The Experience of Pregnancy for Women with Bipolar Disorder: An Exploratory Study

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Abstract

Objective: Bipolar disorder often emerges in an individual’s late teens and early twenties. As a result, women with the disorder are impacted for the majority of their childbearing years. Pregnancy brings a unique set of challenges to this population, including risk of relapse, teratogenicity of medications, and increased risk of postpartum psychosis. This study utilized semi-structured telephone interviews to gather qualitative data on the experience of pregnancy for women with bipolar disorder with the long-term goal of developing patient education materials and improving nursing interventions to help manage illness during pregnancy and the postpartum period. Method: A sample of three English-speaking women, aged 29-39, with a confirmed diagnosis of bipolar I or II and who have given birth within the last eighteen months, were recruited. Interviews were audiotaped, transcribed, and coded using a grounded theory approach, in consultation with the faculty advisor. Results: Women with bipolar disorder described a unique pregnancy experience, influenced by the intersection of mental illness, pregnancy and pharmacotherapy. Recurrent themes included hopefulness, patient and provider as advocates, education, community support and the mixed impact of medication. Conclusion: This research will contribute to initiatives designed to improve healthcare for pregnant women with bipolar disorder and augment patient education materials. Existing empirical research findings become even more valuable tools for improving patient care when paired with the voices of patients themselves. As pregnant women are a historically under-studied population, this study also contributes to the larger body of scientific research on this population.

Keywords: bipolar disorder, pregnancy, patient education, nursing, qualitative
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Introduction

An estimated 0.5-1.5% of people in the United States are diagnosed with bipolar disorder. This illness has an onset in the late teens or early 20s, meaning that women are impacted for the majority of their childbearing years (Yonkers et al., 2004). Pregnancy and motherhood bring a unique set of challenges to this population. The experience of motherhood for women with serious mental illness has been extensively researched, and the experience of pregnancy for women with chronic illness is established in the literature (Holton, Kirkman, Rowe, & Fisher, 2012, Meade, Sharpe, Hallab, Aspanell, & Manolios, 2012). The experience of living with bipolar disorder has been briefly chronicled (Driscoll, 2004, Lim, Nathan, O’Brien-Malone, & Williams, 2004) but there is no literature on the experience of pregnancy for women with bipolar disorder (Benders-Hadi, Barber, & Alexander, 2013, Blegen, Hummelvoll, & Severinsson, 2012, Montgomery, Tompkins, Forchuk, & French, 2006).

This study seeks to focus on a particularly vulnerable group with a great number of pregnancy-associated challenges – those with bipolar disorder – in order to contribute to the broader discussion about patient experience and provision of care. Nurses are uniquely positioned within this discussion of perinatal care for women with mental illness due to their role as patient advocates (Allison, S, 2004, Lagan, Knights, Barton, & Boyce, 2009, Kralik, 2002).

Nurses provide a great deal of caring, education and support both at the bedside and at the advanced practice level. As nurses, we are privileged to have a unique provider-patient relationship that is influenced by our holistic education, focus on caring, and the amount of time we have to spend with the patient. We advocate for our patients and help them advocate for themselves. A nursing education focuses on the patient experience, and at its best, encourages us
to empathize and put ourselves in the patient’s place to understand their experience and improve care.

This study utilized open-ended interviews to gather qualitative data about a unique pregnancy experience, influenced by the intersection of mental illness, pregnancy and pharmacotherapy. By focusing on the lived personal experiences of these women from the nursing perspective, this study seeks to address the gap in the literature, contribute to future patient education and participate in the discourse surrounding clinical care for pregnant women with mental illness.

**Bipolar illness during pregnancy**

Pregnancy, particularly the postpartum period, is a time of increased risk of relapse for women with bipolar disorder (Munk-Olsen, Laursen, Mendelson, Pedersen, Mors, & Mortensen, 2009, Freeman, Smith, Freeman, McElroy, Kmetz, Wright, & Keck, 2002, Viguera, Nonacs, Cohen, Tondo, Murray, & Baldessarini, 2000).

