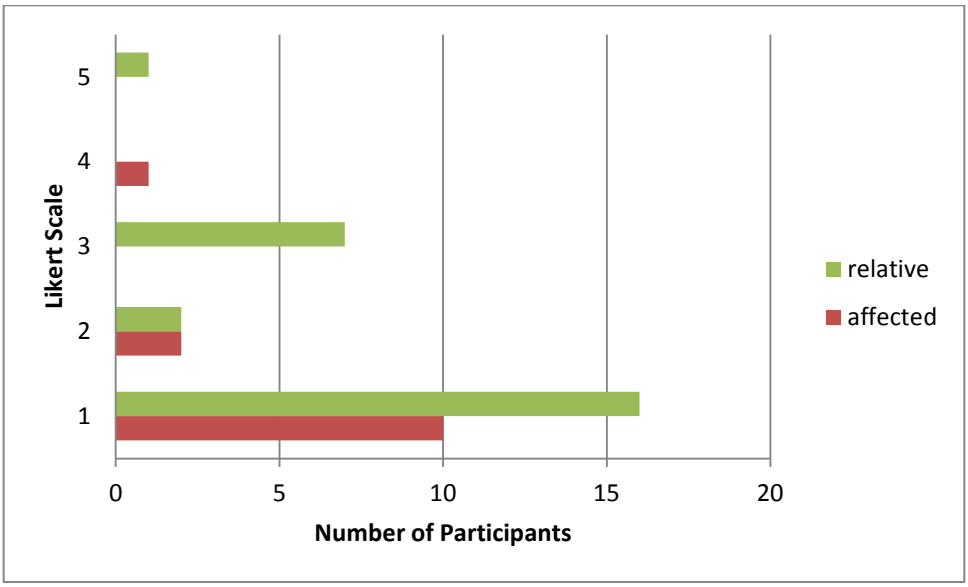


Figure 38: Agreement to "Genetic testing for bipolar disorder is painful and difficult:" post-educational session

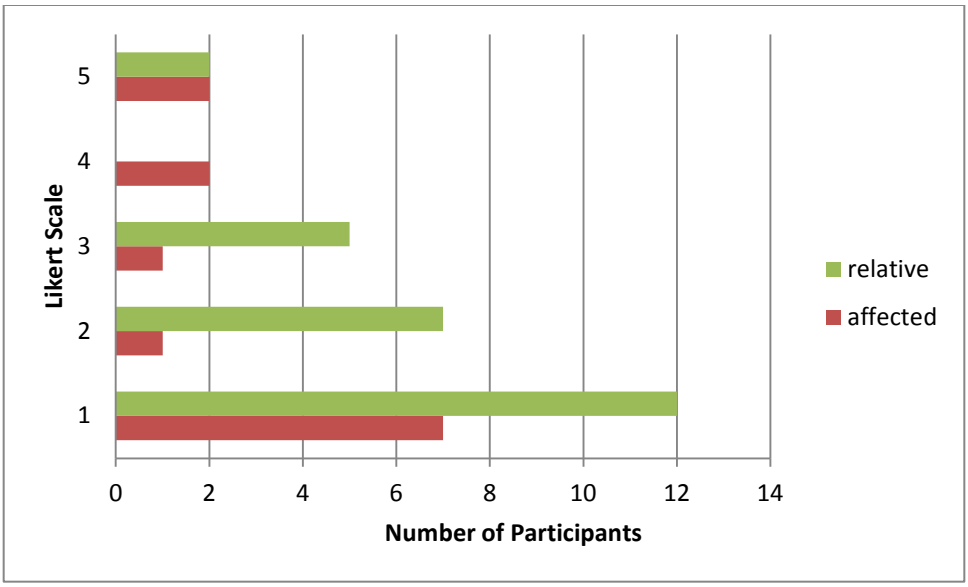


Figure 39: Agreement to "My partner would be hard to convince to have genetic testing:" post-educational session

