

2005

## Between you and me: parental disclosure of their bipolar disorder to offspring

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**BETWEEN YOU AND ME: PARENTAL DISCLOSURE OF THEIR BIPOLAR  
DISORDER TO OFFSPRING**

**Thesis**

**Submitted to**

**The College of Arts and Sciences of the  
UNIVERSITY OF DAYTON**

**in Partial Fulfillment of the Requirements for**

**The Degree**

**Master of Arts in Communication**

**by**

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**August, 2005**

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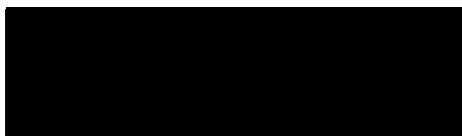


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## **ABSTRACT**

### **BETWEEN YOU AND ME: PARENTAL DISCLOSURE OF THEIR BIPOLAR CONDITION TO OFFSPRING.**

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The purpose of this study was to examine the factors that impact the breadth and depth of parental disclosure of their bipolar disorder to offspring. While bipolar disorder is highly treatable, treatment is frequently inappropriate and inadequate due in part to a lack of understanding of the disorder – an understanding that can be supplemented by other bipolar family members. Framed by Petronio's Communication Privacy Management Theory, the present study was conducted online through a survey that was posted on websites housing online bipolar support groups. One hundred thirteen people participated. They all had some type of connection to bipolar disorder via a parent, child, or themselves.

The results revealed that parents do disclose to their offspring to gain informational support, make the offspring aware of the genetic risk and symptoms, and partner in the healthcare of their own bipolar offspring. Nondisclosing parents believed their offspring too young to understand the

illness. The offspring of bipolar parents reported that the issue was not talked about frequently within the family, but when it was the family discussed the person's odd behavior, health condition, and ways to better care for the individual. Despite these efforts, a majority of the participants did not understand their parent(s) illness until the age of 19 or older. Many of these offspring are bipolar parents themselves and see the advantages of disclosing being to gain informational and tangible support; however, the disadvantages are a powerful deterrent from doing so. Thus, many bipolar consumers have been impacted by knowing or not knowing of a bipolar presence in their family. Those that knew received treatment sooner and had an explanation for their condition. Those that did not suffered from self – medication, surviving the symptoms, and loss of jobs and / or relationships.

## ACKNOWLEDGEMENTS

First and foremost, I wish to thank the support groups that participated in this study. Without you, I would have nothing more than an interesting topic.

Thanks to my committee member Dr. Ronda Scantin, who supplied me with endless amounts of candy and support. It was your initial encouragement that got me to actually stick with a topic and I am so glad it was this one.

To my other committee member Dr. Anna Langhorne, thank you for joining me in this journey. You challenged me to a higher standard, to own my words.

To Dr. James Robinson, thank you for caring enough to step in when I needed you. Your selflessness allowed me to actually finish and to finish well. "Keep it real!"

I would like to thank my mom, the "master coder". Despite having spent hours coding – twice, you never complained. You woke up early, you stayed up late, you sacrificed whatever it took for me to finish successfully – you always have.

To my fellow graduate assistants, this would not have been as enjoyable without you. Molly & Kate, your friendships have blessed my life. Our laughter fueled us to the end.

And finally, to Teri, the title "advisor" means nothing compared to all the other roles you play in my life. Thank you for always encouraging me to pursue my passions. Your life inspires me and your integrity challenges me. The investment you have made in my life has helped me grow into the person you already believe me to be. Thank you.



## TABLE OF CONTENTS

ABSTRACT.....	iii
ACKNOWLEDGEMENTS .....	v
TABLE OF CONTENTS .....	vii
LIST OF TABLES .....	ix
CHAPTER	
I.    INTRODUCTION .....	1
Self – disclosure	
Communication Privacy Management Theory	
Families & Disclosure	
Bipolar Disorder	
Rationale	
II.    METHOD .....	33
Subjects	
Instrumentation	
III.   RESULTS .....	41
Research Questions	
Supplemental Analyses	
IV.   DISCUSSION .....	61
Research Questions	
Limitations	
Suggestions for Future Research	
Conclusion	
APPENDICES .....	76

## Appendix A

BIBLIOGRAPHY .....	82
--------------------	----

## LIST OF TABLES

1. Frequency of Participant's Connection to Bipolar Disorder.....	43
2. Frequency of Parents Disclosing Bipolarity to Offspring.....	45
3. Frequency of Why Parents Have Not Disclosed Bipolarity to Offspring .....	44
4. Frequency of Why Parents Have Disclosed Bipolarity to Offspring .....	45
5. Means for Topics Discussed .....	48
6. Frequency of What Age Offspring Was When He or She Understood Bipolar Parents Condition .....	48
7. Frequency of Factors that Determine A Person's Decision to Disclose Bipolarity to His or Her Family .....	49
8. Frequency of Factors that Determine A Person's Decision Not to Disclose Bipolarity to His or Her Family .....	50
9. Chi – square of Sex and Not Disclosing .....	51
10. Frequency of Impact on One's Health .....	54
11. Factorial Analysis of Variance with Age of Participant and Offspring's Knowledge of Parents Condition .....	55
12. Tukey's HSD One – Way ANOVA with Age of Participants and Offspring's Knowledge of Parents Condition .....	56
13. Chi – square of Children and Disclosing .....	58

14. Chi – square of Children and Not Disclosing .....	59
15. Chi – Square of Children and Impact of Disclosing .....	60

## CHAPTER I

### INTRODUCTION

"The social sharing findings point to an inherent puzzle that has intrigued researchers, poets, and philosophers for generations: talking about your problems is good for you, but at the same time, if you are talking about your problems, something is the matter with you" (Pennebaker, Zech, & Rimé, 2001, p. 535). Although a number of research studies detail the benefits of self-disclosure, many people find it very difficult to self disclose to the extent suggested by experts (Jourard, 1958; Pennebaker et al., 2001; Petronio, 2002). This study will examine the communicative patterns of self – disclosing about mental illness.

Self-disclosure has been identified as a dialectical tension of disclosure and privacy, or revealing and concealing (Petronio, 2002; Rosenfeld, 2002). This tension is further complicated by one's relationships, the level of sensitivity of the content, and the potential risks involved, i.e., rejection, stigmatization, and loss of control over the information disclosed (Baxter & Montgomery, 2004; Vangelisti, 1994). Despite these risks, people continue to engage in self-disclosure because it is the only way to fulfill the desire to be known.

While self-disclosure literature emphasizes the role disclosure plays in enhancing one's personal relationships and improving one's health, research is lacking in the area of family health disclosure (Greene, 2000; Vangelisti, 1994). Specifically, very few studies have investigated the communicative event surrounding genetic risk within families (Daly et. al, 1999; Sorenson, Jennings-Grant, & Newman, 2003). Research on disclosure relating to genetic risk has primarily focused on ovarian and breast cancer, Huntington's disease, families with balanced translocations (a chromosome abnormality that can cause birth defects in one's offspring), and disorders acquired through recessive genes (Forrest et. al, 2003; Shaw, 2005). Research on mental illnesses and disclosure tends to focus on the importance of the patient, or consumer, disclosing all of the necessary information to his or her healthcare providers and significant others, enabling them to monitor the patient's mental state when he or she is unable to do so. The purpose of the present study is to (1) identify privacy rules within families as they relate to disclosure of a parent's bipolar disorder to his or her children, (2) determine the rate of disclosure of mental health disorders within a family to children, and (3) examine possible preventive benefits for children as a result of their parents' disclosure of information about the disorder.

Bipolar disorder is known to have a genetic component; yet, it is only detectable through symptomatic measures – the DSM-IV – because research lacks the knowledge of a specific gene (NIMH, 2001). Because this genetic link cannot be detected by any type of scanning device, such as an MRI, the only means available to diagnose the disorder are observation and communication.

In order to establish a foundation for this study, a review of the self-disclosure literature, including family and health disclosure, is provided to see where disclosure research has been, where it is going, and how this study is an extension of disclosure research. Basic information about bipolar disorder is necessary to connect with the need and value of communicating about genetic risk within the family. Finally, Communication Privacy Management theory is explained because it serves as the lens through which to view this study.

### Self-disclosure

"The courage to be [entails] the courage to be known" (Jourard, 1959, p. 505). Frankly, people desire to be known, yet for many it is much easier to get to know someone than to give others the opportunity to get to know them. Self-disclosure is the process of revealing oneself to others (Jourard & Lasakow, 1958). Researchers tend to measure self-disclosure by assessing the amount of information revealed (breadth), the level of vulnerability required for the disclosure (depth), and the amount of time spent on a particular topic (Cozby, 1973).

Early research determined that the majority of people are willing to talk about attitudes, personal tastes, and work, but tend to avoid topics dealing with money, personality, and body image (Jourard, 1958). The extent to which people talk about these things depends on the intimacy of the relationship and the expected level of reciprocity that accompanies the disclosing event (Jourard, 1959). However, a high level of disclosure does not necessarily equal a healthy relationship. In fact, "[M]any married people are almost strangers to each other"

(Jourard, 1958, p.81).

The act of disclosing itself reduces the stress of repressing painful or tragic events, thoughts, or feelings, and often aids the individual in dealing with it (Pennebaker et al., 2001). Repression creates stress because it is an attempt to push one's emotions, feelings, or thoughts in an unnatural direction; it is like trying to suppress the eruption of a volcano (Pennebaker et al., 2001). The impact self-disclosure may have on an individual or circumstance depends on four factors – content (what is being shared), valence (whether the content is positive or negative), required vulnerability (how much one must reveal of oneself), and self esteem (how a person views him or herself going into a conversation) (Gilbert, 1976). “The reality of relational life is communicators seeking a variety of important, yet apparently incompatible goals” (Rosenfeld, 2000, p. 5). This internal struggle creates a dialectical tension. Dialectics theory examines tensions created in a relationship resulting from opposing feelings, which naturally pulls those involved in opposing directions. Baxter and Montgomery (1996) developed a theory on dialectics while researching close relationships. They focused on three dialectics: integration – separation, stability – change, and expression – privacy (Baxter & Montgomery, 1996). These tensions are experienced as people try to balance individuality and togetherness. They occur both internally, within the relationship, and externally, between the relationship and outside individuals/society.

Integration – separation occurs internally when people within a relationship struggle with maintaining their individuality, while operating as a



group or a couple. This tension is also referred to as the dialectic between connection and autonomy. The external dialectic, inclusion – seclusion, is a struggle between wanting to be included in what everybody else is doing and wanting to be alone, e.g. wanting to be invited on a trip that you did not want to go on in the first place (Baxter & Montgomery, 1996). Stability — change produces an internal struggle of wanting to know everything about a person, while maintaining a certain level of mystery. This is also referred to as the dialectic between predictability and novelty. Externally, it manifests itself when a person chooses to do something different for the sake of being different and is labeled as the conventionality – uniqueness dialectic (Baxter & Montgomery, 1996). This may occur with the student who may say “present” when the role is being called simply because the rest of the class responded with “here”. Finally, expression – privacy exists internally within the struggle to be completely vulnerable in a relationship and to keep certain pieces of information to oneself (also referred to as openness – closedness). Externally, a couple also struggles with what to share with family and friends, and what to keep between the two of them and is labeled the revelation – concealment dialectic (Baxter & Montgomery, 1996). Rosenfeld (2000) summarizes the reasons for these internal conflicts stating that people disclose to clarify things about the self which seem ambiguous – attitudes, feelings, etc.; for validation, enhancing one's self-esteem; to form and manage a certain image; to deepen and maintain one's personal relationships; to exercise social influence over others; and to manipulate others.

The ability to disclose is the ability to risk (Gilbert, 1976). One must risk being rejected in order to risk being known and, at some point along the way, decide that it is worth it. Jourard (1964) asserts that to refuse to disclose is to deny oneself, hindering one's growth as a person. Petronio extends this inward focus of disclosure to include the communicative process of disclosure in her theory, Communication Privacy Management (CPM).