Munk et al. (2009) found the risk of postpartum readmission was eight times greater for women with bipolar disorder than for women with schizophrenic disorders, leading the authors of the study to suggest strongly that women with bipolar disorder considering pregnancy should be told of the risk of relapse after birth. Discontinuation of mood stabilizers with pregnancy has been strongly associated with relapse (Viguera et al., 2007), while prophylactic pharmacologic treatment throughout pregnancy has been shown to reduce but not eliminate the risk of relapse (Bergink, Bouvy, Vervoort, Koorengevel, Steegers, & Kushner, 2012, Cohen, Sichel, Robertson, Heckscher, & Rosenbaum, 1995).

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* This literature review was submitted as part of my proposal for N371 in April 2013. It has been updated with minor changes as of March 2014.
Women with bipolar illness are faced with an exceptional conundrum when considering conception because of the risks not only to themselves but also to their unborn child. Some of the most effective mood stabilizers are classified as category C (potential evidence of human fetal risk) or D (positive evidence of human fetal risk) by the FDA’s classification system for medications to be administered during pregnancy (Allison, 2004). Sodium valproate (Depakote) and carbamazepine (Tegratol) are both considered human teratogens (Yonkers et al., 2004). Lithium exposure in utero has been associated with low birth weight, floppy baby syndrome, and an increased risk of Ebstein’s Anomaly, a cardiovascular malformation (Yonkers et al., 2004). A population registry study in Sweden indicated that women with affective psychosis were at a higher risk for giving birth to preterm, growth restricted or low birth weight infants (MacCabe et al., 2007). Other research suggests that women with bipolar disorder, treated or untreated, are at increased risk for adverse birth outcomes including preterm birth, neonatal hypoglycemia and microcephaly (Bodén, Lundgren, Brandt, Reutfors, Andersen, & Kieler, 2012). A recent study examining neuromotor function in 6-month-old infants with in-utero exposure to antipsychotics, antidepressants or no psychotropic medication suggests there may an impact of antipsychotics as infants exposed to antipsychotics had significantly lower scores on neuromotor performance (Johnson, LaPrairie, Brennan, Stowe, & Newport, 2012). However, with the discontinuation of medication, there is the concern of exposure of the fetus to maternal stress hormones as well as the aforementioned risk of relapse (Newport, Wilcox, & Stowe, 2001). Other than a previous history of postpartum psychosis, the biggest predictor of an episode of postpartum psychosis is a history of bipolar disorder (Munk-Olsen et al., 2009). Postpartum psychosis is a psychiatric emergency and a potential complication that can threaten the life of mother and infant.
A case study documenting pregnancy management for a primiparous woman with bipolar disorder underscores the complicated path to motherhood that women with bipolar disorder may face (Burt, Bernstein, Rosenstein, & Altshuler, 2010). The case study followed a 29-year-old woman whose bipolar disorder was well managed for five years pre-pregnancy and recounted the hospitalization, suicidal thoughts, multiple medication changes and postpartum hypomania that she endured during her pregnancy. This particular patient decided that subsequent pregnancies would be conducted via a surrogate. This case study confirms the need to educate women of childbearing age with bipolar disorder of the risks associated with pregnancy and options for medical management, in order to promote informed decision-making.

Experiential accounts of bipolar illness

Driscoll (2004) examined the lived experience of women with bipolar II (Driscoll, 2004). The study author, a psychiatric clinical nurse specialist, interviewed a sample of 11 women with bipolar II disorder using descriptive phenomenological methods. Interviews were audiotaped, transcribed and mined for subthemes (Driscoll, 2004). Themes that appeared in participant conversations about the clinical care they received for bipolar disorder included the difficulties of being diagnosed and treated, lack of validation from healthcare providers, poor results from pharmacotherapy, and the impact of their menstrual cycle on their symptoms (Driscoll, 2004). The study author found that many of the experiences these women described were the result of care that contradicted the care recommendations available in the psychiatric literature (Driscoll, 2004). A second study, utilizing a focus group format to interview 18 patients with bipolar I, uncovered common themes of chaos, circumstances beyond control, isolation from community, and lives featuring prominent themes of loss and deficit (Lim et al., 2004). Despite the great need
for information regarding patients’ perceptions of their care, minimal research has been published on this topic.