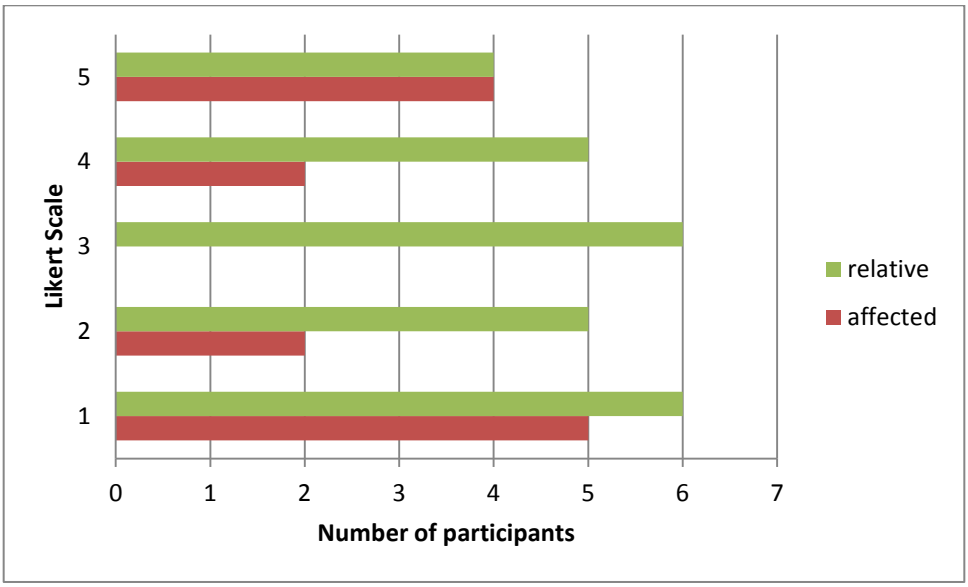


Figure 40: Agreement to "I would not want to pay for genetic testing:" post-educational session

A.3 KNOWLEDGE DATA

Table 20 represents the scores per participant for the knowledge questions pre and post educations session.

Table 20. Score of the knowledge questions pre- and post-educational session

	Pre-educational session	Post-educational session
Affected	7	8
	7	8
	6	7
	4	5
	7	8
	5	8
	7	8
	5	3
	3	3
	4	3
	8	8
	6	6
	4	7
Average	5.615384615	6.307692308
Unaffected	5	8
	7	7
	4	5
	7	7
	6	5
	7	8
	3	7
	3	4
	7	8
	8	8
	6	5
	7	7
	7	6
	6	7
	6	8
	6	6
	6	7
	8	8
	6	6
	5	4
	6	8
	6	7
	8	7
	7	6
	5	6
	6	7
Average	6.076923077	6.615384615

APPENDIX B

INSTITUTIONAL REVIEW BOARD (IRB) APPROVAL LETTERS

Pitt Seal

University of Pittsburgh
Institutional Review Board

3500 Fifth Avenue
Pittsburgh, PA 15213
(412) 383-1489
(412) 383-1508 (fax)
http://www.irb.pitt.edu

Memorandum

To: Elizabeth Gettig

From: Sue Beers PHD, Vice Chair

Date: 12/22/2010

IRB#: REN10110051 / IRB0610128

Subject: TITLE: Improving knowledge, evaluating opinions, and ascertaining the acceptance of genetic counseling for bipolar disorder.

Your renewal for the above referenced research study has received expedited review and approval from the Institutional Review Board under:
45 CFR 46.110.(7) characteristics/behaviors

Please note the following information:

Approval Date: 12/22/2010
Expiration Date: 12/21/2011

Please note that it is the investigator's responsibility to report to the IRB any unanticipated problems involving risks to subjects or others [see 45 CFR 46.103(b)(5) and 21 CFR 56.108(b)]. The IRB Reference Manual (Chapter 3, Section 3.3) describes the reporting requirements for unanticipated problems which include, but are not limited to, adverse events. If you have any questions about this process, please contact the Adverse Events Coordinator at 412-383-1480.

The protocol and consent forms, along with a brief progress report must be resubmitted at least **one month** prior to the renewal date noted above as required by FWA00006790 (University of Pittsburgh), FWA00006735 (University of Pittsburgh Medical Center), FWA00000600 (Children's Hospital of Pittsburgh), FWA00003567 (Magee-Womens Health Corporation), FWA00003338 (University of Pittsburgh Medical Center Cancer Institute).

Please be advised that your research study may be audited periodically by the University of Pittsburgh Research Conduct and Compliance Office.

University of Pittsburgh
Institutional Review Board

3500 Fifth Avenue
Pittsburgh, PA 15213
(412) 383-1480
(412) 383-1508 (fax)
http://www.irb.pitt.edu

Memorandum

To: Elizabeth Gettig

From: Christopher Ryan PHD,Vice Chair

Date: 11/23/2011

IRB#: REN11110085 / IRB0610128

Subject: TITLE: Improving knowledge, evaluating opinions, and ascertaining the acceptance of genetic counseling for bipolar disorder.