### Communication Privacy Management Theory

While Jourard identifies the human desire to disclose and the consequences of *not* doing so, Sandra Petronio takes a closer look at the "not doing so" with an emphasis on the fact that people also desire to conceal information about themselves. Petronio's (2002) Communication Privacy Management (CPM) theory deals with the question of "...when to let others know our private side and when to let it stay confidential?" (p.1). She argues that we are constantly trying to maintain a balance between the two extremes, which creates a dialectical tension of when to reveal and when to conceal information (Petronio, 2002). It is a tension of risks and benefits.

Irwin and Altman (1973) examined the relationship of risks and benefits as it relates to self-disclosure in their Social Penetration theory. This theory states that people socially penetrate once they see that the benefits of this action outweigh the costs. The theory measures the growth of interpersonal relationships by comparing the amount of information shared, the level of intimacy achieved, and the length of conversations.

CPM extends this theory by first restricting the type of disclosure from *self* disclosure to *private* disclosure. The theory "makes private information, as the content of what is disclosed", "...sets parameters and gives substance to the heart of disclosures, that is, what is considered private", and "...does not restrict the process to only the self, but extends it to embrace multiple levels of disclosure including self and group" (Petronio, 2002, p. 3). In other words, disclosure is not restricted to one revealing about him or herself, but includes the revealing of any information that is considered private by a person or group of persons, hence the term "private disclosure". Secondly, Petronio focuses on the relationship of this dialectic within a rule-based system to reveal how people manage their private information. These rules are based on four assertions:

- that the relationship is dialectical;
- that people decide to disclose according to criteria and only under certain conditions;
- that people believe they are the gatekeepers of their private lives; and
- that other people are necessary in order to observe the communicative process of revealing and concealing, and to understand its full impact (Petronio, 2002).

Privacy issues within families are further complicated by the necessity to reveal and conceal: (1) in order to maintain healthy connections throughout the family system; (2) due to the struggle amongst members for autonomy and connectedness; and (3) because of the tendency for family members to be

selective in who and what they tell (Caughlin & Petronio, 2004). Petronio explores these complexities using five suppositions.

#### The five suppositions of CPM

1. Private Information: As mentioned earlier, CPM differs from previous disclosure research by focusing on private information (Petronio, 2002). Private information refers to anything that is not accessible without some type of disclosure, focusing on the entire process of disclosure, and not just the self (Petronio, 2002). For instance, if person A reveals that his or her cousin is bisexual to a friend of the family, yet, the family intentionally does not discuss that topic with others, then person A engaged in a private disclosure, rather than a self-disclosure, because the information revealed did not specifically pertain to person A.
2. Privacy Boundaries: The phrase "[M]ind your own business!" often signifies a boundary violation. CPM uses a boundary metaphor to illustrate how people act as gatekeepers and expeditors of information, believing that they own what is considered private. There are two types of boundaries – personal and collective boundaries. The former concerns that which people keep to themselves; the latter forms when people invite others into private areas of their lives, allowing others to co-manage that information with them. Thus, the private information remains within the

confines of one's personal boundaries, while the shared information falls under a collective boundary, giving ownership to both or all parties involved (Petronio, 2002).

3. Control and Ownership: People act as gatekeepers to their private lives due to the belief that they own that information. The level of control one exercises over one's information depends on the nature of what is being shared (Petronio, 2002). For example, sharing about one's family vacation presents fewer risks than sharing about one's health issues or family disputes.
4. Rule-Based Management System: This system provides a framework in which to study privacy management. Not only do people have criteria for sharing, they also have expectations of those within their collective boundary once they have shared (Petronio, 2002). If person A discloses something to which he or she assigned thick boundaries, person A expects person B to treat that information with the same level of confidentiality.
5. Privacy Management Dialectics: Petronio (2002) asserts that privacy and disclosure are in fact opposites and are dialectically related. "These dialectical forces are critical to understanding how people manage their public and private lives" (Petronio, 2002, p. 13). The two opposites occur simultaneously – the very essence of a dialectical relationship (Rosenfeld, 2000).

### Privacy Rule Management Processes

Understanding the assumptions under which CPM operates provides the foundation needed to understand its rules. "Privacy rules are used in all matter of managing revealing and concealing, for example, in determining who receives a disclosure, when, how much or how little, where the disclosure occurs, and how a person might conceal information" (Petronio, 2002, p. 23). The three rule management processes establish (1) how rules are formed and their characteristics, (2) boundary coordination, and (3) boundary turbulence (Petronio, 2002).

### Privacy Rule Development

Six criteria are utilized in describing privacy rule development (Petronio, 2002). Essentially, these criteria are the foundation on which the rules are based. First, a cultural criterion is used when one decides to base his or her privacy boundaries on what is considered normal for his or her culture (Petronio, 2002). A person from the country of X may not share certain information about his or her life because it is not a norm of his or her culture. Second, a gendered criterion applies to disclosure patterns that are consistent with one's gender. For example, one can conclude that person A shares more than her husband because women tend to disclose more than men (Petronio, 2002). Third, motivational criteria evaluate privacy rules based on the reasoning, or motivation, behind their formation (Petronio, 2002). Person A may conceal why he was fired at his last job in order to maintain a certain image, or status, at his new job.

Fourth, a contextual criteria applies to the social environment or physical setting surrounding the situation in which the tension to reveal or conceal is present. For instance, person A may desperately want to share with a small group of friends about her recent miscarriage, but chooses not to because they are at a large gathering. Finally, the risk – benefit ratio criteria weighs both the risks and benefits involved in sharing private information. Person A may decide to share vulnerable information with his daughter in hopes of deepening their relationship. The potential success, or benefit, of this disclosure outweighs the risk.

Partnered with these criteria are two attributes – rule acquisition and rule properties. The acquisition of rules occurs through socialization and negotiation (Petronio, 2002). We learn of privacy rules from the people around us; however, rules are negotiated each time we enter into a collective boundary because control is now divided amongst all parties involved. Both the socialization and negotiation of rules exhibit their flexible and static properties (Petronio, 2002).

### Boundary Coordination

The second management process concerns the coordination of boundaries. The nature of life causes one to belong to a number of collective boundaries in addition to one's own personal boundaries. Managing these boundaries requires applying rules to the information and to the boundaries themselves (Petronio, 2002). Boundary rules include linkages, ownership rights, and permeability. Linkages are formed once a person is made privy to private information – directly or indirectly. Ownership boundaries concern the control

people feel entitled to over their private lives. Finally, boundary permeability refers to the amount of control exercised over the information and range from high accessibility and low accessibility (Petronio 2002). For example, if person A shares something with a small group of people and instructs them not to tell anyone, his or her boundary permeability is low, meaning that he or she is exercising a high level of control over the information to decrease its accessibility.

### Boundary Turbulence

The third management process is boundary turbulence. Turbulence occurs anytime there is conflict while attempting to coordinate boundaries. Violating an understood boundary, applying a different set of rules, or unclear permeability boundaries are all causes of turbulence. Continuing with the example above (boundary permeability), if a member of the small group decides to discuss person A's private information with a person that is not a member of that group, he or she has created boundary turbulence. The privacy rule of not telling another person would have been violated.

A review of research utilizing CPM is provided in the next section to provide an overview of how these management processes operate on a day-to-day basis. Most of the research reviewed pertains to health related issues. An understanding of this material will usher the reader into an examination of the relationship between mental illness and privacy rules.

### CPM Research



The Communication Privacy Management approach has been used to study a number of disclosure processes. The theory establishes the means used to manage one's private information (Petronio, 2002). Once a discloser identifies what is desired from the interaction, then he or she may develop a plan that will meet those needs (Petronio, 2002). It is important to note that these desires are accompanied by expectations. In order for boundary coordination to be successful, the recipients of the information must utilize their own criteria to understand the purpose of the disclosure if they are to know how to respond appropriately (Petronio, 2002).

Yep (2000) studied the disclosure of one's HIV status to friends and family. He and other researchers have found that revealing may satisfy a need for social support, but it can also result in stigmatization (Cline, 2000; Greene, 2000; Yep, 2000). Earlier, this review mentioned five reasons people tend to disclose – Yep's study gives an example of each. He found that a person with HIV may want to educate others (personal expression), achieve a better understanding through verbal processing (self-clarification), gain social support (validation), increase the intimacy level of the relationship (relational development), or manipulate a person or social group to achieve an undisclosed goal (social control) (Yep, 2000). In a high risk situation such as this, the HIV discloser must be very particular in both forming the message and conveying the message. CPM has also been used to interpret the face-saving rules surrounding physician mistakes (Petronio, 2002). In all matters dealing with

private information, the content must communicate the purpose, while the manner in which the message is delivered must convey the desired boundary rules (Petronio, 2002). For instance, person A may call person B away from a crowd to reveal private information. The act of taking person B away from the crowd communicates that the information was not meant for the group and should be kept between the two of them.

In addition to the content and delivery, disclosers are also very selective about to whom they disclose, introducing another aspect of boundary coordination. Greene's (2000) research on HIV and cancer disclosures found that people choose to disclose traumatic issues to their partners and friends over their families, with mothers and sisters being preferred over fathers and brothers. A high level of selectivity is also exercised by children who are victims of sexual abuse (Petronio, 2002). From these results one can infer that thinner boundaries accompany relationships with partners and friends and thicker boundaries accompany relationships with family members. This follows because if one cannot choose who is a member of his or her family, then the only way to distance oneself is through disclosure, meaning that the less one shares with a family member, the less he or she is allowing that member to be involved in his or her life.

CPM has also been used to investigate how friends and relatives who serve as informal healthcare advocates manage the collaborative boundary between themselves, the physician, and their loved one (Petronio, Sargent,

Andea, Reganis, & Cichocki, 2004). The relative is a member of the boundary because these persons often attend the patient's doctor visits. By allowing the relative or friend to care for him or her, the patient automatically invites these relatives/friends to co-own private information. Petronio et al. (2004) discovered boundary turbulence disguised as good intentions. While both the patient and informal healthcare advocate agreed that this union was meant to provide support and additional information to assist the patient, these advocates often played the role of voluntary informants to the physicians. For example, a father with lung cancer may purposely choose not to reveal that he is still smoking; however, the healthcare advocate may offer this information out of perceived responsibility. This example makes apparent the relevance of another area of disclosure research – disclosure within the family.

#### Families & Disclosure

Jourard and Lasakow (1958) reported that children disclose more to their parents if they perceive themselves to have good relationships with them, while the reverse is true when they do not feel they have good relationships with them. Apparently, for children, parents are the number one disclosing targets. When they grow into adults, they frequently prefer people outside of the family (Greene, 2000; Pennebaker et al., 2001). Self-esteem also plays a role in self-disclosure, as Gilbert (1976) details in her study on family communication. She states that "[s]elf-esteem has been found to be related to the following: the level at which one discloses; the husband's capacities to meet the wife's needs; the flow of

communication between parents and their children; and the way in which conflict is approached in family interaction" (p. 225). People with low self-esteem have trouble self-disclosing because they lack confidence.

In 1994, Vangelisti conducted a study to identify possible motivational criteria to maintain privacy boundaries within families. First was *bonding*, which enhances the connectedness created amongst the family members within a specific collective boundary from which others may be excluded. Second, Vangelisti found that secrets are often kept to avoid *evaluation* of other members out of a fear of being rejected. This is a common occurrence in issues of children 'coming out of the closet' about their sexual orientation (Ben – Ari, 1995). Third, many families do not disrupt privacy boundaries because it is uncomfortable to deal with the sensitive nature of the information. These are labeled *maintenance* reasons. Fourth, many families maintain *privacy* because they believe the information to be irrelevant to the other family members. Fifth, *defense* is a motivating factor when one fears that the information will be used to hurt them. And, finally, others do not reveal because they do not believe in the target's ability to handle the information. These same motivations can also be identified within health disclosures.

#### Health Disclosure & Stigmatization

Because disclosing one's health condition has been shown to improve one's physical and mental health, healthcare professionals encourage it, especially within the patient-doctor relationship (Greene, 2000; Pennebaker et

al., 2001). However, the desire to suppress information about serious illnesses is encouraged by the fear of being stigmatized (Greene, 2000). Caughlin and Petronio (2004) also state that concealing may be routed in prosocial reasons, such as acceptance. Yet, the costs of acceptance are alienation, low social support, anxiety and depression, and low self-esteem (Greene, 2000).