**Purpose**

This exploratory pilot study utilized semi-structured interviews to gather qualitative data on the experience of pregnancy for women with bipolar disorder with the long-term goal of developing patient education materials for managing illness during pregnancy and the postpartum period. This study aimed to recruit 10 women to demonstrate the practicability of interviews, our ability to recruit participants from this population, as well as collect preliminary data to inform the design of future interventions and refine research questions for further quantitative inquiry.

**Methods**

**Participants**

Eligible participants were female, age 18 or older, primiparous or multiparous, within 18 months postpartum of their most recent pregnancy, and with a history of DSM-IV bipolar disorder as determined by the M.I.N.I. clinical interview (Sheehan, 1998). In January 2014, we modified our IRB protocol to allow the inclusion of women who were currently pregnant as well as postpartum, in order to gather a more comprehensive, real-time assessment of the experience of pregnancy and motherhood in women with bipolar disorder. By including pregnant women we aimed to increase the diversity of perspectives, reduce recall bias, and increase our ability to recruit, given that we were potentially doubling the number of women eligible to participate. Exclusionary criteria included a current manic or psychotic episode (as determined by the M.I.N.I.) and male gender. There were no exclusions based on race or ethnicity.

**Recruitment**
Participants were recruited via university-wide e-mails, postings on the research pages of the National Alliance for Mental Illness (NAMI), the Bipolar Support Alliance (DBSA), the Volunteers page of the Raleigh Craigslist.org website (Appendix A), community flyers (Appendix B), ResearchMatch.org (Appendix C), and via a Facebook advertisement (Appendix D), all of which contained a link to our brief online screening tool (Appendix E). The screening tool was created in consultation with both advisors, and was programmed into Qualtrics to allow participants to complete the questionnaire online and anonymously. The screening tool utilized questions modified from sections D: (Hypo)Manic Episode and M: Psychotic Disorders of the Mini-International Neuropsychiatric Interview (M.I.N.I) (Sheehan, 1998) to screen for current mania or psychosis (exclusionary). A website address was created to redirect to the Qualtrics questionnaire, housed on the secure UNC server: http://www.bpdpregnancy.com (Appendix F). Use of this succinct web address, allowed participants who saw the flyer to type in an easy-to-recall address and access the screening tool directly without having to e-mail the researcher. This preserved participants' anonymity until they decided to participate in the study, and increased access to the screening tool. Those who were eligible were presented with the consent form at the end of the screening tool. They clicked through the consent form and entered their contact information, which served as their consent to participate. The researcher received results of the online screening tool and contacted those who consented to participate. The researcher called to schedule a study interview, using a standardized phone script, and answered any questions about the study. The researcher e-mailed participants copies of the consent form for their records. There was an option to conduct the screening tool over the phone, though no participants requested this option.

**Study Design**
For the participant, this research study involved a brief online screening questionnaire, one scheduling phone call, one 1-2 hour telephone interview, one short questionnaire about the participant's emotions and one optional follow-up phone call. The interview included completion of a demographic questionnaire, administration of sections A: Major Depressive Episode, Major Depressive Episode with Melancholic Features, B: Dysthymia, and C: Suicidality of the M.I.N.I. clinical interview, and a semi-structured qualitative interview created to assess participants’ bipolar disorder during pregnancy. Sections A (over the phone) and D (online) of the M.I.N.I. were used to confirm diagnosis of bipolar disorder. Following a modification midway through this study, participants were asked to complete the Inventory of Depression and Anxiety Symptoms (IDAS) Questionnaire online via Qualtrics. The follow-up phone call provided a chance for participants to share information that may have been stimulated by the original interview. Participants received a $15 gift card from Target or Wal-Mart (their choice) for participating in the telephone interview.

**Research personnel.** See Appendix G for brief biographies of research personnel.

**Risk management.** A risk management protocol was developed to specify actions for the researcher to take in the event of any indication that a participant was experiencing a manic or psychotic episode during the telephone interview. In summary, the participant would be withdrawn and offered referral materials and a phone consultation with the psychiatry faculty overseeing the project, one of whom was on call for every telephone interview. The Institutional Review Board at the University of North Carolina at Chapel Hill approved this research.

**Data Collection**

Interviews were conducted using the semi-structured qualitative interview guide (Appendix H), featuring prompts if needed. The telephone interview took 20-90 minutes.
depending on the participant. The researcher took notes throughout and audiotaped the interview using an Olympus TP-8 Telephone Pick Up Microphone and Olympus VN-702PC Voice Recorder.