Your renewal for the above referenced research study has received expedited review and approval from the Institutional Review Board under:
45 CFR 46.110 (7) characteristics/behaviors

Please note the following information:

Approval Date: 11/23/2011
Expiration Date: 11/22/2012

Please note that it is the investigator's responsibility to report to the IRB any unanticipated problems involving risks to subjects or others [see 45 CFR 46.103(b)(5) and 21 CFR 56.108(b)]. The IRB Reference Manual (Chapter 3, Section 3.3) describes the reporting requirements for unanticipated problems which include, but are not limited to, adverse events. If you have any questions about this process, please contact the Adverse Events Coordinator at 412-383-1480.

The protocol and consent forms, along with a **brief** progress report must be resubmitted at least **one month** prior to the renewal date noted above as required by FWA00006790 (University of Pittsburgh), FWA00006735 (University of Pittsburgh Medical Center), FWA00000600 (Children's Hospital of Pittsburgh), FWA00003567 (Magee-Womens Health Corporation), FWA00003338 (University of Pittsburgh Medical Center Cancer Institute).

Please be advised that your research study may be audited periodically by the University of Pittsburgh Research Conduct and Compliance Office.

APPENDIX C

CONSENT FORM

_____

Participant's Name

"I certify that I have explained the nature and purpose of this research study to the above named individual(s), and I have discussed the potential benefits and possible risks of study participation. Any questions the individual(s) have about this study have been answered, and we will always be available to address future questions, concerns or complaints as they arise. I further certify that no research component of this protocol was begun until after this consent form was signed."

_____ _____

Printed name of Person Obtaining Consent Role in Study Date

_____ _____

Signature of Person Obtaining Consent Date

APPENDIX D

SURVEY

D.1 DEMOGRAPHIC AND PSYCHIATRIC HISTORY QUESTIONNAIRE

1. How old are you?

2. What is your marital status?
   - Single
   - Married
   - Separated
   - Divorced
   - Widowed

3. How many children do you have?

4. Do you live with your partner?

5. What is the highest level of education you have finished?
   - Some High School
   - High School Graduate
   - Some College
   - College Graduate
   - Graduate/Doctoral/Professional School

6. Do you have, or have you had, bipolar disorder?
   - Yes
   - No

7. Do you have a relative who has been diagnosed with Bipolar disorder?
   - Yes
   - No

7b. If yes, which family member or family members have bipolar disorder? (all that apply)

□ Myself
□ Mother
□ Father
□ Child
□ Adopted child
□ Brother
□ Sister
□ Grandparent
□ Aunt / Uncle (blood relation)
□ Cousin
□ Other (please state) _____

Follow up questions for "affected subject with no affected first-degree relatives" and "affected subject with one or more affected first-degree relatives":

1. How long ago were you diagnosed?
   - In the last 6 months
   - 6-12 months ago
   - 1-2 years
   - 3-5 years
   - 5+ years
   - Other

2. When did you last actively have symptoms?
   - Currently in an active phase
   - In the last 6 months
   - 6-12 months ago
   - 1-2 years
   - 2-5 years
   - 5+ years
   - Other

3. Are you currently being treated for Bipolar disorder?
   - Yes
   - No

   3b. If yes, what type of treatment? (all that apply)
      - Taking medication
      - In day therapy
      - In residential therapy (hospital)
      - Other

4. Do you have any other psychiatric diagnoses?

- Yes
- No
- Do not know

4b. If yes, what is the diagnosis?

- Personality disorder
- Manic depression
- Depression
- Schizophrenia or Schizoaffective disorder
- Other
- Do not know

D.2 GENETIC COUNSELING QUESTIONNAIRE

13. Have you heard of genetic counseling?

- Yes
- No

14. Do you know what genetic counseling is?

- Yes
- No

15. Have you ever had genetic counseling?

- Yes
- No

16. If yes, was it due to a family or personal history of bipolar disorder?

- Yes
- No

17. Do you think genetic counseling would be useful to you?

- Yes
- No

Comments:

D.3 KNOWLEDGE QUESTIONNAIRE

Following are some questions about Bipolar disorder. I will read each question to you, along with five possible answers. Please select the one best answer for each question.

