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## "Born Out of Fear": A Grounded Theory Study of the Stigma of Bipolar Disorder for New Mothers

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## "Born Out of Fear": A Grounded Theory Study of the Stigma of Bipolar Disorder for New Mothers

### Abstract

Childbirth is an established trigger for the onset of bipolar disorders (BD) in the postpartum period, causing significant pathology and disability. Research has shown that the stigma of mental illness for new mothers is a powerful obstacle to care, preventing women from accessing critical treatment and social support. However, the majority of research has examined the relationship between the stigma and postpartum depression, leaving a gap in knowledge regarding stigma and postpartum bipolar disorder. The problem addressed in this grounded theory study was the lack of knowledge regarding the stigma of a diagnosis of bipolar disorder (BD) in the first year postpartum. A theoretical sample of 15 women given a clinical diagnosis of a BD in the first year postpartum participated in one, 60-90-minute recorded interview using semi-structured questions. I analyzed typed interview transcripts using open, axial, and selective coding according to grounded theory methods. Emergent categories: Diagnosis, Experiencing Stigma, and Lack of Understanding revealed the relief in the initial diagnosis and the subsequent experience of stigma in the form of stigmatizing stereotypes, prejudicial attitudes and discrimination, and the development of the belief that stigma was caused by universal lack of understanding regarding BD. The core category of Born Out of Fear was identified. Selective coding confirmed that the stigma experienced by participants was consistent with existing models of stigma, with the exception that women did not describe their babies or other children as components of the experience of stigma. Increased understanding of the stigma of mental illness for new mothers creates pathways for future research.

### Keywords

Stigma, Bipolar Disorder, Postpartum, Grounded Theory

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# “Born Out of Fear”: A Grounded Theory Study of the Stigma of Bipolar Disorder for New Mothers

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*Childbirth is an established trigger for the onset of bipolar disorders (BD) in the postpartum period, causing significant pathology and disability. Research has shown that the stigma of mental illness for new mothers is a powerful obstacle to care, preventing women from accessing critical treatment and social support. However, the majority of research has examined the relationship between the stigma and postpartum depression, leaving a gap in knowledge regarding stigma and postpartum bipolar disorder. The problem addressed in this grounded theory study was the lack of knowledge regarding the stigma of a diagnosis of bipolar disorder (BD) in the first year postpartum. A theoretical sample of 15 women given a clinical diagnosis of a BD in the first year postpartum participated in one, 60-90-minute recorded interview using semi-structured questions. I analyzed typed interview transcripts using open, axial, and selective coding according to grounded theory methods. Emergent categories: Diagnosis, Experiencing Stigma, and Lack of Understanding revealed the relief in the initial diagnosis and the subsequent experience of stigma in the form of stigmatizing stereotypes, prejudicial attitudes and discrimination, and the development of the belief that stigma was caused by universal lack of understanding regarding BD. The core category of Born Out of Fear was identified. Selective coding confirmed that the stigma experienced by participants was consistent with existing models of stigma, with the exception that women did not describe their babies or other children as components of the experience of stigma. Increased understanding of the stigma of mental illness for new mothers creates pathways for future research. Keywords: Stigma, Bipolar Disorder, Postpartum, Grounded Theory*

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## Introduction

Mental and behavioral disorders represent the fifth leading global cause of non-fatal burden of disease (World Health Organization [WHO], 2014). Between the years 2000 and 2012, an estimated 64 million Disability Adjusted Life Years (DALYs), or the sum of years of life lost (YLL), due to premature mortality was lost due to psychiatric illness, more than all forms of cancer, or other neurological disorders (WHO, 2002). Evidence demonstrates that women and girls have two times greater prevalence rates for mental illness compared to men or boys (Kessler et al., 2005). The occurrence of mental illness for women is most prominent during childbearing years, with depression as the leading cause of hospitalization after childbirth for women aged 18 to 44 in the United States (Jiang et al., 2002). Jiang et al. reported that in the year 2000, 205,000 women aged 18-44 were discharged from a hospital with a diagnosis of depression, which accounts for seven percent of all hospitalizations for women in this age group. Furthermore, prior research illustrates that most women with severe mental illness have children (Howard, Kumar, & Thornicroft, 2001). The epidemiological evidence regarding the connection between childbearing and the onset of psychiatric illness has been established.

Bipolar and related disorders are closely associated with perinatal onset, high prevalence, and significant impairment to mother and infant. Bipolar disorders present complex challenges for mothers and impairs a woman's health at many points throughout motherhood, presenting an increased risk of: hospitalization, suicidal ideation, and suicide attempt (Bilszta, Ericksen, Buist, & Milgrom, 2010; Dennis & Chung-Lee, 2006; Goodman, 2007). The disruption in health directly impacts the mother-child relationship across the lifespan of both mother and child. While the most common treatment intervention is psychopharmacology (Marcus, Flynn, Blow, & Barry, 2003), studies have demonstrated most women are resistant to taking medication without being offered a range of nonmedical based treatment options (Zittel-Palamara, Cercone, & Rockmaker, 2009).

Despite the high prevalence and significant risks associated with postpartum BD, the disease is "under-diagnosed and under-treated" (Merrill et al., 2015, p. 579). Medical and psychiatric care providers' beliefs and attitudes regarding mental health in the postpartum period have been reported as significant barriers to treatment (Byatt, Simas, Lundquist, Johnson, & Ziedonis, 2012). However, stigma research regarding mothers diagnosed specifically with BD is lacking. Similarly, while qualitative methodology has been widely used in the literature regarding the lived experience of postpartum mental illness and the stigma of mental illness, there is a paucity of qualitative literature regarding bipolar disorders with new mothers. Therefore, the objective of this qualitative inquiry was to use a grounded theory study to address the lack of knowledge regarding the nature of stigma for women diagnosed with bipolar disorder during the first year postpartum.

### **Theoretical Framework**

Pragmatism provides the theoretical framework supporting this research. In contrast to the positivist assumption of empirical science, pragmatism purposes subjective experience toward a deeper understanding of the individual, social, and global contexts underlying basic social processes (Glaser & Strauss 1967). Pragmatism purposes problems as the basis for reflective inquiry (Mead, 1938/1972). Knowledge itself is born through the "acting and interacting of self-reflective beings" (Corbin & Strauss, 2015, p. 19). With strong roots in pragmatism, grounded theory offers inductive, deductive, and abductive analyses of multiple meanings to derive theoretical conceptualization (Cherryholmes, 1994; Corbin & Strauss, 2015). Therefore, exploring the meanings assigned to the experience of the stigma of mental illness for mothers diagnosed with bipolar disorder in the first year postpartum, reveals what we have yet to understand about the complex intersection of maternal mental health and social stigma. In this way, the application of grounded theory to this study puts the wisdom of women's lived experience to work in the world.