Semi-structured qualitative interview guide. Open-ended questions were utilized deliberately in the interview guide, in keeping with the exploratory nature of this study. With so little literature available on the experience of women with bipolar disorder during pregnancy, the goal was to learn more about their experience, particularly as it related to support, patient education and interactions with healthcare providers. Semi-structured interviews, as described by Doody (2013), allowed flexibility for participants to share their experience and for the researcher to explore pertinent themes as they arose.

The interview guide (Appendix H) was developed following a thorough review of the literature, including studies on the experience of living with serious mental illness, motherhood and mental illness, and pregnancy and chronic illness. A series of open-ended questions and follow-up probes were developed to address potential areas of interest such as preconception and planning, support needs, pregnancy, medication and postpartum care. The guide was vetted by a variety of healthcare providers with relevant professional experience including a clinical psychologist with extensive experience working with perinatal women with bipolar disorder, a women’s health nurse practitioner experienced in working with vulnerable populations and a doctorally prepared nurse-researcher.

Data Analysis

The interviews were transcribed in Microsoft Word and compared to the original audio recording for accuracy. Data was coded using a grounded theory approach as described by Chermaz (2006), in consultation with the faculty advisor. Transcripts were read multiple times,
with initial codes developed in the first readings by moving quickly through the data in a line-by-line approach (Charmaz, 2006). In the second stage of “focused coding”, the codes were edited to the most significant and frequent codes, through continued readings and comparison of transcripts. Throughout, the researcher maintained a focus on emergence, with analysis deriving from the data and codes themselves, rather than from a pre-existing theory or framework (Chermaz, 2006).

Results

From November 2013 to March 2014, 75 women began the online screening tool and 57 completed it. Five eligible participants were identified and agreed to an interview. Two participants were lost to follow up: one stated she was too busy, and one did not return the researcher’s calls. Therefore, three participants completed the full study protocol.

Participants

The participants ranged in age from 29 to 39 years old and all were Caucasian. Two were married and one lived with a partner. One lived in the Southwest and two lived in the Southeast, with one moving to a new state in the Southeast during her pregnancy. All participants pursued some form of higher education: one had a master’s degree in a health science field, one was a registered nurse, and one completed a portion of her college degree. The time between diagnosis of bipolar disorder and pregnancy ranged from one and thirteen years. One participant dealt with significant fertility issues prior to her pregnancy, including premature ovarian failure, the use of an egg donor, two rounds of IVF and one miscarriage. Other complications included gestational diabetes and preeclampsia. One participant was currently pregnant in addition to being postpartum.
Participants’ medication management varied widely during pregnancy, and is described in greater detail below. All participants gave birth to healthy infants without complication and one is currently pregnant with her second child.

**Patient Experience**

**Hopefulness: Wanting to share a positive experience.** While not glossing over the challenges that they faced at various points of pregnancy, all of the women spoke of their experiences with a sense of hopefulness and overall positivity. As one participant put it, “I heard that it was either going to be really good or really bad” when it came to pregnancy with bipolar disorder. They spoke of their surprise at their emotional stability during pregnancy, and of a sense that in the end, things do work out. One woman was able to compare her experiences of pregnancy both on and off medication and spoke eloquently of the importance of hopefulness reflected not only internally, but also externally:

I liked my mom’s advice because she talked to – she talked to a doctor who specializes in exactly what I needed, like, a um, uh, you know a women’s uh specialist at [the hospital], so I really liked that advice because I felt like there was hope. Because this lady knew everything about pregnancy and medicines in pregnancy and psychiatric issues in pregnancy, so that was the one that was most hopeful to me.

Words they used included hopeful, awesome, calm, content, and stable. One participant spoke directly of wanting to advocate for women with bipolar disorder following her experience. Another reached out to the researcher over e-mail following the interview to ensure that she had been clear that she did so well during pregnancy because she truly did do well, not because she was manic.