Cancer, HIV/AIDS, and sexually transmitted diseases, or STDs, are examples of conditions that carry varying levels of stigma due to the nature of how the disease is acquired (Greene, 2000). In other words, when a disease is acquired by chance, the stigma is low because no one can be held responsible. This once again highlights the fact that one's willingness to disclose is greatly dependent upon the costs. Is risking marginalization worth the possibility of being received with open arms? Only the discloser can answer this question once the purpose and motivation of the event are identified.

Despite the fact that the stigma may be low for diseases acquired by chance, the barriers to disclosing remain high. Recent research has examined potential barriers to communicating genetic risks (Forrest et al., 2003). The participants were genetically connected to Huntington's disease or hereditary breast/ovarian cancer. These participants struggled with questions of who possessed the responsibility and authority to tell and how and when to do so (Forrest et al., 2003). Although the majority of the families saw it as the responsibility of the family to disclose the information, a lack of understanding or poor family relationships, they felt, required the assistance of a healthcare

professional. Within the family, they felt that the parents were the best choices to disclose the information, due to their familial position. Tercyak, Peshkin, DeMarco, Brogan, and Lerman (2002) found that when mothers with breast cancer disclosed possible risk to their children, they were motivated by their child's right to know, a sense of responsibility to let them know, and concern for the burden placed on both the child and their relationship with the child. Finally, the actual telling of the information was viewed as a process of 'pragmatism' or 'prevarication'. The former initiates this process, while the latter waits for the process to happen (i.e. they think it is all a matter of timing.) Whereas pragmatists may take a week to disclose, prevaricators take months or years (Forrest et al., 2003).

In the same study, Forrest et al. found that a person may not disclose because he or she has yet to accept the condition him or herself. It is not that these people are not willing to tell, they just need time. Three other barriers identified were a desire to protect the family, bad existing family relationships where communication was already hindered, and feeling that some people did not need to know. An example of the last factor may happen if breast and ovarian cancer run in a family consisting of mostly boys. Because the risk is lower, the chances of revealing that information is lowered as well (Forrest et al., 2003).

A study conducted to assess people's attitudes about disclosing potential carriers of alpha - 1 - antitrypsin deficiency, a genetic disorder connected with

both lung and liver disease (A1AD), with or without their consent revealed that most people consider the rights of those at risk over the rights to privacy of those infected (Wilcke, Seersholm, Kok-Jensen, & Dirksen, 1999). This was determined by a questionnaire presenting a hypothetical situation about a person first exhibiting the symptoms of A1AD, and then being diagnosed. One of the questions following the narrative asked, "Should Nina disclose the identities of her parents, siblings, and children, to enable her physician to offer them testing for A1AD?" (Wilcke et al., 1999, p. 903). An overwhelming majority, 97.2% (N = 1,609) marked "perhaps yes" or "definitely yes" on the questionnaire (Wilcke et al., 1999).

Choosing not to disclose serious genetic health conditions could have serious repercussions for other family members. In Bennetts's (2004) family, three of her great-aunts died from some type of reproductive cancer; however, their "prim Victorian sensibilities" did not warrant discussion about such sensitive topics (p. 143). As a result, Bennetts's (2004) medical history still lacks information about illnesses to which the rest of her family are predisposed.

The consequences of a parent not disclosing his or her child's HIV/AIDS status affect the child's willingness to go through seemingly unnecessary steps to care for him or herself. It follows that if a child does not know that he or she is sick, then the child would not perceive the need to take steps to maintain his or her health. Discussing sexual activity is another area that is significantly impacted by knowledge of one's HIV/AIDS status. The child may also

experience undue stress about death and dying when not given the opportunity to talk about it. Finally, the child may piece together an incorrect picture of what is actually wrong in trying to make sense of the hospital visits, medications, etc. (Lee & Johann–Liang, 1999). Yet, despite these things, children are not told about HIV/AIDS at a high rate (Lee & Johann–Liang, 1999).

Interviews conducted after mothers disclosed their HIV status to their children revealed that the preparation for the disclosing event, age of the child, context of the message, and post-disclosure expectations need to be carefully examined before the actual conversation occurs (Murphy, Roberts, & Hoffman, 2003). One third of the 135 parent–child dyads in this HIV study reported regret about disclosure due to either not being prepared, the child being too young to understand, the incompleteness of the mother's message, and/or the mother's post-disclosure expectations being too high (Murphy et al., 2003). It seems the best way to prevent these regrets is through support from another HIV mother. Unfortunately, such a support system is hard to find (Murphy, 2003).

Many times parents avoid disclosing by rationalizing that the child is not old enough to receive this information. They do not feel the child can obey the collaborative boundary rules, is able to comprehend the information, or is able to form an understanding of death (Lee & Johann–Liang, 1999). When the disclosure is done gradually and communication remains open, these barriers can be overcome (Lee & Johann – Liang, 1999). It may be that the parents are the ones not ready to disclose. Past communication patterns are indicative of



future communication patterns; if the parent did not disclose vulnerable information before a diagnosis, he or she was less likely, or more challenged to do so afterwards (Tercyak, 2002).

Carriers of breast cancer causing genes, *BRCA-1* and *BRCA-2*, are more willing to disclose this information to relatives once they have an understanding of what being a carrier means and what type of carrier they are (Costalas et al., 2003). Women are more willing to disclose to their adult sisters and daughters than brothers and sons (Costalas et al., 2003). Gender is also considered when deciding to whom to disclose outside of the immediate family; once again, women are the intended recipients, possibly due to the fact that they are at higher risk for these genes (Costalas et al., 2003). Curability and prognosis are also factors in disclosing these types of cancers, as well as other cancers (Peteronio et al., 2003).

In general, people tend to more readily disclose what is socially acceptable (Greene, 2000). This can be seen with the now common disclosure of cancers (Peterson et al., 2003). As mentioned earlier, research also shows that people would rather disclose to others outside of the family, versus within the family (Greene, 2000). These preferences fall under CPM's framework of rules because a certain level of permeability accompanies the information recipient. Thus, a friend may receive more detailed information than a brother based on the past coordinated boundaries, present relationship, and purpose. The concepts of rule-making criteria, boundary coordination, and boundary turbulence are

evident in these examples.

Now that the management processes have been illustrated throughout both family disclosure and health disclosure research, the following section will address bipolar disorder. Because the present study focuses upon parental disclosure as it pertains to bipolar disorder, it is important to have a basic understanding of the disorder's impact on one's life.

### Bipolar Disorder

There are many organizations that exist to study and provide accurate information on mental illnesses. The National Institute of Mental Health (NIMH), a branch of the Federal government's National Institute of Health (NIH), is one of those organizations. NIMH's president, Dr. Insel, states that "[o]ur mission is to reduce the burden of mental illness and behavioral disorders through research on mind, brain, and behavior" (2004, About NIMH, para. 2). Another major organization is the National Alliance for the Mentally Ill, a non-profit organization whose subtitle reads *The Nation's Voice on Mental Illness*. They strive to be the voice of millions suffering from any type of severe mental disorder. Their mission statement reads, "NAMI is dedicated to the eradication of mental illnesses and to the improvement of the quality of life of all whose lives are affected by these diseases" (2005, About NAMI, para.1). These two organizations will serve as primary sources in attempting to describe Bipolar disorder.

Dr. Kay Redfield Jamison is not only a leading researcher in the field of mood disorders, she also has been diagnosed with the Bipolar disorder. In her

book, *An Unquiet Mind*, she says "Manic-depression distorts moods and thoughts, incites dreadful behaviors, destroys the basis of rational thought, and too often erodes the desire and will to live" (1995, p.6). Bipolar disorder, commonly referred to as manic-depressive illness, is a chemical imbalance in the brain "that causes unusual shifts in a person's mood, energy, and ability to function" (Spearing, Hyman, Rudorfer, & Pearson, 2001, p.2). These shifts, also referred to as episodes of mania and depression, last for varying periods with normal moods in between. Currently, the disorder is known to affect 5% of the general population (Thomas, 2004).

Scientists have not identified the exact cause of the disorder; however, they have found the disorder to run in families. Genetics research shows that "[d]ata from family, twin, and adoption studies unequivocally demonstrate the involvement of genetic factors in the transmission of bipolar disorder" (NIMH, 2000, p. 4). The closer one is genetically to a person with bipolar, the more likely he or she is to be affected (NAMI, 2004). Symptoms of the disorder tend to start during one's adolescent years or in one's early twenties (NAMI, 2004). Although gene research may allow scientists to locate the gene or genes responsible for the imbalance, it is important to note that other factors, such as life events and one's environment, also influence the likelihood of developing the disorder (Spearing et al., 2001).

Bipolar disorder is typically classified as one of two subtypes, Bipolar I and Bipolar II, although continued research has developed less common subtypes (Thomas, 2004). Bipolar disorder, also characterized as a mood disorder, varies

between states of depression and mania; these two states are opposite sides of the spectrum, or polar opposites.

Manic episodes elevate one's mood to an extreme level. A person may become highly energetic, overly active, or restless. The person begins to lose touch with reality, slipping into a euphoric state of mind. This results in impaired judgment possibly resulting in spending sprees, drug and alcohol abuse, aggression, or an increased sexual drive. Sleep is no longer a necessity and focus becomes utterly impossible (Spearing et al., 2001). A less intense form of mania is hypomania, which is characterized by the same symptoms as mania, but more difficult to recognize because it can be easily masked as enhanced productivity (Spearing et al., 2001). Symptoms of depression typically follow the manic episode, taking the person from one extreme to the other. A person becomes hopeless and feels helpless. The individual no longer sees purpose in the things that were once enjoyed, nor does the person have the energy to engage in the activities. This emptiness affects the ability to concentrate, causes an increase in sleep, and often is accompanied by suicidal thoughts (Spearing et al., 2001). In fact, 25% to 50% of patients attempt suicide, while 15% succeed; the rate increases when the disorder goes untreated (Goodwin & Jamison, 1990; Thomas, 2004). These numbers are significant considering that in 2001 suicide was the eleventh leading cause of death and the third leading cause in 15 to 24 year olds, with 90% of these deaths committed by people with mental disorders (Spearing et al., 2001).

The distinguishing factor between whether a person has Bipolar I or

Bipolar II depends on the cycle of moods he or she experiences. Bipolar I is when one cycles between depression and mania and Bipolar II is when one cycles between depression and hypomania (Spearing et al., 2001). A person may also experience *mixed* states if feelings of depression and mania occur at the same time (Spearing et al., 2001).

The harsh transition from mania to depression is what makes the disorder terribly difficult to manage. Mania creates a world that is more than exciting and a life that is better than great; depression comes along and flips that world upside down, while reality gets lost somewhere in between. Medication and psychotherapy seem to be the best ways to combat these drastic mood swings; however, oftentimes people stop their medication once their moods seem stable for a significant period of time (NAMI, 2004).

Typically consumers are treated with "mood stabilizers", often taken for the duration of a person's life unless it is recommended that he or she be taken off of their medication (Spearing et al., 2001). Periodically, other medications may be added to specifically treat periods of mania and depression (Spearing et al., 2001). In addition to medication, it is also recommended that people with bipolar enter into psychotherapy, or "talk therapy", such as "cognitive behavioral therapy, psychoeducation, family therapy, and interpersonal and social rhythm therapy" (Spearing et al., 2001, p. 17). "Studies have shown that psychosocial interventions can lead to increased mood stability, fewer hospitalizations, and improved functioning in several areas" (Spearing et al., 2001, p. 17). Despite the effective treatment available, many people go untreated because the disorder is

difficult to diagnose. Of the people that do not receive treatment, 40% self-medicate by abusing drugs and alcohol (NAMI, 2004). Drug abuse, alcohol abuse, and suicide are three motivating factors in improving the diagnosis rate and accuracy of bipolar disorder.