### **Literature Review**

In systematic grounded theory (Corbin & Strauss, 2015; Strauss & Corbin, 1998), the literature review provides rigor and trustworthiness, developing researcher theoretical sensitivity and revealing social, historical constructs of concepts under study. What follows here is a review of the literature regarding BD (i.e., perinatal prevalence, risk factors, and effects), and stigma (i.e., theoretical models and extant literature regarding stigma and perinatal mood and anxiety disorders).

## Bipolar Disorder Prevalence

**Prevalence in general population.** Lifetime prevalence of BD in general population is 0.0% - 6.5% (Bauer & Pfenning, 2005; Kessler, et al., 2009; Merikangas, et al., 2011; Pini et al., 2005). Given the rates of misdiagnosis (31%) and underdiagnosis (49%), the prevalence of BD may be higher than quoted (Hirschfeld et al., 2003). In a systematic review that measured the costs of BD, Kleine-Budde et al. (2014) reported the overall per capita cost of BD between \$8,000 and \$14,000—ignoring for outliers. The high cost of BD has been related to the chronicity and severity of the condition, leading to increased inpatient hospitalization, disability, absenteeism, presenteeism, and increased medical insurance expenditures (Fajutrao, Locklear, Priaux, & Heyes, 2009; Peele, Xu, & Kupfer, 2003; Pini et al., 2005). Furthermore, a 75% rate of comorbidity with other disorders (Jacobi et al., 2004) contributes to the chronicity and disability of the illness.

**Prevalence in postpartum population.** The perinatal period or the period of time around childbirth represents a critical timing for the onset of maternal psychiatric illnesses, as evidenced in the literature over the past 30 years. Current prevalence rates for some type of mental illness during pregnancy is 10% and 13% in the postpartum period (Fisher, Cabral, Patel, Rahman, Tran, Holton, & Holmes, 2012; Sit, 2004). While early literature focused on postpartum depression and, to a lesser extent, anxiety and psychosis, current research has demonstrated a clearer understanding of the high prevalence of bipolar disorders in the postpartum period: 0-12 months following childbirth (Freeman, Smith, Freeman, McElroy, Kmetz, Wright, & Keck, 2002; Viguera et al., 2007). One US study has reported prevalence for BD in past-year pregnant women at 2% - 8% (Vesga-Lopez et al., 2008). A large study of an obstetric sample of 10,000 women found that 22.6% screened positive for bipolar disorders (Wisner et al., 2013). A more recent (2015) pilot study investigating the use of the EPDS in screening for BD identified prevalence rates among 277 women at 16.4%, similar to the rates of gestational diabetes and perinatal hypertension (Merrill et al., 2015).

**Risk factors.** Childbirth is an established risk factor for the onset or recurrence of a BD in the postpartum period (Sharma et al., 2014). In fact, the postpartum period represents the highest lifetime risk for both first-time onset and recurrence for bipolar disorder (Kendell, Chalmers, & Platz 1987; Munk-Olsen, Laursen, Pederson, Mors, & Mortensen, 2006). Women with previous episodes of bipolar disorder have a 50% to 70% risk of a recurrence with subsequent births (Munk-Olsen et al., 2006). There is evidence that extreme withdrawal of gonadal steroid levels after childbirth may contribute to the vulnerability for the onset of disease (Bloch et al., 2000). Risk factors for BD in pregnancy and postpartum include previous history of BD (Munk-Olsen, Laursen, Pederson, Mors, & Mortensen, 2009), previous episodes of postpartum psychosis (Robertson, Jones, Haque, Holder, & Craddock, 2001), and family history of bipolar disorder or postpartum psychosis (Binder et al., 2010; Jones & Craddock, 2005; Mahon et al., 2009; Munk-Olsen, Laursen, Meltzer-Brody, Mortensen, & Jones, 2012; Sanjuan et al., 2008). Sleep disturbance associated with labor, birth breastfeeding, and caring for a newborn may contribute to increasing risk of BD postpartum onset (Yonkers et al., 2004). Evidence also suggests a correlation between BD and the onset of postpartum psychosis (Jones, Chandra, Dazzan, & Howard, 2014).

**Effects of a maternal mental illness on children.** A plethora of research examining the effect of maternal psychiatric disorders on the developing fetus, infant, and child exist (Stein et al., 2014). Research reports increased risk of preterm birth (Grigoriadis et al., 2013; Grote et al., 2010) and low birth weight (Schetter & Tanner, 2012).

Research also reports an association between antenatal depression and increased risk for emotional problems in children (Gerardin et al., 2011; Leis, Heron, Stuart, & Mendelson, 2014; Velders et al., 2011) and adolescents (Korhonen, Luoma, Salmelin, & Tamminen, 2012;

Pawlby, Hay, Sharp, Waters, & O’Keane, 2009). Behavioral disorders such as oppositional defiant disorder, attention deficit hyperactivity disorder, and conduct disorder in children of mothers with a history of perinatal mental illness, have been noted (Barker, Jaffee, Uher, & Maughan, 2011; Galéra et al., 2011; Korhonen et al., 2012; Velders et al., 2011). Attachment has been defined as when a child “uses a caregiver as a secure base from which to explore and, when necessary, as a haven of safety and source of comfort” (Waters & Cummings, 2000, p. 164). Extensive literature has emphasized a link between perinatal mental illness and disrupted attachment (Hayes, Goodman, & Carlson, 2013) and insecure attachment (Atkinson et al., 2000; Hipwell, Goossens, Melhuish, & Kumar, 2000; Martins & Gaffan, 2000). Perinatal depression has been associated with impaired cognitive development in children and adolescents (Conroy et al., 2012; Kaplan et al., 2014; Kersten-Alvarez et al., 2012; Letourneau, Tramonte, & Willms, 2013; Sutter-Dallay et al., 2011).

### **Stigma Literature**

Despite a significant amount of literature regarding the stigma of mental disorders such as schizophrenia and major depression, research regarding bipolar disorders and stigma remains lacking (Ellison, Mason, & Scior, 2013). What can be gleaned from studies of other populations is that the stigma of bipolar disorder is associated with public stigma (Furnham, 2009; Furnham & Anthony, 2010; Loo, Wong, & Furnham, 2012), public beliefs about treatment (Day, Edgren, & Eshelman, 2007; Furnham, 2009), and stereotypes regarding symptoms (Day et al., 2007; Stip, Caron, & Mancini-Marie, 2006; Sugiura, Sakamoto, Kijima, Kitamura, & Kitamura, 2000; Wolkenstein & Meyer, 2008). At this time, only two studies have examined the extent of internalized stigma for people with bipolar disorder (Aydemir & Akkaya, 2011; Cerit, Filizer, Tural, & Tufan, 2012). No studies exist regarding internalized stigma for mothers with bipolar disorder.