1) Bipolar disorder is caused by
   a. dirty needles
   b. a virus
   c. inheriting genes from parents
   d. the exact cause is unknown currently
   e. none of the above

2) How many genes must someone inherit to have Bipolar disorder?
   a. zero, it is not caused by genes
   b. one from their mom
   c. two, one from their mom, and one from their dad
   d. the number of genes is not presently known
   e. none of the above

3) Bipolar disorder can cause
   a. euphoria, feeling "high"
   b. racing thoughts, talkativeness
   c. drug or alcohol use
   d. inability to concentrate well
   e. all of the above

4) Bipolar disorder is most likely caused by
   a. genes
   b. the environment such as a major life event
   c. a combination of genes and environment such as a major life event
   d. radiation
   e. none of the above

5) Bipolar disorder is a serious conditions that causes shifts in
   a. mood
   b. energy
   c. functioning
   d. all of the above
   e. none of the above

6) Bipolar disorder is present

a. More in poor people
b. More in rich people
c. Same across all ethnic and economic groups
d. More in some ethnic groups
e. More in some regions

7) Bipolar disorder is treated by
a. medications known as mood stabilizers
b. liver transplant
c. rest
d. blood transfusions
e. none of the above

8) How can you tell if someone carries genes for Bipolar disorder?
a. They look sick
b. They will eventually have Bipolar disorder
c. With a simple blood test
d. There is no way of knowing
e. None of the above

D.4 HEALTH BELIEF ASSESSMENT

Please rate your level of agreement with each of the following statements on a 5-point scale where 1 means "strongly disagree" and 5 means "strongly agree."

D.4.1 Severity

1. Bipolar disorder is a serious disease.

Strongly Disagree 1 2 3 4 5 Strongly Agree

2. Having a child with bipolar disorder would be very scary.

Strongly Disagree 1 2 3 4 5 Strongly Agree

3. My life would change if my child had bipolar disorder.

Strongly Disagree 1 2 3 4 5 Strongly Agree

D.4.2 Susceptibility

4. My children are at risk for bipolar disorder

Strongly Disagree 1 2 3 4 5 Strongly Agree

5. Bipolar disorder could happen in my family.

Strongly Disagree 1 2 3 4 5 Strongly Agree

6. My partner may be a carrier of genes for bipolar disorder.

Strongly Disagree 1 2 3 4 5 Strongly Agree

D.4.3 Benefits

7. It is useful to know if I have genes that make bipolar disorder more likely.

Strongly Disagree 1 2 3 4 5 Strongly Agree

8. It is useful to know if my partner has genes that make bipolar disorder more likely.

Strongly Disagree 1 2 3 4 5 Strongly Agree

9. Knowing the risk of having a child with Bipolar disorder would change my plans about a future pregnancy.

Strongly Disagree 1 2 3 4 5 Strongly Agree

D.4.4 Barriers

10. Genetic testing for Bipolar disorder is painful and difficult.

Strongly Disagree 1 2 3 4 5 Strongly Agree

11. My partner would be hard to convince to have genetic testing.

Strongly Disagree 1 2 3 4 5 Strongly Agree

12. I would not want to pay for genetic testing.

Strongly Disagree 1 2 3 4 5 Strongly Agree

D.4 OPEN-ENDED QUESTIONS

13. When you first heard about mental illness in your family, what did you think caused it? How do you think it happened or occurred?

14. When we say a condition might be inherited, what does that mean to you?

15. How do you think a hereditary condition would affect your family now and in the future?

16. Do you think bipolar condition is hereditary?

If response is Yes and you have bipolar disorder – what do you think your risk is for passing it on to a child?
If response is Yes and you do not have bipolar disorder – what do you think your risk is for developing the condition?

17. Do you have any other comments you would like to share?

APPENDIX E

EDUCATIONAL SESSION OUTLINE

a) Contracting: In this educational session we will discuss what is known and what is not known about the genetics and effects of bipolar disorder. Please feel free to ask any questions that you may have. This will be similar to a genetic counseling session.

b) What is genetic counseling?

i) Genetic counseling is a discussion of the genetic causes for a disorder, the chance that other family members will show signs and symptoms of the disorder, how the diagnosis may affect the family, and where people can go for more information.

c) Genetic counseling usually involves a brief discussion of genetics.

i) Genetics is the study of DNA. You may have heard of DNA before, DNA is like an instruction manual for the body. We each have our own, unique DNA code, but we also share some of that code with our family members.

(1) We know that changes in the DNA can put people at risk for developing certain conditions.

(a) For bipolar disorder, the exact causes are not completely understood, but at present it seems that both genetic and environmental factors may increase the risk of BPD.

(b) Threshold model of multifactorial inheritance.