Dr. Thomas (2004, p. S3) writes, "[a]lthough bipolar disorder has been known since about [sic] the classic work of Aretaeus in the first century AD, the gap between the age at onset and the age when first treated remains large reflecting the poor recognition of this disorder by clinicians". Although scientists have not identified the exact cause of the disorder, they do know that there is a family component, so it is here that we must start in our examination of the disorder.

#### Rationale

"Genetic diseases are family diseases" (Sorenson, Jennings - Grant, & Newman, 2003, p. 3). Research on communication surrounding genetic risk typically focuses upon cancers, Huntington's disease, families with balanced translocations, and disorders acquired through recessive genes (Forrest et al., 2003). Very few studies have investigated the communicative events surrounding genetic risk within families (Daly et al., 1999).

"All family members are affected by a loved one's mental illness. The entire family system needs to be addressed. To assure us that we are not to blame and the situation is not hopeless. To point us to people and places that can help our loved one. The impact still lingers on" (Marsh & Johnson, 1997, p. 229).

The impact of mental illness on family members has been categorized by researchers as carrying two types of burden – subjective and objective (Lefley, 1996). “Subjective burden is the personal suffering experienced by family members in response to their relative’s illness; objective burden refers to the daily problems and challenges associated with the illness” (Marsh & Johnson, 1997, p. 229). How a family chooses to deal with these burdens is a determining factor in a family’s ability to cope and to experience resilience (March & Lefley, 1996). Many programs have been established to aid families in this struggle.

It has been discovered that raising children in a home while caring for a family member with a mental disorder, particularly a parent, creates stress and a need for additional support for the children (Ostman & Hansson, 2001). “Among the most vulnerable and most affected by a family member with mental illness are the children who live with that member” (Kinsella & Anderson, 1996, p. 24).

“The needs, however, of children with parents who have a serious mental illness (e.g., psychosis) have for a long time been underrecognized” (Pitman & Matthey, 2004, p. 383). In response to the research exposing this need, a number of support programs have been established over the last few years. These programs are designed to create a support system, serve as a voice for the child, increase the child’s understanding of the condition, and enhance the parent–child relationship (Pitman & Matthey, 2004).

One such program is SMILES. This program is 3 days long and seeks to improve a child's ability to cope and a child's resilience (Pitman & Matthey, 2004). "The aims are achieved through education about mental illness, communication exercises, problem solving, artwork, music, interactive and relaxation exercises, and peer support (Pitman & Matthey, 2004, p. 384). The benefits of such programs can be seen in the following statements: "Through guidelines learnt, [my daughter] has the ability to listen, observe and recognize symptoms associated with mental illness"; "This is the first time we've been able to discuss mental illness as a family"; "Great benefits. He is aware now of what mental illness is, what side effects the medications have and knowing that mental illness is like any other illness..." (Pitman & Matthey, 2004, p. 387).

*Positive Connections* is another program that seeks to assist in supporting and educating children about living with someone with a mental illness. The program first identifies children who do in fact struggle with their parent's, or caregiver's conditions, and then pairs them up through *Big Brothers Big Sisters*, while working with mental health groups. The mentorship relationships provide support, while the Unison Behavioral Health Group and Alliance for the Mentally Ill of Greater Toledo provide education and coping skills (Orel, Groves, & Shannon, 2002). The five – week program is effective in making the children feel like they are not alone, and increases their mental health knowledge and self – esteem (Orel et al., 2002). Yet, issues of genetic risks do not seem to be apart of such programs.



Since 1959, researchers have focused on the benefits of disclosing – for the discloser (Jourard, 1959). After all, “[i]f self disclosure is one of the means by which healthy personality is both achieved and maintained, we can also note that such activities as loving, psychotherapy, counseling, teaching and nursing all are impossible of achievement without the disclosure of the client” (Jourard, 1959, p. 505). However, given the genetic risk of bipolar disorder, the benefits of disclosing for the recipients of the disclosure deserve a closer look. The disclosure of such information has the potential to improve both diagnosis accuracy, as well as healthcare for future bipolar consumers.

Research supports the claim that bipolar disorder contains a genetic component; however, a specific gene has not been identified (NIMH, 2001). While nothing can currently be done genetically to increase the accuracy of diagnosing bipolar disorder, something can be done communicatively within families in which bipolar is already present. Although programs for children of family members with mental disorders have been established, none of these programs specifically prepare future generations of these bipolar parents to identify and live with the risk of developing bipolar disorder themselves.

Bipolar disorders are both difficult to diagnose and to treat. The purpose of this study is to explore ways to improve diagnosis accuracy and treatment through communication. By increasing communication about the disorder, those at risk of developing the disorder simply because of their family history, will be better able to receive the proper diagnosis early on in seeking treatment and to take the necessary steps to care for themselves, armed with the knowledge of

their family history and experiences to guide them away from making the same mistakes.

Communication about the genetic risk associated with the disorder and the behaviors directly related to the disorder can prevent future bipolar consumers from making and suffering from the mistakes of current bipolar family members. In order to fully assess the benefits of such disclosure, the prevalence of the disclosure itself must be noted. In other words, how often are conversations such as this taking place? This raises the first research question:

#### RQ1

To what extent do parents disclose their bipolar disorder to their children?

Establishing the extent of disclosure provides the groundwork for applying Petronio's Communication Privacy Management theory. The Health Insurance Portability and Accountability Act of 1996 (HIPAA) is evidence of the belief that one's mental health is one's own business (Thacker, 2003). Stigmatization and discrimination are just two reasons why mental health consumers refrain from openly sharing information about their mental health (Jamison, 1995). While this is understandable, these reasons do not provide an understanding for why parents do not share information about bipolarity with their own family members, given the potentially devastating effects of the disorder on the consumer and his or her family (NIMH, 2001). Petronio's theory gives insight into the possible reasons for concealment through the six criteria she uses to assess privacy rules, which is the basis for the second research question.

**RQ2**

**What factors affect a person's decision to reveal or conceal the diagnosis of bipolar disorder to members of their family?**

Knowing the privacy rules governing a parent's decision to reveal or conceal are of interest because a number of studies have not only demonstrated the benefits of disclosing, but also the benefits of psychoeducational programs for children (Greene, 2000; Jourard, 1958; Pennebaker et al., 2001; Petronio 2002). These programs enhance their coping skills and resiliency (Pitman & Matthey, 2004; Orel et al., 2002). If disclosure is beneficial, and if providing information about the disorder is beneficial, then it would follow that parental disclosure of the disorder would also be beneficial. In addition to impacting coping and resiliency in children, this information may also benefit children by equipping them with the ability to manage their own mental health in the event that they too are diagnosed with the disorder. Currently, there is no research linking parental disclosure and potential health benefits for their offspring. The third research question addresses this issue.

**RQ3**

**Does the extent to which people disclose about a bipolar condition relate to the ability of offspring to cope with their own bipolar struggles?**

In answering these research questions, it is hoped that diagnosis and healthcare of bipolar consumers can be improved. To collect the data, a website was created for the purposes of posting a survey for a period of 30 days. The

prevalence of conversations concerning the disorder were established using a Likert – type scale. The actual rules governing the disclosure of one's bipolar condition were assessed using a Likert – type scale and open – ended questions. Establishing the impact of these disclosures were then analyzed with open – ended questions. The next section will discuss how the data will be analyzed specifically.

## CHAPTER II

### METHOD

Due to the private nature of mental health information and HIPPA regulations, which does not allow for public release of personal health information, participants for this study were recruited from the internet (Thacker, 2003). The internet provides a number of online support groups for bipolar consumers and others impacted by the illness, as well as the ability to maintain anonymity of participants (NIMH, 2001). A number of mental health sites, locatable by internet search engines, provide current information about the disorder, links to various chat rooms, as well as ways to increase awareness about the illness in their community.

A website was created containing a survey to be filled out by each participant (see Appendix A). The website opened with a page providing basic information about the study and the option of viewing and/or participating in the survey. The address of the site was sent to webmasters whose sites provided online support for bipolar consumers, extending an invitation to participate in the study by posting the website address to their own homepages. Participants could only gain access to the website containing the survey by first accessing a mental health website on which the link was posted. A person deciding to

participate had to electronically fill out the survey and then click "submit" to deliver the data.

### Subjects

It is important to note that, of the 113 participants, 93 were female and 20 were male. Eighty – two percent of the participants were Caucasian. Although internet research provides the possibility of receiving international data, this study did not yield enough diversity to make cultural interpretations outside of the United States.

The following demographics will be important based on the key factors of the study. They will be discussed in greater detail within the context of the research questions. The factors are as follows – age, parental status, participant's personal and familial connection to the disorder, and emerging factors relating to the research questions.

Forty – one percent of the participants were between the ages of 19 and 30, 48% were between the ages of 31 and 50; these two groups account for 88.5% of participants. Based on those demographics, responses to items concerning family communication within families that have a bipolar presence are assumed to be retrospective in nature assuming these participants no longer reside in their family's home. Marital status is broken down into three groups with 18.6% being married, 38.9% divorced, and 42.5% single.

Overall, 59.4% of the participants had biological children and 49.6% did not. Seven of the parents were single parents, 33 were married, and 17 divorced. Twenty – one of these parents were offspring of bipolar or suspected

bipolar parents. These participants provided a unique perspective, having experienced both sides of the issue.

The three main ways participants indicated being connected to bipolar disorder were that 1) they themselves were bipolar (29.2%); 2) they suspected a parent(s) was bipolar and they were bipolar (12.4%); or 3) they were a bipolar parent (10.6%). Forty – one participants indicated that they were offspring of bipolar parents, and 60 indicated a bipolar presence within their extended family. Forty - five percent of the bipolar participants were diagnosed between the ages of 19 and 30 and 31% were diagnosed between the ages of 31 and 50. Factors influencing the disclosure of their bipolarity were directly linked with informational support, tangible support, emotional support, and coping strategies. Factors deterring them from disclosing were directly linked with the age of their offspring, the denial of informational support, stigma, the “universal excuse” mentality, and existing feelings of there being no advantages to doing so at all.

### Instrumentation

The survey was constructed to determine the communication behaviors of people affected, directly or indirectly, by bipolar disorder. The communicative behaviors being investigated specifically relate to disclosure patterns of the individuals about their experiences with the disorder. The survey questions were developed to provide insight into the communication about mental health within families.

The initial survey items are demographic in nature, establishing the participant's connection to bipolar disorder and the prevalence of the disorder in

his or her family. They are categorical in nature. Eight items focus on the amount of communication that took place within a family about the disorder. Responses to these items are measured on a Likert – type scale and include five steps ranging from “never” to “very often”. Eight other items, also on a Likert – type scale, are concerned with the consumer’s beliefs about disclosure and its impact on offspring, as well as their own difficulties with coping with the illness. These questions range from “strongly agree” to “strongly disagree”. There is another group of items, Likert – type scale, ranging from “very comfortable” to “very uncomfortable” that deals specifically with how comfortable a bipolar consumer is with disclosing to members of his or her immediate family.

Finally, the survey contains five open – ended questions allowing participants to comment on the following: 1) reasons for disclosing their bipolarity to their offspring, 2) reasons for not disclosing their bipolarity to their offspring, 3) the advantages of disclosing their bipolarity to family members, 4) the disadvantages of disclosing their bipolarity to family members, and 5) the impact knowing or not knowing of a bipolar presence in their family has had on their own health. Each open – ended response was categorically coded for the purposes of performing data analysis. The coding system was developed by reviewing the responses for each question in order to assess whether any response patterns had emerged. For instance, if a number of responses indicated that they were unlikely to disclose because of sort of stigma, then those responses were grouped together into one category. Initially the categories were very specific, and then they were refined so that they could yield meaningful results.