### **Theoretical Literature**

Theoretical literature regarding stigma has presented models of self-stigma (Corrigan & Watson, 2002) and stigma formation (Goffman, 1963/2009; Jones et al., 1984; Thornicroft, Brohan, Rose, Sartorius, & Leese, 2009; Thornicroft, Rose, Kassam, & Sartorius, 2007). However, the theories of stigma construction remain generalized to all mental illness, including both men and women or parents of children with a severe mental illness. In essence, there is scant literature regarding stigma and bipolar disorders in women or women in the perinatal period. To date, there remains no theoretical literature regarding the stigma of mental illness for women diagnosed with a BD in the postpartum period.

One of the few studies examining experienced discrimination for parents reported that of 304 participants (73% female) the prevalence rate for experienced discrimination regarding starting a family was 22.5% and parenting 28.3% (Jefferey et al., 2013). While the data from this study provided rich insight into the prevalence and themes of experienced stigma for parents, specific data regarding new mothers and bipolar disorder was not reviewed and resolution of the stigma was not explored.

**Stigma literature and the postpartum period.** In a qualitative study using semi-structured interviews, Edwards and Timmons (2005) discovered that mothers with postpartum mood disorders experienced stigma both internally and externally. Women reported internal concerns regarding the incongruity between their sense of motherhood and the reality of their feelings. Underlying stigma presented by healthcare services strongly influenced women’s choice not to pursue treatment or disclose symptoms (Edwards & Timmons, 2005).

Several qualitative studies have examined the help-seeking behaviors, stigma, and perceptions of treatment for women experiencing postpartum mood disorders. For example, Dennis and Chung-Lee (2006) reviewed 40 studies in a systematic qualitative review. Common barriers reported were culture (Chan & Levy, 2004; Knaack, 2009; Rodriguez, Patel, Jaswal, & De Souza, 2003) and reluctance to seek professional treatment or disclose feelings of depression (Dennis & Chung-Lee, 2006). Other barriers reported included lack of awareness about mental health after delivery (Rodriguez et al., 2003), loss of relationships (Nicolson, 1999), fear of disclosing to family and partners (Amankwaa, 2003), and fear of loss of custody (Dennis & Chung-Lee, 2006). Women's perceptions of healthcare professionals influenced whether they sought professional assistance or not; when healthcare professionals minimize a mother's symptoms, she is less likely to seek help (Holopainen, 2002). Bilszta et al. (2010) explored the ways 40 women experienced postpartum depression and how their perceptions shaped help-seeking beliefs and attitudes. Core findings included 8 clusters of barriers to help, one of which was stigma (Bilszta et al., 2010). In a thematic content analysis of semi-structured interviews with 22 women regarding views and experiences of severe mental illness (i.e., schizophrenia, bipolar disorder, depression with psychotic features), Diaz-Caneja and Johnson (2004) identified that while mothers reported enjoyment and fulfillment from motherhood, the majority reported stress of parenting while managing a severe mental illness (SMI) and fear of losing custody of their children. However, the study did not specifically address the lived experience of BD postpartum period or stigma related to a diagnosis of BD. Especially in comparison to the substantive literature regarding the effects of perinatal mood and anxiety disorders on the developing child, there is a lack of research regarding the impact of these disorders on the mother over the lifespan.

The literature reviewed clearly demonstrates the prevalence of perinatal mood and anxiety disorders, the effects on mothers and children, and the impact of stigma on help seeking behaviors for new mothers experiencing these disorders. However, qualitative research on the specific experience of the stigma associated with the diagnosis of a bipolar disorder postpartum has yet to be explored. The current research addresses the gap in knowledge regarding the stigma of bipolar disorder for new mothers. It offers necessary research for the advancement of qualitative literature to the field.

### **Relationship to Topic**

As a researcher in the area of maternal mental health, my interest stems from personal experience nearly 20 years ago. Following the birth of my son, I developed postpartum depression, anxiety, and post-traumatic stress disorder. Once I recovered, I returned to school to obtain my doctorate in order to conduct research in this field. I continue to conduct qualitative research in the area of maternal mental health.

### **Methods**

Grounded theory seemed the most appropriate. The qualitative literature regarding maternal mental health (Dolman, Jones, & Howard, 2013; Doucet, Letourneau, & Stoppard, 2010) offers critical insight into the research regarding perinatal mood and anxiety disorders. Moreover, grounded theory (GT) has been widely accepted as an appropriate method for exploring subjective experiences of perinatal mood and anxiety disorders (Abrams, & Curran, 2009; 2011; Abrams, Dornig & Curran, 2009; Barimani, & Hylander, 2008; Beck, 1993; Karraa, 2014; Knudson-Martin, & Silverstein, 2009).

## Rationale

Regarding suitability to the topic, Glaser (1978) posited the four criteria for a grounded theory study: (a) it fits; (b) it works; (c) it is relevant; (d) it is modifiable. *Fitness* is reflected through allowing data to reveal categories grounded in participant experience versus pre-existing concepts or theories present in literature. The data in this study were treated pragmatically to discover properties, conditions, and consequences of stigma for new mothers diagnosed with BD not previously conceptualized in theoretical literature (Corbin & Strauss, 2015). In doing so, novel data emerged quickly and refitted to emerging categories. According to Glaser (1978), grounded theory *works* if it can “explain what happened, predict what will happen, and interpret what is happening in an area of substantive or formal inquiry” (p. 4). In this regard, the inductive, deductive and abductive analysis, rooted in the lived experiences of the participants, provided an accurate description of the experience of stigma for mothers diagnosed with BD in the first year postpartum, later validated by member checking and debriefing.

*Relevance*, according to Glaser (1978), is discovered in the absence of professional pretense. The author examined the nature of the stigma of BD for new mothers outside previous theories of stigma (Corrigan & Watson, 2002; Goffman, 1963/2009; Jones et al., 1984; Link & Phelan, 2001; Thornicroft et al., 2007). Data collection and analysis examined the participants' social, historical, and personal, structural conditions of the experience of stigma following diagnosis (Glaser, 1978). As GT is inherently generative, *modifiability* engages the researcher in rejecting finality of theory discovery but yielding to the generation of ongoing, multiple iterations of theoretical development (Glaser, 1978, p. 5). Adherence to the systematic procedure of open, axial, and selective coding resulting in the development of a conditional matrix allowed for “ready, quick modification to help explain surprising or new variations” (Glaser, 1978, p. 5). A central research question drove the pragmatic application of grounded theory design, “*What is the nature of stigma of mental illness for mothers diagnosed with bipolar disorder in the first year postpartum?*”

## Rigor and Trustworthiness

Grounded theory procedures suggested by Corbin and Strauss (2015), based in the foundational work of Glaser (1978) and Strauss and Corbin (1998), supported the rigor of the study. The literature review, detailed audit trails (Rodgers & Cowles, 1993), member checks (Sandelowski, 2002), researcher self-reflection (Hall & Callery, 2001), and peer debriefing with a grounded theory expert (O'Connell & Iurita, 2000) established trustworthiness.

## Data Collection and Analysis

What follows is a description of the data collection protocol, including a description of participants, recruitment procedures, and interview protocol.