(c) The number and exact locations of the predisposing genes are not known.

(d) If you have one first-degree relative with BPD, your risk is about 3-15%, although some studies say the risk is as high as 24%.

ii) At present, there is no way to tell if a person carries genes that make them more susceptible to BPD. You cannot tell by looking at someone, by a physical exam, or with genetic testing.

d) What are the effects of BPD?

i) BPD can affect moods, energy level, and functioning.

e) Who does BPD affect?

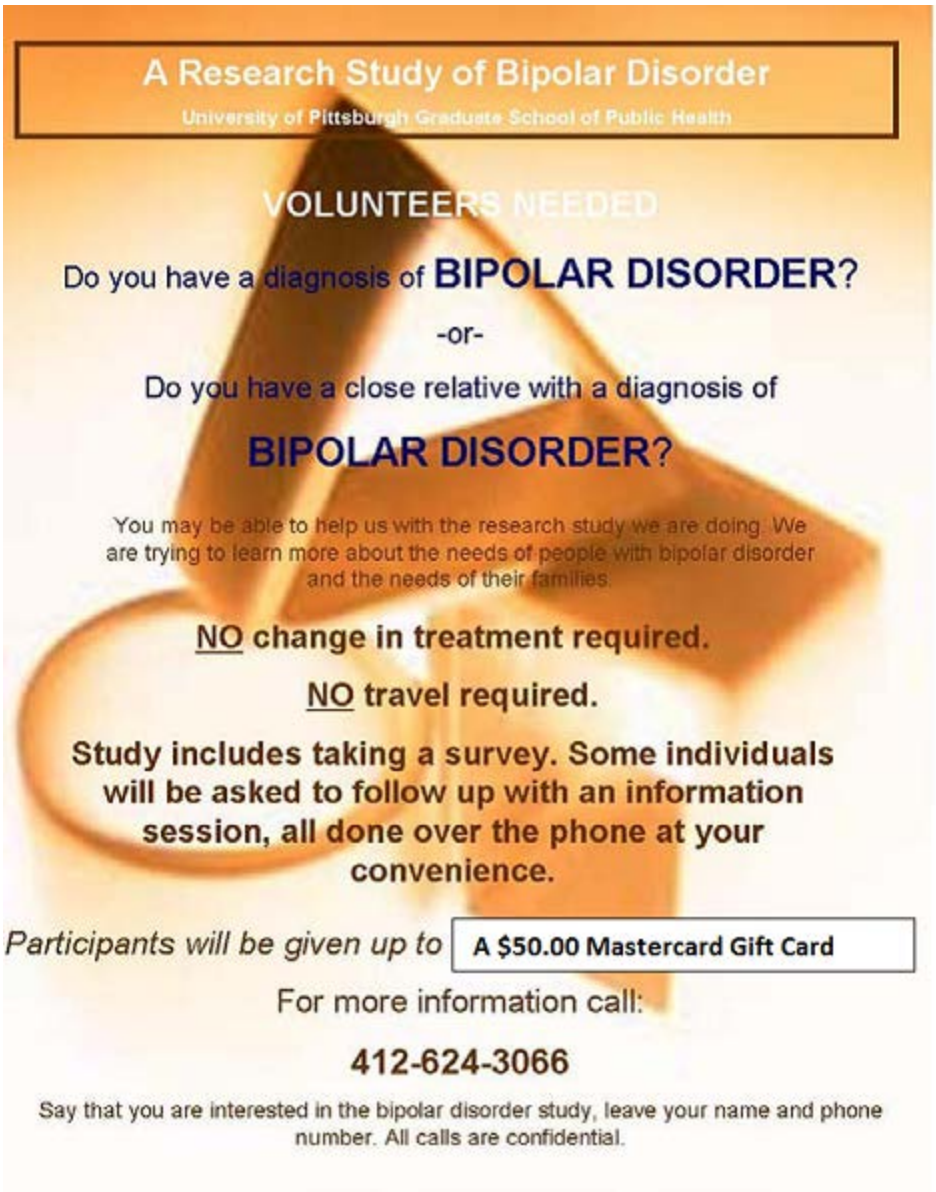
i) BPD affects about 1% of the population, current evidence suggests that it affects men and women equally, and the rate is equal across ethnic groups.

f) Treatment

i) Most individuals affected with BPD are treated with mood stabilizers. Sometimes antidepressants are also prescribed. Doctors work with their patients to find the best possible management.

APPENDIX F

RECRUITMENT FLYER



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