Inter – coder agreement was achieved by training a secondary coder to categorize responses from each question (Holsti, 1969). The researcher first explained the definition of each category, and provided examples of typical responses. The coder then coded some responses under the supervision of the researcher to ensure that the instructions and definitions were understood. The coder was to place each response in the appropriate categories, which were represented by numbers. Once the coder completed the questions, the researcher calculated percentages for inter – coder agreement. This was done by first summing the number of times a specific category was used by both the researcher and coder. Second, the number of times the researcher coded a response differently from the coder was summed. Third, the total number of times that a specific category was used was divided by the number of disagreements between the researcher and coder. In order to attain acceptable inter – coder agreement, the final percentage must be higher than 80%. Inter – coder agreement remained at 80% or better for each category and appears with each variable below.

1) Coding: Primary reasons for not telling all of offspring about bipolar condition.

- Believe child is too young to understand (96%);
- Irrelevant – the response was too specific to the individual (83%).

2) Coding: Primary reasons for telling all of offspring about bipolar condition.

- Symptoms were life intruding – parent's condition interrupted daily routine due to hospitalizations, job loss, suicide attempt, etc. (100%);
- Informational support – parent wants offspring to understand the illness

and how it affects one's behaviors and moods; this knowledge prevents the offspring from thinking that they are the cause of their parent's behavior, and it allows them to separate the illness from the individual (93%);

- Child is bipolar – offspring is bipolar (100%);
- Genetic/Symptomatic awareness – parent wants to make offspring aware that bipolar has a genetic tendency and to equip them with the ability to identify symptoms within themselves or others (86%);
- Other – the response was too specific to the individual (100%);
- Irrelevant – responses do not pertain to the question (100%).

### 3) Coding: Advantages of disclosing one's bipolarity to family members.

- None/unsure – participant does not believe, or is unsure that there are any advantages (100%);
- Emotional support – the potential of receiving compassion or empathy (96%);
- Tangible support (self) – the potential for physical support such as having a loved one to attend doctor's appointments, monitor moods, etc. (95%);
- Information support – the potential gaining understanding from family about the illness and how it affects one's moods and behaviors (97%);
- Coping – the potential of helping others to cope with a bipolar family member, or of helping others cope with their own bipolar struggles i.e. a bipolar consumer may acquire new coping skills from another bipolar consumer who was willing to disclose (92%);

- Tangible support (others) – equipping non – bipolar consumers with knowledge that will allow them to identify bipolar symptoms in themselves or others (84%);
- Other - the response was too specific to the individual (100%);
- Irrelevant – responses do not pertain to the question (100%);

#### 4) Coding: Disadvantages of disclosing one's bipolarity to family members.

- None/unsure - participant does not believe, or is unsure that there are any disadvantages (100%);
- Denial – family members deny the existence of the disorder within their family or in general (97%);
- Family dismissal – family does not take the illness or its symptoms seriously (96%);
- Universal excuse – family falsely attributes behaviors to the illness when the consumer is not experiencing its effects (95%);
- Pejorative connotations/stigma – consumer is thought of as unstable or crazy, incapable of performing at a certain standard (97%);
- Other - the response was too specific to the individual (96%);
- Irrelevant - responses do not pertain to the question (100%).

#### 5) Coding: The impact knowing or not knowing of a bipolar presence in one's family has on his or her health.

- None/unsure – participant does not believe that there was an impact (100%);
- Social proof – knowing keeps consumer from feeling like the only one/ not

knowing creates a feeling of aloneness (92%);

- Informational Support – knowing provides an explanation for symptoms he or she was experiencing and an understanding of how the disorder impacts his or her moods and behaviors/ not knowing prevents a person from having a reason for his or her experiences (92%);
- Physical or Mental Health – knowing allowed participants to receive the proper treatment sooner, preventing them from harming themselves or others physically or relationally and from dealing with the symptoms without medical assistance/not knowing forced the participants to survive with the symptoms or resulted in them causing physical harm to themselves or others (93%);
- Emotional tension – knowing created increased emotional tension (92%);
- Other - the response was too specific to the individual (100%);
- Irrelevant - responses do not pertain to the question (100%).

### Data Analysis

The data were examined using the Statistical Package for the Social Sciences (SPSS 11.5 for Windows). Data were analyzed by a series of descriptives, frequencies, t-tests, chi-squares, Pearson product-moment correlations, and one-way ANOVAs. The descriptive data addressed the first two research questions and the remaining analyses addressed the third research question.

## CHAPTER III

### RESULTS

The data that follow are presented in three ways. First, the demographics are provided, giving the reader insight into the data. Second, data specifically pertaining to the research questions will serve to connect the actual questions with the study. Third, some supplemental analyses that go beyond the research questions but that address some interesting issues will be included towards the end of this section.

There were 113 participants. The majority of the participants were Caucasian, and 82% of the participants were female. The survey was distributed via the internet, which allowed people from other countries to access it; international respondents accounted for 15% of the participants. Because the study focuses on family communication, it is also important to note that 43% of the participants were single, 39% divorced, and 19% married. Fifty – nine point four percent of the people have biological children ( $M = 2.15$ ,  $SD = 1.34$ ) and 50% of them do not. In relation to bipolar disorder, participants identified themselves by choosing one of the options presented in Table 1. The most common selection was that the participant was bipolar (29%), followed by that the participant was bipolar and the offspring of a suspected bipolar parent(s)

(12%), and that the participant was a bipolar parent (11%).

### Research Question One

Research question 1, "To what extent do bipolar parents disclose their bipolar condition to their offspring?" was analyzed from two directions. This allows the participant to comment on being the offspring of a parent with a mental illness, as well as raising offspring in a house with mental illness. The first analysis examined bipolar parents' responses to whether or not they have disclosed to all of their offspring, which can be seen in Table 2. This response is broken down further into the reasons for their decision.

Thirty percent of bipolar parents decided to disclose this information to their offspring, while 15.9% did not. Tables 3 and 4 list the reasoning behind both decisions. The most common reason for why parents did not disclose their bipolarity was that they felt their offspring were too young to understand (63%). The most common reasons why parents chose to disclose to their offspring were that they wanted them to understand the reasons for their moods and behaviors (24%), they wanted to inform them of the genetic risks and symptomatic warnings (18%), and their offspring was also diagnosed with bipolar (15%). One should also note that although genetic/symptomatic awareness and having a bipolar child were the second and third highest ranked reasons for disclosure, the majority of participants indicated these reasons in addition to wanting their offspring to understand the illness, placing an even greater emphasis on parent's disclosing to their offspring for the purpose of providing understanding, or insight into bipolar disorder.

TABLE 1

## FREQUENCY OF PARTICIPANT'S CONNECTION TO BIPOLAR DISORDER

	Frequency	Valid Percent
Valid		
I have bipolar.	34	30.1
I suspect my parent(s) have bipolar and I am bipolar.	14	12.4
I am a parent with bipolar.	12	10.6
I suspect my parent(s) have bipolar; I am a bipolar parent.	11	9.7
My parent(s) have bipolar and I have bipolar.	8	7.1
I am the parent of bipolar child.	8	7.1
I am an offspring of a suspected BP parent.	6	5.3
My parent(s) have bipolar; I am a bipolar parent.	5	4.4
other	5	4.4
I am an offspring of a bipolar parent.	3	2.7
My parent(s) have bipolar; I am a BP parent of BP offspring.	3	2.7
I am the bipolar parent of bipolar offspring.	2	1.8
I suspect my parent(s) have BP; I am a BP parent of BP kids.	2	1.8
Total	113	100.0
Total	113	

TABLE 2

## FREQUENCY OF PARENTS DISCLOSING BIPOLARITY TO OFFSPRING

		Frequency	Valid Percent
Valid	I am not a parent.	61	54.0
	yes	34	30.1
	no	18	15.9
	Total	113	100.0
Total		113	

TABLE 3

## FREQUENCY OF WHY PARENTS HAVE NOT DISCLOSED BIPOLARITY TO OFFSPRING

		Frequency	Valid Percent
Valid	Believe child is too young to understand (1)	12	63.2
	Irrelevant (2)	5	26.3
	1,2	2	10.5
	Total	19	100.0
Missing	System	94	
Total		113	

1,2 represents a combination of variable numbers one and two.



**TABLE 4**  
**FREQUENCY OF WHY PARENTS HAVE DISCLOSED BIPOLARITY TO**  
**OFFSPRING**

		Frequency	Valid Percent
Valid	Informational		
	support-understanding/ insight (3)	8	23.5
	3,5	6	17.6
	3,4	5	14.7
	Child is bipolar (4)	4	11.8
	Genetic/symptomatic awareness (5)	3	8.8
	Symptoms were life intruding (2)	2	5.9
	4,5	2	5.9
	Irrelevant (1)	1	2.9
	other (6)	1	2.9
	2,3	1	2.9
	2,5	1	2.9
	Total	34	100.0
Missing	System	79	
Total		113	

The second analysis evaluates the rate at which topics were discussed among families with known or suspected bipolar disorder as displayed in Table 1. These questions were assessed with a Likert – types scale with one meaning “never” and five meaning “very often”. When asked how frequently the issue was discussed, the data show that it was not a frequently discussed topic ( $M = 2.73$ ,  $SD = 1.38$ ). The means representing what topics were discussed at what rate are displayed in Table 5. The most discussed topics within families who knew of a bipolar family member were the consumer’s odd behavior ( $M = 3.21$ ,  $SD = 1.28$ ), concerns for the consumer’s condition ( $M = 3.21$ ,  $SD = 1.36$ ), and ways to better care for the bipolar family member ( $M = 2.84$ ,  $SD = 1.41$ ). Despite these conversations, only 6.2% of offspring who knew of their parent’s bipolarity understood the diagnosis before the age of 18, 13.3% understood sometime between the ages of 19 and 30, while 16.8% understood between the ages of 31 and 50. See Table 6.

### Research Question Two

Research question 2 asked, “What factors affect a person’s decision to reveal or conceal the diagnosis of bipolar disorder to members of their family?” Tables 7 and 8 display the key factors that determine whether a person with bipolar disorder will or will not disclose that information within his or her family.

Table 7 shows that the major factors influencing whether a consumer will reveal his or her bipolar condition are to provide or receive different types of support. Informational support involves the consumer educating and providing insight into the disorder for others; 21% of the respondents gave this reason

within the text of the open – ended question. Second was tangible support (16%), which means that participants disclose desiring to receive tangible, or physical, assistance from loved ones, i.e. helping to track moods, attending doctor's appointments, monitoring medication, etc. Third, 13% indicated that they most valued both receiving tangible support and providing informational support. Ten percent of participants indicated that they did not see any value in disclosing to family members.

Two primary reasons influence consumer decisions to conceal their bipolarity (See Table 8). Twenty – four percent of consumers are influenced not to reveal based on pejorative comments, or stigma. Twenty percent indicated that they are discouraged from disclosing due to their families' denial of the 'disorders existence or presence within their family member – this includes the majority of the males. A chi – square was performed on these factors and sex and found that the majority of the females were discouraged mostly by stigma, while the majority of the males were discouraged by their family's denial (see Table 9).