**Participants.** A purposive, theoretical sample of 15 participants was obtained. Participant inclusion criteria were: (a) having received a clinical diagnosis for a bipolar disorder in the first year following the birth of a child; (b) being able to give informed consent; (c) speaking English; (d) having access to phone and email; (e) and willingness to participate; (f) over 18 years of age.

**Recruitment.** Once university Institutional Review Board approval was obtained, calls for participation were published through perinatal mood and anxiety scientific and support organizations. Recruitment yielded an initial 19 participants. Participants were screened for

inclusion criteria, producing a final sample of 15. Following receipt of signed Informed Consent, participants completed a demographic survey before the interview.

**Interview protocol.** The investigator conducted semi-structured interviews with 15 participants. Descriptive, exploratory, explanatory, and emancipatory questions were crafted in alignment with the four types of qualitative interview questions employed for experiences not widely understood (Karraa, 2014; Marshall & Rossman, 2010). Interview questions were delivered in the same order for each participant. I used specific probing questions throughout the interviews to develop theoretical sensitivity. The interview questions were as follows:

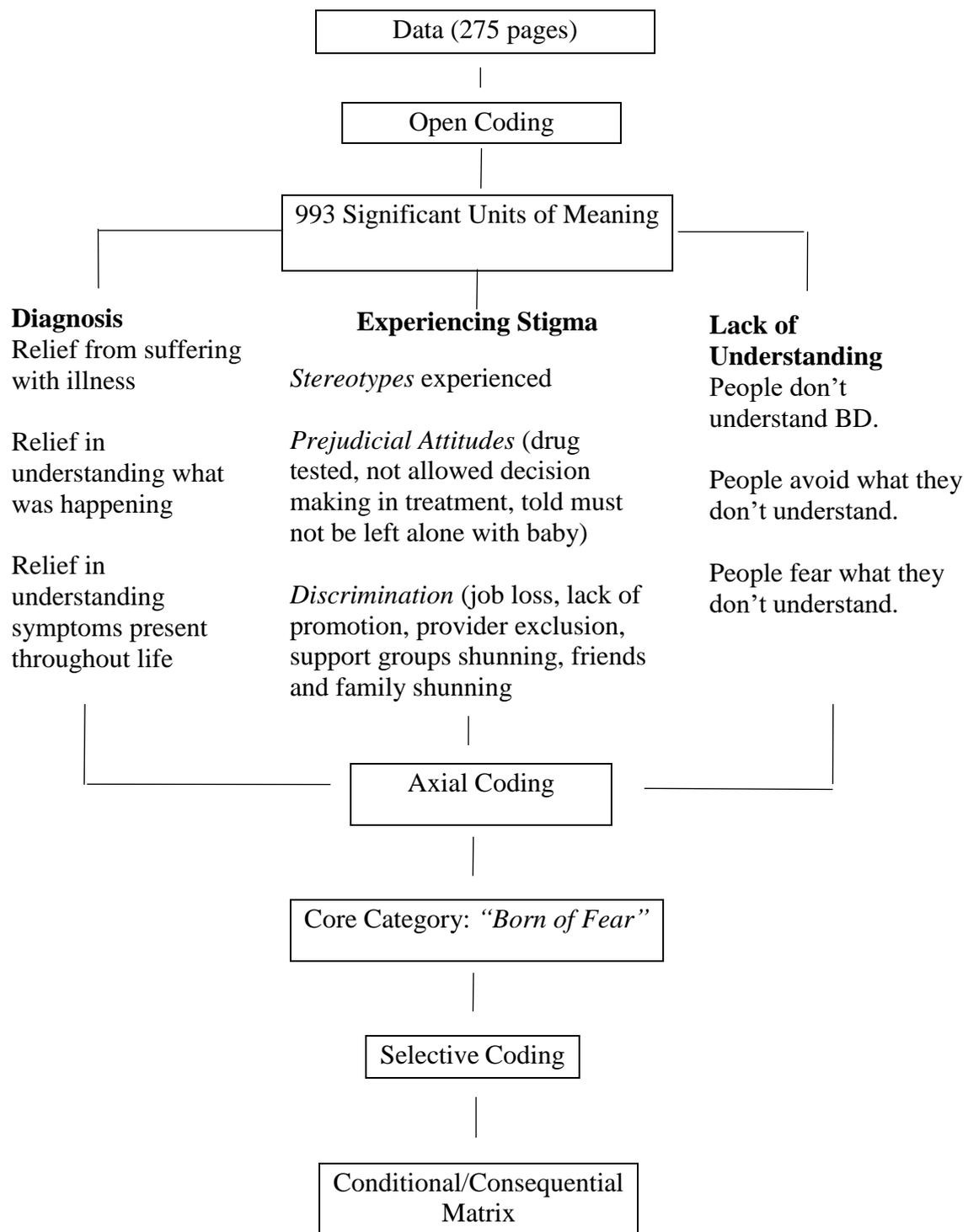
- 1) A descriptive question elicited the participants' explanatory text regarding the experience: *How would you describe your experience of being diagnosed with bipolar disorder following the birth of your child?*
- 2) An exploratory probed for responses revealing the processes involved with the experience: *What were the ways you saw yourself stigmatized by your diagnosis?*
- 3) An explanatory interview question revealed patterns and properties of the conditions related to the experience: *How do you think you worked through the stigma?*
- 4) An emancipatory interview question explored participants' experience of the evolution of the experience over time: *Are there ways you experience stigma now?*

**Interview transcripts.** All interviews were audiotaped using a conference calling system. The average length of the interview was 59.53 minutes. A total of 275 pages of verbatim transcripts were produced, with the average of 16.8 pages of transcribed data. Transcriptions were sent to participants for member checking validation prior to analysis.

## Data Analysis

Following receipt of member-checked transcripts, data were analyzed using grounded theory methods (Corbin & Strauss, 2015). Data were coded in open, axial, and selective order using analytic tools of comparative analysis, in vivo codes, theoretical questioning, and schematic memos. Axial coding revealed relationships between categories and the core category, "*Born out of fear*" emerged. The core category was then analyzed using the Corbin and Strauss (2015) paradigm of conditions, consequences and actions/interactions in the development of a conditional/consequential matrix (Figure 1).

**Open coding.** Open coding or, "Breaking data apart and delineating concepts to stand for blocks of raw data" (Corbin & Strauss, 2015, p. 239), was conducted through line-by-line comparative analysis of the raw data. Beginning with comparative analysis, each significant unit of meaning was labeled, iteratively compared for similarities and differences, and assigned to an early category. A total of 993 significant units of meaning were lifted from the raw data and comparatively analyzed. A total of 3 early categories were identified: (a) Diagnosis; (b) Experiencing Stigma; (c) Lack of Understanding.