**TABLE 5**  
**MEANS FOR TOPICS DISCUSSED**

	N	Mean
Discussed person's odd behaviors.	106	3.21
Expressing concerns about the member's condition.	107	3.21
Better caring for the person with BP.	107	2.84
To increase family's understanding of BP.	106	2.83
Tendency of BP to occur within families.	105	2.58
Possibility of current family to have BP b/c of family history of BP.	107	2.52
Discussed helping others to cope with the symptoms of BP.	107	2.51
Valid N (listwise)	102	

**TABLE 6**  
**FREQUENCY OF WHAT AGE OFFSPRING WAS WHEN HE OR SHE UNDERSTOOD BIPOLAR PARENTS CONDITION**

		Frequency	Valid Percent
Valid	N/A	72	63.7
	31 - 50	19	16.8
	19 - 30	15	13.3
	12 - 18	5	4.4
	younger than 12	2	1.8
	Total	113	100.0
Total		113	

TABLE 7

**FREQUENCY OF FACTORS THAT DETERMINE A PERSON'S DECISION TO  
DISCLOSE BIPOLARITY TO HIS OR HER FAMILY**

		Frequency	Valid Percent
Valid	Informational support-education/ understanding/insight (4)	21	21.0
	Tangible support for bipolar consumer (3)	16	16.0
	3,4	13	13.0
	none (1)	10	10.0
	Emotional support-compassion/ empathy (2)	6	6.0
	2,4	6	6.0
	4,5	6	6.0
	4,6	6	6.0
	Coping-helping others to cope with BP member or their own BP struggle (5)	4	4.0
	Tangible support for BP loved one's/equip them to ID symptoms (6)	4	4.0
	Irrelevant (7)	2	2.0
	other	2	2.0
	4,7	1	1.0
	1,5	1	1.0
	3,4,5	1	1.0
	2,7	1	1.0
	Total	100	100.0
Missing	System	13	
Total		113	

TABLE 8

**FREQUENCY OF FACTORS THAT DETERMINE A PERSON'S DECISION NOT  
TO DISCLOSE BIPOLARITY TO HIS OR HER FAMILY**

		Frequency	Valid Percent
Valid	Pejorative connotations/Look down on me/Stigma (5)	24	24.0
	Denial - they won't understand the illness (2)	20	20.0
	None/unsure (1)	10	10.0
	Used as a universal excuse;falsely attribute behavior to BP (4)	9	9.0
	other (6)	8	8.0
	May deny/dismiss seriousness of illness/symptoms (3)	7	7.0
	2,5	6	6.0
	Irrelevant	5	5.0
	5,6	4	4.0
	2,3,5	3	3.0
	3,5	2	2.0
	2,3,4	1	1.0
	2,3	1	1.0
	Total	100	100.0
Missing	System	13	
Total		113	

**TABLE 9**  
**CHI-SQUARE OF SEX \* DISADVANTAGES OF DISCLOSING**

								Total
		None/ unsure	Denial	Famiy dismissal of serious- ness	Universal excuse	Pejorative Connata- tions	Other (includes all combination variables)	
sex	female	8	14	7	8	22	20	79
	male	2	6		1	2	5	16
Total		10	20	7	9	24	25	95

### Research Question Three

The final research question asked, "Does the extent to which people disclose about a bipolar condition relate to the ability of offspring to cope with their own bipolar struggles?" Table 10 lists the frequency of responses to the survey question which asked, "How has knowing/not knowing of a bipolar presence in your family impacted your own health?" The broad wording of this question yielded very personal responses, which explains why 14% of the responses were not particularly connected with the direction of the study and thus were categorized as "irrelevant". Twenty percent did not see how their health was impacted at all, while 26% felt that knowing or not knowing of a bipolar presence in their families impacted their physical and/or mental health. Within this category, respondents either said that knowing allowed them to

receive help sooner, prevented opportunities for dangerous behavior against oneself and/or others, or that not knowing delayed them receiving the treatment they needed, causing them to make some dangerous decisions relating to self – medication and the negative symptoms associated with bipolar disorder.

#### Supplemental Analyses – Family communication about bipolar disorder

Supplemental analyses were performed to see what other factors may play a significant role in family communication about bipolar disorder. The first factor is that bipolar consumers felt more comfortable discussing their condition with their mothers ( $M = 3.74$ ,  $SD = 1.58$ ) versus their fathers ( $M = 3.53$ ,  $SD = 1.65$ ). A one – way ANOVA (see Table 11) found a significant difference based on age in whether or not participants thought it was important for offspring to know of their parent's bipolar condition, ( $F = 2.48$ ,  $p < .05$ ), such that older participants thought it was more important than younger ones . Tukey's HSD (see Table 12) revealed significant differences between the age groups of 19 – 30 ( $M = 4.37$ ,  $SD = .71$ ) and 31 – 50 ( $M = 4.70$ ,  $SD = .46$ ). A t – test compared those who have parents with bipolar to those who do not have parents with bipolar to see if there were any significant differences regarding what topics families discussed, and at what rate they discussed them. None of these comparisons were significant. Finally, chi – square were used to see if those with children felt differently than those without about the advantages and disadvantages of disclosing their bipolarity, as well as the perceived impact of knowing or not knowing of a bipolar presence in one's family. Those with children found tangible and informational support to be key factors in disclosing;



those without children agreed, however, they also indicated that it was better not to disclose to family members (See Table 13). The factors influencing the decision to mark 'none' as a response to the previous question for those without children are denial, or having the diagnosis be rejected by one's family, and pejorative connotations, or stigma. Those with children were discouraged from disclosing mostly based on comments related to stigma (See Table 14). Lastly, those with children found the greatest impact of knowing or not knowing of a bipolar presence within their own family to be on one's physical and mental health, while those without children indicated that they were 'unsure' or that there was not any impact (See Table 15).

#### Supplemental Analyses – Healthcare of bipolar consumers

The following analyses focus specifically on issues regarding the healthcare of bipolar consumers. Ninety three percent of the bipolar participants were diagnosed within the last fifteen years and 95% of these participants were diagnosed after the age of nineteen; however, when asked whether or not they received an accurate diagnosis initially from their healthcare provider, 25 of the participants replied "yes", while 73, or 74.5%, replied "no". The final section of the survey contains statements that were rated on a Likert – type scale. The two statements that need to be highlighted pertain to how well the bipolar consumer felt prepared to care for him or herself by 1) his or her healthcare provider and/or 2) his or her bipolar family member. In response to the former, bipolar consumers replied that they did not feel adequately prepared by their healthcare provider ( $M = 2.31$ ,  $SD = 1.50$ ). In response to the latter, respondents indicated

feeling even less prepared by their own family members ( $M = 1.46$ ,  $SD = 1.45$ ).

TABLE 10  
FREQUENCY OF IMPACT ON ONE'S HEALTH

		Frequency	Valid Percent
Valid	Physical/Mental issues - prevention/progression of symptoms (4)	24	25.8
	None/unsure (1)	19	20.4
	Irrelevant (0)	13	14.0
	Informational support-education understanding/insight (3)	12	12.9
	Emotional tension (5)	7	7.5
	Social proof - feels alone/does feel alone (2)	5	5.4
	3,6	4	4.3
	Other (6)	3	3.2
	4,5	2	2.2
	2,5,6	1	1.1
	2,6	1	1.1
	3,5	1	1.1
	5,6	1	1.1
	Total	93	100.0
Missing	System	20	
Total		113	

TABLE 11

## FACTORIAL ANALYSIS OF VARIANCE

INDEPENDENT VARIABLE: AGE OF PARTICIPANTS

DEPENDENT VARIABLE: IMPORTANCE OF OFFSPRING KNOWING OF  
PARENT'S BIPOLAR CONDITION

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	3.509	4	.877	2.477	.048
Within Groups	38.243	108	.354		
Total	41.752	112			

TABLE 12

## TUKEY'S HSD FOR ONE - WAY ANOVA

INDEPENDENT VARIABLE: AGE OF PARTICIPANTS

DEPENDENT VARIABLE: IMPORTANCE OF OFFSPRING KNOWING OF  
PARENT'S BIPOLAR CONDITION

(I) age	(J) age	Mean Difference (I-J)	Std. Error	Sig.
younger than 12	12 - 18	-.467	.435	.820
	19 - 30	-.036	.355	1.000
	31 - 50	-.370	.353	.832
	50 +	-.467	.435	.820
12 - 18	younger than 12	.467	.435	.820
	19 - 30	.430	.280	.542
	31 - 50	.096	.278	.997
	50 +	.000	.376	1.000
19 - 30	younger than 12	.036	.355	1.000
	12 - 18	-.430	.280	.542
	31 - 50	-.334*	.119	.047
	50 +	-.430	.280	.542
31 - 50	younger than 12	.370	.353	.832
	12 - 18	-.096	.278	.997
	19 - 30	.334*	.119	.047
	50 +	-.096	.278	.997
50 +	younger than 12	.467	.435	.820
	12 - 18	.000	.376	1.000
	19 - 30	.430	.280	.542
	31 - 50	.096	.278	.997

\* The mean difference is significant at the .05 level.

TABLE 12 (cont.)

(I) age	(J) age	Mean Difference (I-J)	Std. Error	Sig.
younger than 12	12 - 18	-.467	.435	.820
	19 - 30	-.036	.355	1.000
	31 - 50	-.370	.353	.832
	50 +	-.467	.435	.820
12 - 18	younger than 12	.467	.435	.820
	19 - 30	.430	.280	.542
	31 - 50	.096	.278	.997
	50 +	.000	.376	1.000
19 - 30	younger than 12	.036	.355	1.000
	12 - 18	-.430	.280	.542
	31 - 50	-.334*	.119	.047
	50 +	-.430	.280	.542
31 - 50	younger than 12	.370	.353	.832
	12 - 18	-.096	.278	.997
	19 - 30	.334*	.119	.047
	50 +	-.096	.278	.997
50 +	younger than 12	.467	.435	.820
	12 - 18	.000	.376	1.000
	19 - 30	.430	.280	.542
	31 - 50	.096	.278	.997

\* The mean difference is significant at the .05 level.

TABLE 13

CHI – SQUARE OF CHILDREN \* FACTORS THAT DETERMINE A PERSON'S  
DECISION TO DISCLOSE BIPOLARITY TO HIS OR HER FAMILY

	Biological children?		Total
	no	yes	
Irrelevant	2		2
None	8	2	10
Emotional support	5	1	6
Tangible support for BP consumer	9	7	16
Informational support	9	12	21
Coping-helping others to cope with BP member	1	3	4
Tangible support for BP loved one's	1	3	4
Variable Combinations + others	13	14	27
Total	48	42	90

TABLE 14

CHI – SQUARE OF CHILDREN \* FACTORS THAT DETERMINE A PERSON'S  
DECISION NO TO DISCLOSE BIPOLARITY TO HIS OR HER FAMILY

	Do you have biological children?		Total
	yes	no	
Irrelevant	2	3	5
None	5	5	10
Denial	7	13	20
Family dismissal of illness	5	2	7
Universal excuse	5	4	9
Pejorative connotations/ Stigma	13	11	24
Variable combinations + other	8	12	20
Total	45	50	95

TABLE 15

CHI – SQUARE OF CHILDREN \* IMPACT ON DISCLOSING HAS ON ONE'S HEALTH

	Do you have biological children?		Total
	no	yes	
Irrelevant	7	6	13
None	13	6	19
Social proof	3	2	5
Informational support	4	8	12
Physical/mental issues	10	14	24
Emotional tension	3	4	7
Variable combinations + other	5	5	10
Total	45	45	90



## CHAPTER IV

### DISCUSSION

The purpose of this study was to determine what factors impact the breadth and depth of parental disclosure of their bipolar disorder to offspring. A website containing the survey was linked to a number of online bipolar support groups and forums after receiving permission from their webmasters. Only people using these websites could access the survey's website. The results will be interpreted as they pertain to the research questions from both a theoretical and practical perspective beginning with an overview of the descriptive data.

#### Research Question 1

Basic descriptive information was used to answer RQ1, "To what extent do bipolar parents disclose their bipolarity to their offspring?" The majority of the parents indicated that they have told their offspring in order to provide them with an understanding of the illness, a symptomatic and genetic awareness of the illness, and/or the necessary tools needed for their offspring to care for themselves due to their own bipolarity. The parents who replied "no" said that they felt their offspring were too young to understand.

An understanding of the illness equips the offspring with the ability to separate the illness from the individual so that he or she does not blame his

or her parent or even him or herself for the behavior. One parent wrote, "My daughter needs to know that mommy is 'sick' and can be a difficult person but that its [sic] not her fault and she's not bad. She is 5 years old." A symptomatic and genetic awareness prepares the offspring for future encounters with the illness. This way, he or she knows that bipolar is a permanent part of his or her family history and to be watchful for symptoms of the disorder. A parent cites another reason why this information is important, "I think they should know about any inheritable conditions the family has so they can make educated decisions regarding healthcare and having children." The third most cited reason was that their offspring were also diagnosed with bipolar. "I have three children; two of whom are afflicted. Without knowledge about their disorders, about my disorder, there is the inability to cope and inability to learn to take care of oneself properly."

Although discussions are taking place with offspring, those offspring that grew up with a bipolar parent indicate that they did not understand their parent's bipolarity until after they were adults. These offspring also indicated that conversation rarely took place about the illness, but when it did the topics of choice were the consumer's odd behavior, health condition, and caring for that individual. While this may be an indication that these offspring have improved their communication about this issue with their own children, one cannot be sure that this lack of understanding will not continue repeating itself. After all, where would they be acquiring these new communication skills? Communication Privacy Management theory refers to this as 'family

rule socialization' (Petronio, 2002, p. 72). Rules are not simply taught, but lived; therefore, if parents with bipolar are going to improve the quality of communication regarding mental health, they must develop new privacy rules.

What does this say about disclosure? Past research has focused on the benefit of disclosing for the discloser (Jourard, 1959). These results provide incentive for a paradigm shift. It is not only important for the discloser, but also for the disclosee, especially within families. CPM discusses privacy boundaries, which are established for the purposes of controlling who has access to one's private information. If a person co-owning a boundary decides to share with a person outside of that defined boundary, it is considered a boundary violation. If the one controlling access to the information cannot control whom the information impacts, can they then claim ownership of that information? In other words, if bipolar is genetic and has the potential of significantly impacting the lives of other family members, should it not also be a boundary violation on the part of the bipolar consumer if he or she intentionally conceals this information?

If communication about mental health is going to be beneficial for offspring, mental health consumers must approach the issue with this in mind as they begin to develop privacy rules regarding their mental health. The difficulties of this will be discussed in RQ2 using CPM's privacy development criteria.

## Research Question Two

Factors affecting the future of parental disclosure of their bipolarity to offspring were assessed with open – ended questions that were coded into broader categories. Items 24 and 25 addressed “What factors affect a person’s decision to reveal their bipolarity?” and were answered by looking at the means of each category. This section will begin with a discussion of the factors that influence one’s decision to disclose.

The primary advantages people indicated of disclosing their bipolarity were informational support and tangible support. The third highest ranking category was “none”, which means that participants did not see any value in disclosing to their family. Consumers desired informational support to achieve a level of understanding regarding their condition and the cause of it. Most participants wanted to communicate that if they could change their behavior they would. One participant wrote, “Perhaps they will understand my behavior better and see that I am not selfish, lazy, or stupid.” Another person wrote, “They better understand my ‘moods’, and understand that my reactions to them are not always based on ‘true’ unaltered feelings...”

Tangible support *from* others, as opposed to wanting to provide tangible support *for* others, was mentioned in relation to bipolar consumers improving their own healthcare by communicating their needs to their loved ones.

“Making them aware of what I deal with and how I feel. Letting them know [what] my needs are.” “They might be more understanding when I get in my ‘moods’, also they could look out for warning signs of depression/mania.”

Some participants indicating that there were not any advantages expounded on their responses. One person said, "None because they don't accept the illness in themselves, let alone in me." Other people cited denial by their family as the reason for there not being any advantages; this factor will be discussed further in the next section.

It is not surprising that informational support is one of the primary factors influencing a person's decision to disclose according to Jourard's earlier research. "The courage to be [entails] the courage to be known" (Jourard, 1959, p. 503). The desire for informational support is the means to becoming known.

CPM's criterion for privacy rule development provide insight into why these two factors have emerged as the primary reasons for disclosure, while emotional support, coping, and tangible support for others did not receive much consideration. Because being known has been identified as a need innate to being human, one could say that informational support is motivated by an intangible need.

CPM's motivational criteria deal specifically with revealing or concealing in order to meet a need (Petronio, 2002). In fact, both factors fall into this category. Informational support will provide a foundation for privacy rules that work to achieve a deeper understanding among family members and loved ones. Tangible support will provide a foundation for rules that work to improve the consumer's healthcare. " They are my main support group – my husband is Navy and goes to sea a lot , and I have just been diagnosed

...I need help all the time right now and they need to know how to help me..”

This statement also highlights another CPM criteria being used to develop these privacy rules – contextual.

Bipolar disorder is a mood disorder; it affects one's moods and behaviors (NIMH, 2004). Sometimes these behaviors result in the consumer being hospitalized. A contextual criterion can be used to develop a set of rules for a specific, even traumatic, event (Petronio, 2002). In other words, loved ones need to know how to respond during these times as one participant says “...to achieve understanding as a unit to be able to work together as a team to combat the illness and achieve stability, thereby forming a strong support group that will last throughout life.”

These factors would not only improve healthcare for current bipolar consumers, they would also impact how bipolar disorder was viewed as family members multiply these privacy rules within their own social circles as they form new boundary linkages. In the previous research question, the idea of breaking the intergenerational communication patterns about bipolar disorder was introduced. In order to achieve this, a family's rule socialization must change. CPM's criteria are the basis for this change; however, there are opposing rules at work that prevent such growth from taking place.

Stigma, denial, and the “universal excuse” mentality are the key factors deterring disclosure about bipolar disorder. Many participants said they were less likely to share because of the stigma of having a mental illness. “They think I'm crazy or faking.” Another person said, “Disadvantages...the public

stigma, I have a mental disorder, therefore I must be crazy. I hate that...HATE it. But it is something that I have to deal with." A chi – square was performed on these factors using gender and showed that more women struggled with stigma, while men struggled with the second factor – denial. Out of a desire to be known comes a frustration when people refuse to get to know a person. "They wouldn't understand even if I were to layout all of the basics and my research. They're very stubborn and bull – headed. They're set in their ways. One they have a mindset it cannot be changed." Thirdly is the "universal excuse" mindset, which falsely attributes behavior to bipolar disorder. "They don't understand and think I am exaggerating or they blame everything I do on bipolar."

If communication is going to increase and improve within families, then these factors must be eliminated. The primary criterion operating here is the risk – benefit criterion. The question each bipolar consumer must answer is, "Is revealing my bipolarity worth experiencing stigma, denial, and false accusations?" These are the same issues that arise when dealing with many health issues such as HIV and AIDS (Cline, 2000; Greene, 2000; Yep, 2000). Although the natures of these illnesses greatly differ, the responses to them do not. The question is, "What can be done to address these issues specifically from within the family?" which can serve as a nucleus for one's support system.

Boundaries surrounding the issue of disclosure will remain thick until the information is handled with sensitivity and respect. The goal is to increase

boundary permeability, so that education can increase and ignorance can decrease. Unfortunately, this inverse relationship starts with increase risks and decreased benefits for the bipolar consumer, who may already be struggling to cope with his or her condition.

### Research Question 3

RQ3, "Does the extent to which people disclose relate to the offspring's ability to cope with his or her own bipolar struggles?" This question was analyzed using another open – ended question, item 26, which was coded into broad categories. The answer to the question is "yes". The majority of participants noted that knowing or not knowing of a bipolar presence in their family impacted their physical and mental health. Those consumers who knew gave responses like the following: "Having the knowledge has impacted my health because my mother is more apt to be aware of behavioral changes, as well as making sure I take care of my self physically.", "I have an acute awareness of mine and my children's mental health, how we need to take care of ourselves and how to treat the illness so we live well."

Unfortunately, most of the participants could only comment on the negative affects of now knowing. "Not having the knowledge that there was a history of mental illness in the family greatly caused problems during my diagnosis and subsequent treatment." "Not knowing what I was dealing with until I was 18 was extremely difficult and dangerous for me. Perhaps if I had known and been treated when it first presented itself when I was about 10, the numerous suicide attempts and erratic dangerous behavior and self injurious behavior



could have been prevented or at least I could have been safer.”

The impact points to the need for a communication transformation when it comes to privacy and mental illness. Though the risks of revealing are high, the risks of not knowing are higher. Research already supports the benefits of disclosing for the discloser, now these benefits can be augmented by the benefits also available to the disclosee.

The issues surrounding one's medical family history are less about privacy rules and more about boundaries. If the family is at risk of developing the illness, the family needs to be aware of it because they automatically co-own the boundary based on genetic risk alone. Although it is the choice of the consumer to reveal or conceal this information, disclosure should occur out of responsibility. It is no different than pulling the fire alarm in an apartment building to warn the other tenants of a fire; this attitude is reflected by the participants.

Item 27 listed a number of statements dealing with how participants felt about disclosing their bipolarity in relation to offspring. The results indicate that consumers believe offspring should know of their parent's bipolarity ( $M = 4.57$ ,  $SD = .611$ ); and that parents play a significant role in the quality of their bipolar offspring's healthcare through disclosure ( $M = 5.00$ ,  $SD = .000$ ).

Items 28 and 29 address why present research is needed. Item 28 asked, “If you are bipolar, were you accurately diagnosed the first time you went to see a medical professional about your symptoms?” Seventy – three of the 98 respondents responded “no”. Responses to item 29 show that bipolar

consumers have a considerable amount of difficulty when it comes to being properly diagnosed ( $M = 2.88$ ,  $SD = 1.68$ ), again highlighting the importance of this issue. The second reason that communication must increase is because consumers do not feel adequately prepared to care for themselves by their bipolar family members ( $M = 1.46$ ,  $SD = 1.45$ ), or even by their healthcare provider ( $M = 2.31$ ,  $SD = 1.45$ ). This is significant, considering that the majority of participants were diagnosed between the ages of 19 and 50 within the last 10 to 15 years. In fact, 30 of the diagnoses occurred within the last 5 years! The amount of current information available regarding this issue symbolizes that this problem is not due to a lack of knowledge, but a lack of communication.

### Limitations

Several demographics limit the generalizability of the research findings. Because the study was conducted on the internet, only people who had access to a computer were able to participate. This would have prevented a number of people from lower socioeconomic brackets from participating in the study, which may also be linked to the lack of racial diversity. In addition to the socioeconomic bracket, those falling into the 'younger than 12' or 'older than 50' age bracket may have been hindered from participating due to their lack of experience with technology. Another group of people whose participation would have been invaluable is that of bipolar consumers who are housed in special facilities. The fact that 82% of participants were female also impacts the generalizability of the findings, and

with 88.5% of the participants between the ages of 19 – 49, the results cannot speak to cohort differences.

Although a strength of the study was that participants could remain anonymous, there was no way to verify whether they were answering honestly. And given that the survey items covered some sensitive issues, the responses could have been driven by emotion, which could lead to dramatizations of reality. There was also no way to verify if the participants were actually bipolar, self – diagnosed bipolar consumers, or pretending to be bipolar. While other aspects of the survey were susceptible to the same levels of dishonesty, whether or not the participant has any connection to the disorder is truly a significant factor given the research questions.

Communication Privacy Management is a relatively new theory, meaning it has not yet acquired many resources. The survey was developed without any past research resources that had been used to operationalize this theory; therefore, the operationalization of certain theory components could be improved.

#### Suggestions for Future Research

This study examined parental disclosure about bipolar disorder to their offspring using Communication Privacy Management theory. Little research has yet been conducted to test the theory. Future research could focus on developing the field of mental health research as it relates to both self – disclosure and communication in general.

This study examined the absence of disclosure about bipolar disorder

from the perspective of a parent or offspring. The majority of parents who said they did not disclose believed that their child was too young to understand. Future studies could examine how a parent defines the appropriate age of disclosure with open – ended questions. One participant in particular said that she thought her child was too young; however, her child was thirteen. As an adolescent, her child is more than likely capable of developing an understanding about mental illness.

Knowing that mental illness was dealt with very differently in the past, the participants of the older generations may be operating out of a different mindset than their offspring. In the future, the results of this study could greatly differ because the results will represent participant experiences during a different time period. Then, the offspring of our current adult offspring will be at the age to comment on their own upbringings retrospectively. These results would also reflect what has happened communicatively with this issue.

Now that the advantages and disadvantages of disclosing have begun to be weighed, a few additional questions should be asked. The responses may vary based on how long after one's diagnosis did he or she disclose to his or her family members. Other research could look specifically at the differences between males and females and their views on mental illness. Is one sex more reluctant to admit there is a problem, creating yet another barrier in increasing communication? Do men and women need different skills to cope with the same illness?