**Figure 1.** Data Analysis Procedure

**Axial coding.** Thematic data revealed in open coding were then analyzed for intersecting, conflicting, relative connections between thematic content using the analytical tools of questioning and schematic memos to further develop theoretical conceptualization in a core category (Corbin & Strauss, 2015). Specific types of analytical questioning engaged the data, probing for early theoretical connections. Sensitizing questions were asked of the data by the researcher and noted in memos and schematic diagrams. Sensitizing questions included:

“What are the processes at play?”, “How are the participants defining experiences similarly or differently?”, and “What are the consequences of these events?”. Responses were noted in memos. Theoretical questions: “What larger systems are at play?” and “How do concepts relate to properties, qualities, time, or consequence?” probed for connections between the concepts. Memos generated in the consideration of sensitizing and theoretical questions were identified and micro-analyzed using guiding questions. Observational and reflective memos were abstracted into schematic form to facilitate conceptualization of emerging theoretical material. Finally, implementation of the Corbin and Strauss (2015) paradigm of conditions, consequences and actions/interactions revealed the properties of stigma and consequences of the experience. The core category, using in vivo text, “*Born out of fear*” was identified.

**Selective coding.** During selective coding, the use of conditional/consequential matrix and summary memo revealed that the experience of stigma for women diagnosed with bipolar disorder during the postpartum period was rooted in a perceived universal lack of understanding about BD. The lack of understanding was experienced in all areas of public, social and personal relationships with the exception of women’s relationships with their babies, or other children.

## Results

What follows is a description of (a) participant demographics; (b) open coding emergent categories; (c) axial application of the paradigm of conditions, consequences and actions/interactions and the resulting core category; (d) selective coding application of the conditional/consequential matrix.

### Participants

All participants (N = 15) completed demographic survey yielding the following results. The majority of respondents reported being Caucasian, married, residing in the United States, employed full time and receiving an income of \$50,000 or greater annually. When asked to rate overall mental or emotional health, (n = 2) reported *Excellent*, (n = 3) reported *Very Good*, (n = 6) reported *Good*, and (n = 4) reported *Fair*.

### Open Coding Emerging Themes

Following three initial passes of open coding and the generation of memos regarding non-apparent meanings were noted and emerging thematic content was coded into 3 categories: (a) Diagnosis as Relief; (b) Experiencing Stigma; (c) and Lack of Understanding.

**Diagnosis as relief.** The thematic category “Diagnosis as Relief” presented concepts of meaning regarding how women experienced being diagnosed with a bipolar disorder as a relief. Relief resulted from the diagnosis contributing to their understanding of their illness, relief in getting treatment to help symptoms, and relief in understanding regarding previous experiences of psychiatric distress before childbirth. All participants reported hospitalization as the initial means of receiving a BD diagnosis. The level of illness was severe enough to require inpatient psychiatric treatment. Women reported having spouses drive them to the emergency room for assessment. Once diagnosed, women reported relief from symptoms as a result of treatment appropriate for BD. Getting the diagnosis was expressed as relief in finally understanding what they had been experiencing from the illness. As Participant 11 stated, “I was relieved thinking at least I can put a name to this and figure out where to go from here.” Participant 10 echoed, “So I think I was surprised, slightly relieved because we could go forward and figure out how to make me stop feeling so crappy.” A similar explanation was expressed by Participant 2:

It was a diagnosis that once I had it explained to me, it was very clear that was what I had suffered from. And that it was very encouraging that we knew some probably treatments that would work right away that we could start. So that was really encouraging to receive that, to have a little bit more direction rather than just trying random medications and hoping something works (Participant #2).

Women also expressed a sense of relief through getting the diagnosis in that finally had clarity as to the previous history of psychiatric symptoms. Participant 11 noted, “Everything seemed to come together for me as just kind of making sense of how my life was up until that point.” As Participant 7 reflected,

Everything just click, click, click, click. And I think I knew, I knew exactly then. And it was like; I didn't know a Ph.D. to figure that out. It was exhilarating, but it was also very sickening to realize that this has been going on my whole life (Participant #7).

The conditions of this category were that women were treated by medical providers in the midst of a psychiatric emergency. Themes of relief were the actions-interactions experienced, and the consequences of the experiences included developing an understanding of the illness and an understanding of previous psychiatric symptoms before childbirth.

**Experiencing Stigma.** The emergent category, “Experiencing Stigma,” revealed women’s direct experiences of prejudicial attitudes and discrimination based in stereotypes of bipolar disorder. Stereotypes regarding mental illness, included: general mental illness (*sick, unstable, incompetent, violent, dangerous*); depression (*emotional, controllable, lazy, not a real disorder*); mania (*erratic, unstable, hospitalization, fun, always happy, running through the streets naked, screaming, drug user*); and postpartum mental illness (*drowning babies*). Sources of stigma included mental health care providers (participants 1, 2, 3, 5, 6, 8, 9, 14 & 15), spouse/partner (participants 6, 8, 9, 10, 14 & 15), the workplace (participants 1, 2, 3, 4, 5, 6, 7, 9, 10, 12, 14 & 15), and parents (participants 1, 4, 5, 6, 7, 9, 10, 12, 13, 14).

**Providers.** While the interview questions did not address care providers, all but 2 participants reported the actions of and interactions with healthcare providers as a stigmatizing. Examples include:

The first I knew that something was awry, I was reviewing my medications with my social worker and she told me that I was taking lithium. But when she said it, when she said I was on lithium, I remember her saying, “Oh no, I'm so sorry.” I just kind of knew that something, it kind of felt like something terrible or ominous had happened (Participant #1).

Participant 2 shared,

After four months, I started experiencing hallucinations; my doctor was not comfortable treating me. She thought I was a drug user, and gave me a surprise drug test, which of course showed that I was not on any drugs. It sort of felt like she wasn't comfortable with me, not just that particular condition that I was suffering, but me as a person (Participant #2).

Participant 5, a military spouse, reported her experience of stigma in this way: “He asked me if the suicide attempt was just a cry for attention, and stuff like that that just made me very uncomfortable talking to him.” Participant 8, another military spouse living on a marine base, described:

I was told specifically by my first psychologist, “Well bipolar—when you're bipolar, you want to stop taking their medications” and that you can't be alone with your baby for like a month, for four weeks, or however long they said. Like that was the part of the instructions, you're not allowed to be alone with your baby for a month. You're not even like fit to be alone with your baby? You can't be left alone with him? I ended up having the worse depression of my life ever after this. I guess that's where I felt the first stigma. And that was coming from my mental health care professional; it wasn't coming from a family member or a friend, or anybody (Participant #8).

Similarly, Participant 9 experienced stigma from a psychiatrist, who “told me I wasn't allowed to read the packet for my medications because I might make up that I get the side effects. He told my husband not to let me read the packet. Which was so degrading.” For others, primary care physicians exhibited stigmatizing treatment practices, as Participant 15 explained,

I went to my primary care physician and she said well she was not super comfortable with prescribing, but she said it was fine. And then when I went to get a refill on a prescription and she decided that she was not going to prescribe it anymore. She wouldn't even get on the phone. I talked to somebody in the front office staff and said could you ask her to give me another month? I'm running out in three days! (Participant #15).

**Spouse/Partner.** Women reported their partners as either not understanding the diagnosis, avoiding them, or implying disbelief through suggesting women had control over the disorder. Participant 6 reflected,

He wasn't around; he wouldn't be in the same room as I was. He thought it was something that I could just fix. And he didn't understand why it wasn't being fixed. And my husband now definitely does not understand or agree with the diagnosis. He's very much of the belief that it's all in your head (Participant #6).

For Participant 8, her spouse struggled with “separating the symptoms of depression from me making a personal choice to act or feel a certain way.” Participant 15 shared, “He tries to be supportive, but he doesn't understand it and he doesn't look into it to try to understand it. He doesn't feel the need to.”

**Workplace.** All participants experienced stigma in the workplace. Many women needed to tell employers about their disorder in order to secure medical leave.

I had to go out on FMLA leave. I had to get the doctors note, give it to my employer, explain what was going on. I still feel like they kind of don't know what to say to me, or kind of look at me strangely. They were like, “No, whatever you need to do.” But it was just embarrassing. I just feel embarrassed I guess is the best way to put it. Because it's not like I had surgery or a medical injury that put me out of work. It was me calling my boss at 10 o'clock in the

morning from my office saying I have to go home because I'm having a panic attack. And it was just embarrassing (Participant #5).

Participant 15 experienced discriminatory behavior following disclosure:

I approached the administration with a proposal to reduce the hours that I was in the building. That there were certain duties that I would take home and do some of my work at home. And part of that proposal was a reduced salary, and less benefits. And I thought it was going to be an ideal situation for them. Here's somebody who's going to do the same amount of work for less money. But they actually said, "If you're not going to be working full time, we can't keep you in this position." And then they went on to hire somebody in the same position part-time (Participant #1).

Participant 11 also experienced loss of income as a result of disclosure,

A lady I was doing daycare for came to see me after I got out of the hospital. She's got an anxiety disorder too, and we talked about it and stuff. But then my doing daycare for her fell through. For someone to do that it was just like wow, you do not understand it at all. So that was my experience with stigma (Participant #11).

For others, symptoms were noted by co-workers and assumed to be the result of drugs or alcohol. For example, Participant 15 described,

One of the girls I work with decided that she needed to have a talk with the manager because she thought I was either on drugs, or I was drinking. So, at that point, that's where I decided to tell my managers that I'm bipolar, and it had nothing to do with drugs or alcohol. It was very awkward. She asked me a lot of questions about me, making sure that I was able to function at work. I did notice that after that conversation my hours did get cut at work, and they still haven't gone back up (Participant #15).

Participant 2 explained, voluntary disclosure to colleagues also resulted in stigma. For example,

So, I did share with one member of the administration who I believe also shared it with some other administration to figure out how to fill that role for a week. And I experienced a little bit of stigma there as well when I came back to work. I could tell that some people knew the diagnosis and were more avoidant of me (Participant #2).

Another participant shared her diagnosis with a colleague who asked about her medication in this way, "Doesn't it make you feel happy every time you take it?" (Participant 14).

For several, stigma in the workplace was anticipated, as Participant 13 stated, "I couldn't even risk losing my job so there was no way I told anybody at work." For Participant 4, however, concealment of illness did not mitigate her risk of losing her employment.

My illness was never mentioned. I never—it's like if someone were going to a cancer treatment at that time, of course they would have no problem saying, "Well I'm getting chemotherapy or whatever, that's why I can't be at work." I

mean I was still manic after I came out of the hospital. So, I guess there was this fear of they wouldn't understand so it was never really mentioned. But then I had to resign, and it may have been due to the elephant in the room, the thing that no one could talk about (Participant #4).

**Parents.** Stigma was experienced through the attitudes and behaviors of women's parents. Participant 8 stated, "They don't really believe in it." Participant 9 echoed, "I mean, they don't believe in mental illness. I mean, even my dad's a doctor, but he's actually a surgeon. But they just don't believe any of that is real." Participants described having parents who did not believe in mental illness or who didn't believe them, as Participant 10 stated,

No one really wanted to believe it. I don't know if it was because of a stigma attached the diagnosis or if it's lack of experience with anyone having that diagnosis. I think once my parents finally experienced some of the symptoms of the mania, they recognized that there was really something else going on, it wasn't—it couldn't be explained away at that point (Participant #10).

For others, parents' prejudicial disbelief about psychiatric treatment was expressed:

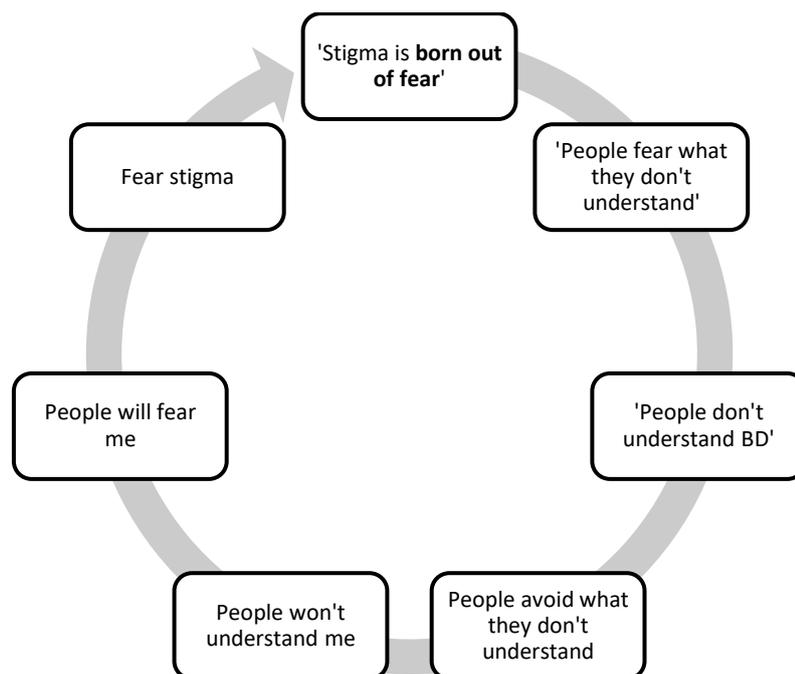
My mother doesn't believe in psychiatric care. I got a lot of crap from her about that. So, I didn't feel like she needed to be involved in anything else. She just told me that I needed to grow up, and get my life together, and stop playing these teenage games (Participant #12).