Given that bipolar is highly treatable, research could look into the treatments available and the responsiveness to that treatment. Does the difficulty in getting a bipolar consumer to consistently take his or her medication fall solely on the consumer, or does his or her healthcare provider play a bigger role than formerly thought? In order to receive a driver's license one must acquire a number of skills and follow a number of rules to enjoy this new found freedom. Is it not like this with anything else? If bipolar can be successfully managed, then is the opportunity to acquire these skills and learn these new life rules provided so that the mentally ill can also live in freedom?

Along the same lines, future research could also dig deeper into the minds of bipolar consumers to see how they view themselves and how they view the illness. Many families did not embrace the seriousness of the illness or they used it as a universal excuse; is this because they know something the consumer does not? Future research should explore how much the bipolar consumer is in control of, or responsible for in terms of behavior and whether or not bipolar consumers agree.

Additionally, studies involving CPM could look specifically at how families learn and more importantly unlearn unhealthy patterns. A child's foundation is laid at a young age, but when a weak spot in the foundation is discovered, it needs to be "shored up and repaired" to break the cycle. While parents often resolve to not repeat "the sins of the father", they need to be given more than a resolution.

## Conclusion

Bipolar consumers within the present study that have grown up with bipolar parents did not understand the condition from which their parent's suffered until adulthood. This was not only due to a lack of communication about the issue, but to the poor quality of communication surrounding the issue. Now, these offspring are parents themselves and have the opportunity to improve how they communicate with their children. CPM says privacy rules are socialized, thus these parents may need to be re-socialized in this area.

Of the parents who have disclosed to their offspring, they have done so primarily to help their offspring understand the illness, to make them aware of the symptoms and genetic patterns, or to partner with their already bipolar child in his or her healthcare. Those parents who have not told their offspring claim they are too young to understand. This is questionable given that judgments of age are subjective about such an issue. If family privacy rules are socialized, then it seems it would be better to start as early as possible with what the child can understand.

The factors that affect one's decision to disclose his or her bipolarity need to be faced head on to overcome particularly the challenges of revealing. Though stigma plays a large part in this challenge, the impact of concealing on future generations has the potential to be deadly given the high suicide rate associated with this illness. A family's medical history cannot only travel genetically, but it must also travel communicatively. This is why

medical records are kept in hospitals. Given that the quality of these records depends on the information the patient can provide, it is very important that families begin to track their medical history within their own families instead of relying on external sources.

Consumers that did not know of a bipolar presence within their families unnecessarily suffered from treatable symptoms. Many said they harmed themselves physically and relationally. Because they had no explanation for their conditions, some suffered from issues of self-medication; others had accepted the notion that they were crazy. Others were inaccurately diagnosed by their healthcare provider. Those that were equipped with the knowledge of their family history were able to receive treatment sooner. The key to better healthcare lies in the ability to receive and the accessibility of receiving proper treatment. Both of these can be enhanced through increased communication.

## APPENDIX A

**Who am I?** I am a 24 year - old graduate student. I study family and health communication and am interested in mental illnesses in family, for obvious reasons :)

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**What am I doing?** I am doing a study on whether or not parents tell their children if there is a history of Bipolar in their family, and why or why not.

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**When will I finish this paper?** When you finish the survey! I can't wait to get the results, and the more that people participate, the better my results will be because they will represent more of our community.

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**Where do I go to school?** The University of Dayton in Dayton, Ohio.

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**Why am I doing this?** I am doing this because I believe that people can benefit from knowing there is a possibility of being diagnosed with bipolar.

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**How do I participate?** Simply click on the survey and fill out the information. I do not ask for your name, so there is no way that your identity will be revealed. However, if you do wish to share your personal story, feel free to email me at Erica.prigg@notes.udayton.edu.

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[Click Here to enter Survey](#)



## Survey

1. Click the appropriate sex. ☐ Male ☐ Female

2. What is your age?

3. What ethnic group do you identify with?

Please type ethnic group here if you selected "other".

4. What country are you from?

5. Indicate your marital status. ☐ Single ☐ Married ☐ Divorced ☐ Widowed

6. Do you have any biological children? ☐ Yes ☐ No

7. If so, how many?

☐ I do not have any children. ☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six or more

8a. Please choose one of the following to identify yourself.

- ☐ I am an offspring of a bipolar parent.  
☐ I am an offspring of a parent whom I suspect is bipolar.  
☐ I am bipolar.  
☐ I am a bipolar parent.  
☐ I am an offspring of a bipolar parent and I have a bipolar disorder.  
☐ I am an offspring of a parent whom I suspect is bipolar and I have a bipolar disorder.  
☐ I am both a bipolar parent and an offspring of a bipolar parent.  
☐ I am a bipolar parent and an offspring of a parent whom I suspect is bipolar.  
☐ Other Please type response.

8b. Do you have any siblings who you know or suspect are bipolar? ☐ Yes ☐ No

9. Please indicate which bipolar conditions apply (check all that apply). If you are unsure of the specific type, then type "unsure" in the blank marked *other* and check all that apply.

Bipolar I: ☐ I am. ☐ My father ☐ My mother ☐ My offspring ☐ My sibling(s)

Bipolar II: ☐ I am. ☐ My father ☐ My mother ☐ My offspring ☐ My sibling(s)

Cyclothymic: ☐ I am. ☐ My father ☐ My mother ☐ My offspring ☐ My sibling(s)

Other (please type) ☐ I am. ☐ My father ☐ My mother ☐ My offspring ☐ My sibling(s)

10a. If you are a person with bipolar disorder, what age were you officially diagnosed by a healthcare provider?

10b. If you are a person with bipolar disorder, what year were you officially diagnosed by a healthcare provider?

11. If you are an offspring of a bipolar parent, what age were you when you understood your parent(s) had bipolar disorder?

N/A

12. If you are a bipolar parent, have you told all of your children about your bipolar condition?

☐ Yes ☐ No ☐ I am not a parent (skip down to question 15).

13. If the answer is "no", what is your primary reason for not telling all of your children?

14. If the answer is "yes", what is your primary reason for telling all of your children?

15. Do you know anyone else in your family who also has a form of bipolar? ☐ Yes ☐ No (if you answered "no" skip down to question 18)

16. What is their relation to you (check all that apply)?

Mother's side:	<input type="checkbox"/> Grandfather	<input type="checkbox"/> Grandmother	<input type="checkbox"/> Uncle # _____	<input type="checkbox"/> Aunt # _____	<input type="checkbox"/> Cousin # _____	<input type="checkbox"/> Other (specify here) _____
Father's side:	<input type="checkbox"/> Grandfather	<input type="checkbox"/> Grandmother	<input type="checkbox"/> Uncle # _____	<input type="checkbox"/> Aunt # _____	<input type="checkbox"/> Cousin # _____	<input type="checkbox"/> Other (specify here) _____

18. How often is / was the disorder talked about within your immediate family?

☐ Never ☐ Rarely ☒ Sometimes ☐ Often ☐ Very Often

19. With what family member do/did the majority of these conversations take place?

**If you and your family held any type of discussion about the disorder, rate the following topics based on how focused the conversations based on how focused the conversations were on the following issues:**

20. Helping others to cope with the symptoms of bipolar was the discussed topic.

☐ Never ☐ Rarely ☐ Sometimes ☐ Often ☐ Very Often

The person's odd behaviors was the discussed topic.

☐ Never ☐ Rarely ☐ Sometimes ☐ Often ☐ Very Often

Increasing the family's understanding of the disorder was the discussed topic.

☐ Never ☐ Rarely ☐ Sometimes ☐ Often ☐ Very Often

Better caring for the individual(s) with the disorder was the discussed topic.

☐ Never ☐ Rarely ☐ Sometimes ☐ Often ☐ Very Often

The tendency of bipolar to occur within families was the discussed topic.

☐ Never ☐ Rarely ☐ Sometimes ☐ Often ☐ Very Often

The possibility of current family members having bipolar disorder based on a family history of bipolar disorder was the discussed topic.

☐ Never ☐ Rarely ☐ Sometimes ☐ Often ☐ Very Often

Expressing concerns about the family member's condition was the discussed topic.

☐ Never ☐ Rarely ☐ Sometimes ☐ Often ☐ Very Often

21. Are you aware that bipolar disorder tends to run in families?

22. If yes, how did you first become aware of the disorder's tendency to run in families?

☐ Family member ☐ Healthcare professional ☐ Personal research ☐ Friend ☐ Co-worker ☐ Other (specify) \_\_\_\_\_

23. If you have bipolar, how comfortable are you with sharing this information with the following members of your immediate family?

Father:	<input type="radio"/> Very comfortable	<input type="radio"/> Somewhat comfortable	<input type="radio"/> Undecided	<input type="radio"/> Somewhat uncomfortable	<input type="radio"/> Very uncomfortable
Mother:	<input type="radio"/> Very comfortable	<input type="radio"/> Somewhat comfortable	<input type="radio"/> Undecided	<input type="radio"/> Somewhat uncomfortable	<input type="radio"/> Very uncomfortable
Sibling - N/A	<input type="radio"/> Very comfortable	<input type="radio"/> Somewhat comfortable	<input type="radio"/> Undecided	<input type="radio"/> Somewhat uncomfortable	<input type="radio"/> Very uncomfortable
Sibling - N/A	<input type="radio"/> Very comfortable	<input type="radio"/> Somewhat comfortable	<input type="radio"/> Undecided	<input type="radio"/> Somewhat uncomfortable	<input type="radio"/> Very uncomfortable
Sibling - N/A	<input type="radio"/> Very comfortable	<input type="radio"/> Somewhat comfortable	<input type="radio"/> Undecided	<input type="radio"/> Somewhat uncomfortable	<input type="radio"/> Very uncomfortable
Sibling - N/A	<input type="radio"/> Very comfortable	<input type="radio"/> Somewhat comfortable	<input type="radio"/> Undecided	<input type="radio"/> Somewhat uncomfortable	<input type="radio"/> Very uncomfortable
Other:					

24. What do you see as the advantages of sharing this information with your family?

25. What do you see as the disadvantages of sharing this information with your family?

26. How has having or not having the knowledge of a bipolar presence in your family impacted your own health?

27. Answer the following statement using the scale provided:

I feel that it is important for the children of a bipolar parent to know of their parent's disorder.

☐ Strongly agree      ☐ Agree      ☐ Neutral      ☐ Disagree      ☐ Strongly disagree

I believe that one's mental health is one's own business.

☐ Strongly agree      ☐ Agree      ☐ Neutral      ☐ Disagree      ☐ Strongly disagree

I believe a bipolar parent with bipolar offspring can improve the healthcare of their offspring by sharing personal experiences with the disorder.

☐ Strongly agree      ☐ Agree      ☐ Neutral      ☐ Disagree      ☐ Strongly disagree

28. If you are bipolar, were you accurately diagnosed the first time you went to see a medical professional about your symptoms?

☐ Yes      ☐ No      ☐ I am not bipolar.

29. If you are bipolar, please answer the following statements using the scale provided:

It was a difficult to receive the proper diagnosis based on my symptoms.

☐ Strongly agree      ☐ Agree      ☐ Neutral      ☐ Disagree      ☐ Strongly disagree      ☐ I am not bipolar.

I have had difficulty coping with this illness.

☐ Strongly agree      ☐ Agree      ☐ Neutral      ☐ Disagree      ☐ Strongly disagree      ☐ I am not bipolar.

The primary reason for my difficulties with coping are due to my lack of knowledge about the disorder.

☐ Strongly agree      ☐ Agree      ☐ Neutral      ☐ Disagree      ☐ Strongly disagree      ☐ I am not bipolar.

Upon my diagnosis, I was adequately prepared by my healthcare professional to care for myself.

☐ Strongly agree      ☐ Agree      ☐ Neutral      ☐ Disagree      ☐ Strongly disagree      ☐ I am not bipolar.

30. If you are bipolar and there is a bipolar presence within your family, please answer the following statement using the scale provided:

I felt adequately prepared by my bipolar family members to care for myself.

☐ Strongly agree☐ Agree☐ Neutral☐ Disagree☐ Strongly disagree☐ N/A 

Clicking "submit" will record your results, then you may exit out of this site by closing it or clicking "back".

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R002592244