For many, the stigma experienced by parents was in the covert and overt message to not talk about their illness. Participant 6's described covert understanding to not disclose in this way, "My parents have never been, I mean, they're supportive but they're not much into talking. It's kind of like, okay, we know there's a problem, and we know there's something going on, but we're not going to talk about it." Participant 13 expressed similar stigmatizing messaging from her parents, "It's almost like when I am having an episode or a bad time, or feeling a little bit off, it's like the white elephant in the room. Nobody mentions it, nobody talks about it." The tacit understanding of stigmatizing disbelief for Participant 7 was explained in this way, "I think just me knowing my parents as well as I do, I think that in a way, they too think that I can control a lot more of it than I can."

Lastly, women described stigma from their parents in the form of expressions of concern regarding the safety of their medication or regarding the risk of stigma from other parents.

Well my parents I think were the driving force with how I handled talking about my illness because they encouraged me to not reveal, to not be open about it. I remember my mom said, "You don't want everyone to know that you have bipolar disorder because what if the moms at your son's preschool don't want their kids playing with him at your house because you have bipolar" (Participant #4).

**Lack of understanding.** The final open coding emerging category, "Lack of Understanding," included concepts of meaning regarding how women perceived the lack of understanding about BD as a central component of stigma formation. Themes included: *People don't understand BD; People avoid what they don't understand; People fear what they don't understand* (See Figure 2).



**Figure 2.** Stigma Conceptualized as Lack of Understanding

***People don't understand BD.*** The core concept described included a fundamental ignorance about BD, as Participant 5 noted, “From my experience, from what I've heard is if someone is bipolar they think schizophrenia.” Participant 10 echoed,

I think a lot of people don't understand the differences between certain types of mental illnesses. They kind of group them all together. I think people just think they're like that and that's it. Like this person's crazy and that's it (Participant #10).

For Participant 14, lack of understanding involved the media,

I mean I think most people have ideas in the media of what bipolar disorder is or other things that are just totally incorrect understandings. So, I feel like when you say depression people sort of get it immediately. But when you say bipolar disorder it's less immediately familiar (Participant #14).

Participant 12 explained, “I mean, it was, not only was it just the complete lack of knowledge, the sheer ignorance of it all, the fear of not being normal I think that led most of the reactions.” Stigma was understood to be rooted in a lack of knowledge, or understanding regarding mental illness, postpartum depression and bipolar disorder.

***People avoid what they don't understand.*** As a result of the experience of stigma, women also understood stigma as a mechanism for social avoidance:

I think just mental illness in itself just kind of just something don't want to talk about, or they're kind of afraid to talk about. And I think something that's not, that's normal depression, or just a panic attack, or anxiety is something that you're calling bipolar. I think it kind of turns people away because maybe they're afraid or they just don't understand. I think they just don't understand. So when

you don't understand something, you're kind of hesitant to talk about it, or be around somebody who says they have that going on (Participant #7).

The nature of avoidance was seen as fear-based:

I don't know if a lot of people think, okay, I'm going to catch it. It's not a virus. But maybe there's some weird subconscious feeling like oh my god, I could be like that. Or maybe I'm really like that, and it just hasn't come out, or who knows. But I think it's more think it's just the lack of control, association lack of control with a mental illness, and feeling vulnerable around somebody who has a diagnosis (Participant #15).

The lack of understanding regarding BD resulted in the avoidance behavior by others. The nature of lack of understanding BD was described as fear (See Figure 2).

**People fear what they don't understand.** Participant 13 shared, "Just the unknown. They don't completely understand so that's scary. It's not a sure thing, so that's scary. It's not normal, it's not what they're used to." Participant 9 explained, "People with bipolar for some reason they think you are what people like to call batshit crazy. Like it's beyond, it's just too scary." Finally, Participant 7 summarized,

Emotions can really scare people. I think that's a big part of it is that people just are afraid of being witness to the unknown. And if they've been lucky enough to not have to deal with that in any capacity or people have been hiding it, then it's very scary. And that's where stigma is born; it's born out of fear (Participant #7).

### **Axial Application of the Paradigm of Conditions**

Through the application of the Corbin and Strauss (2015) paradigm of conditions, actions-interactions and consequences, the analysis revealed that the properties of the category Experiencing Stigma were based on the conditions of re-entering life following the diagnosis of a bipolar disorder. Actions-interactions included women experiencing direct and indirect prejudicial beliefs and behaviors based on stereotypes of bipolar disorder and mentally ill mothers portrayed in media. Experiencing stigma in multiple and intersecting domains of personal, social, and public life reinforced the knowledge of stereotypes of mental illness. Consequences of this experience resulted in the development of the belief that stigma is prevalent, pervasive and based on the lack of understanding regarding BD (Table 1).

**Table 1.** Paradigm Analysis in Axial Coding

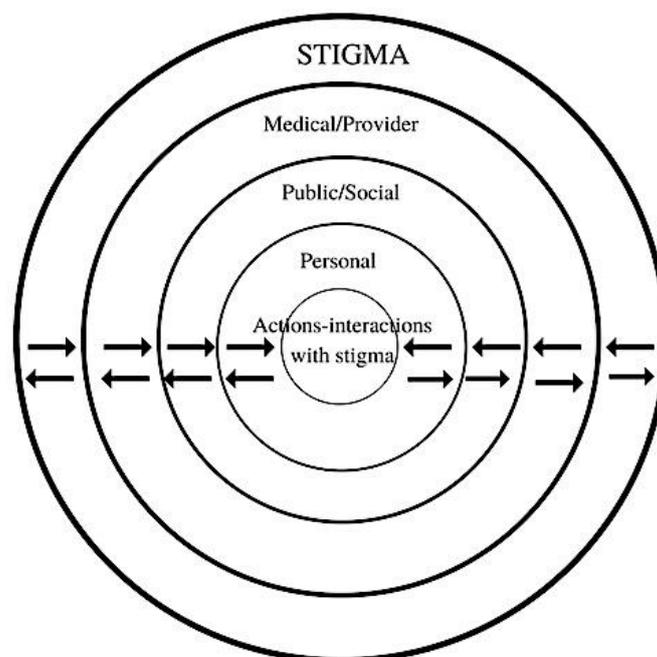
Properties	Conditions	Actions-Interactions	Consequences
Diagnosis	Initial, provider, psychiatric emergency	Relief	Illness treated, emergency ended Understanding the illness Understanding previous symptoms
Experiencing Stigma	Re-entering the world: family, work, providers, social support	Direct experience of stigma resulting from disclosure Reinforcement of stereotypes of mental illness Parents and family reinforce non-disclosure	Discrimination-refused treatment, termination of employment Loss of relationships Stigma of BD is universal and real

Lack of Understanding	Personal, social and public lives.	Belief that people don't understand BD, and not understanding results in fear.  Avoiding disclosure	Stigma is perceived as not understanding BD caused by universal fear of unknown.  Core category: "Born in fear"
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### Theoretical Conceptualization

Once the core category *Born of Out of Fear* emerged, selective coding developed further theoretical understanding. Returning to the raw data for a final search of meaning units of categorical significance relative to the core category developed theoretical sensitivity of the process of coping with the stigma of bipolar disorder. Micro and macro analysis of the meanings of stigma, and the use of summarizing memos assisted in the formation of a conditional/consequential matrix (Corbin & Strauss, 2015).

In a conditional matrix, the outer most layer represents the condition that permeates the subsequent levels. As applied to the current study, the stigma permeated public, social and personal dimensions. Women identified that their diagnosis was associated with negative attributes, stereotypes, and prejudicial assumptions regarding their diagnosis (see Figure 3).



**Figure. 3** Conditional/Consequential Matrix of Stigma of BD for New Mothers

### Discussion

The objective of this study was to describe and explain the nature of the stigma of mental illness for women diagnosed with a BD during the postpartum period. The body of literature regarding the stigma of mental illness has produced hundreds of studies (Pickenhagen & Sartorius, 2002) and several models of stigma formation (Corrigan, Markowitz, & Watson, 2004; Goffman, 1963/2009; Jones et al., 1984; Link & Phelan, 2001; Thornicroft et al., 2007).

The stigma described by participants in this study confirms theoretical models of stigma formation. For example, the stereotypes described by the participants in this study mirror

Goffman's (1963/2009) early conceptualization of stigma as "an attribute that is deeply discrediting" (p. 3). Women's overt and tacit experience with stereotypes as a result of their diagnosis contributed to the belief that society viewed them as "reduced in our minds from a whole and usual person to a tainted, discounted one" (p. 3). The pervasive nature of stigma of BD identified by stereotypes described promoted the construction of separate social identities based on anticipation of stigma, such as avoiding disclosure in work where their identity might be discredited should they be associated with negative attributes (Goffman, 1963/2009). Goffman described stigma as both virtual and actual. The stigmatized individual experiences self as normal, but also perceives that "whatever others profess, they do not really 'accept' him and are not ready to make contact with him on equal grounds" (p. 7). Goffman's work set in motion a relative interest in making the invisible visible with regards to using social science to study stigma, yet the zeitgeist of mid-twentieth century American psychiatry had yet to consider perinatal mood or anxiety disorders distinguishable from the general population.

In *Social Stigma: The Psychology of Marked Relationships*, Jones et al. (1984) conceptualized stigma as having six interconnected dimensions of an individual being "marked" (Jones et al., 1984, p. 7) by society based on signs or symptoms of a disorder. The dimensions range on a spectrum of discernibility by others and include: (a) concealability/visibility; (b) course over time; (c) strain on interpersonal relationships; (d) aesthetics related to the disorder; (e) known cause of the disorder; (f) danger to others associated with the disorder. The model presumed, "The mark is potentially discrediting and commonly becomes so when it is linked through attributional processes to causal dispositions, and the dispositions are seen as deviant" (Jones et al., 1984, p. 7). In the current study, the description of stigma aligned with the Jones et al. (1984) model in that participants described knowing that women with BD had been marked by stereotypes as being deviant, as illustrated by 3 participants using similar language of "running down the street naked and screaming" (Participants 2, 8, 9). The domains put forth by Jones et al. (1984) considered the observer/observed relationship as the totality of the stigma experience, not considering the multiple and intersecting experience of self in the non-marked life, such as mother-infant dyad. Women in the current study experienced self as "marked" in public, social, and personal domains where the observer was not their infant or their other children. Stigma was not present in the interpersonal relationship between mother and child. In essence, women were never "marked" by the infant they brought into the world. Stigma may have been born out of fear, but their child was born stigma free.

Stigma theory put forth by Link and Phelan (2001) suggested stigma as a mechanism of social power, "Thus we apply the term stigma when elements of labeling, stereotyping, separation, status loss and discrimination co-occur in a power situation that allows them to unfold" (Link & Phelan, 2001, p. 367). Stigma occurs when behavior is exhibited and noted as different by the observer, linked to deviant or undesirable personal characteristics through attribution, and separated from normal and mainstream constructs, resulting in the individual's loss of status, discredit, and discriminatory behavior (Link & Phelan, 2001), and negative emotional reactions (Link, Yang, Phelan, & Collins, 2004). In this way, stigma is an expression of the observer, waged through a process of attributional linking of individuals to negative stereotypes, anticipating negative behaviors that may result from a person having the label, and separating from the individual through social avoidance and discrimination.

Participants in the current study experienced the labeling process suggested by Link and Phelan (2001), predominantly by care providers. As reported by every participant in this study, getting the diagnosis itself, while necessary to obtain treatment, was a labeling process that induced stereotyping, separation and discrediting in the eyes of the provider. For most, the labeling process was repeated when the diagnostic label was shared with spouses, parents, and work colleagues. Current findings reveal the perceptions of the process of being stigmatized, a

facet of stigma formation not fully considered in Link and Phelan's model (2001). Moreover, what was evidenced in women's descriptions was the absence of the labeling process occurring with their baby or other children. From this perspective, women's behavior did not elicit labels from their babies, developmentally incapable of cognitive attribution. A lack of understanding, due to developmental age, created a maternal-infant dyad free from stigma.

How might the *lack of understanding* explain both the causes of the stigma and the absence of stigma for mothers diagnosed with BD? The foundational nature of stigma for the women in this study was lack of understanding about BD by everyone who knew they had BD. As evidenced in this grounded theory study, stigma was a problem of ignorance, supporting the theory put forth by Thornicroft et al. (2007), that stigma is a problem of ignorance, a problem of prejudice, and a problem of discrimination.

Findings set the experience of stigma for mothers diagnosed with BD in the first year postpartum, in contrast to existing models of stigma, in that nature of stigma did not include their infant, or other children. As research has determined perinatal mood and anxiety disorders interfere with the critical infant developmental mechanism of maternal attachment, this study provides an expanded theoretical frame with regards to stigma and attachment. While untreated perinatal mood or anxiety disorders may interfere with a mother's ability to attach to her child, the stigma of the disorder may not.

## Limitations

The limitations of this study include the self-reporting of BD by participants and absent documentation of a confirmed medical diagnosis. The sample size is a limitation for generalizability to larger populations. However, the goal of GT is not generalizability, rather, the rigorous analysis of a phenomenon not widely understood. As the first study exploring the specific experience of the stigma of mental illness for mothers diagnosed with BD, future research regarding the relationship between the stigma of perinatal mood and anxiety disorders and maternal attachment is indicated.

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Dr. Walker Ladd has been a thought-leader in the field of maternal mental health for over a decade. Her first book, [\*Transformed by Postpartum Depression: Women's Stories of Trauma and Growth\*](#) (Praeclarus, 2015), was based on her grounded theory study of the transformative nature of perinatal mood and anxiety disorders. She currently serves as Lead Faculty and University Research Methodologist the School of Advanced Studies at the University of Phoenix. Correspondence regarding this article can be addressed directly to: [WalkerLadd@email.phoenix.edu](mailto:WalkerLadd@email.phoenix.edu).

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