**More than a diagnosis: the importance of interdisciplinary care**
All three women described interdisciplinary care that defined the course of their pregnancies. One woman, who struggled to find providers willing to treat her during her first pregnancy, provided articulate comparisons between the care provided during her first and second pregnancies. In describing the first half of her first pregnancy, she said:

I’m trying to think during that time, like what I would’ve given anything for. Just someone who could’ve helped me with both pregnancy and the um, psychiatric aspect. You know, that could combine the two of them, and not treat me like I’m pregnant and I’m a psychiatric patient, but they can treat me as both, and not separate it and make it sound like I have to have one or the other.

In comparing the second half of her first pregnancy experience, once she began seeing specialists in North Carolina, she said:

I came up to North Carolina in January – which was before I moved up here – of 2013. And I talked to the psychiatrist, and I also saw a high-risk doctor, and that's when I felt supported because I found that there was a way I could take medicine and still be safe at the same time.

All participants were able to list the many providers who worked together to provide their care. One worked with her psychiatrist, fertility specialist, obstetrical team, and a nurse from her insurance company. She described the smooth communication between providers, particularly the psychiatrist and fertility specialist. Another woman worked closely with her psychiatrist and her midwives. A third worked with an obstetrician, psychiatrist, therapist (LCSW) and nurses during the first half of her first pregnancy, but her experience illustrates that an interdisciplinary team does not equal teamwork:
I had – yeah – I had an awesome therapist. Here’s where it was a problem: I had a good therapist who wanted me on medication, and I had the OB who wanted me on medicine but would only do so with the psychiatrist, and the psychiatrist would only do it if the OB would sign off on the liability that if anything went wrong, the OB would take responsibility for it and no one wanted to put their name on the line. So, I had three different care providers, a therapist, the obstetrician and the psychiatrist and the therapist was doing everything in her power to work with the two other medical professionals and it just wouldn’t – they just wouldn’t – come to a understanding that — it was horrible.

**Providers: Advocating versus Silence**

All participants spoke of the importance of responsiveness and clear communication with their providers. One said:

> You know, I feel like I have a really close relationship with my doctor. She’s like really great and I mean, I did a lot of research before I chose her as my doctor so I felt really comfortable and she was a really great resource. I can send her messages if I need to, um, and she’s quick to reply and she – she spends the quality time at the office visits when I go to see her.

This responsiveness and history of good communication builds a trusting relationship that relieves some of the uncertainty of the experience with pregnancy with bipolar disorder and can provide trusted guidance. From one woman:

> Uh, there’s only one doctor really in charge and that would be my psychiatrist, so, it was kind of left to him, um, to work with me to make sure I wasn’t taking a pill past – you know, that medication past x day, uh, for when we were lining up my egg donation to retrieve and transfer to me, so um I was in great care because he knows me really well.
The importance of provider as advocate was frequently underscored, and in many cases, a licensed clinical social worker or a nurse filled this role: “The nurses…were the same way as the therapist. They wanted me – they said there were safe medicines, but unfortunately they’re not in the position to put me on them”. Psychiatrists were also mentioned as advocates, in terms of their expert management of medications as well as their enthusiasm for the pregnancy and personal excitement for the patient.

**Preparation/Resources/Education**

Important sources of education and support that these women identified as helpful included online forums, community support groups, literature reviews and providers (midwives). Sources that were wished for included medical specialists, pamphlets, and perinatal (in addition to postpartum) support groups. Interestingly, one participant was a registered nurse and she identified her own educational background as key to her experience of pregnancy with bipolar disorder:

Um…I don’t know. I felt like…I felt like I just knew – I mean obviously I don’t know everything – but I felt like I knew more about the basics than I would say other people would. So I felt like I didn’t have to do as much questioning and research, as maybe other people. Like, I could I don’t know – like if I was doing research, I could really focus in on one thing, rather than having to really try and understand the whole broad subject. I don’t know if that really makes sense? You know I actually did a lot of my research, I would say, in like actual publications, not just like – oh, I googled this, that, you know. I looked in like, publication databases.

Another participant was a member of a support group that focused on postpartum depression, facilitated by a nurse practitioner. This participant was able to articulate the ways in which the
support group was helpful to her during the postpartum period, in contrast to the competition that can sometimes be fostered in an environment with a group of new mothers:

In a way, new moms can’t – aren’t that supportive of each other sometimes, because they’re all trading tips and it can become smug, because you want to feel confident that you’re doing the right thing, and you don’t want to feel like the one in the group that’s not keeping up with what you’re supposed to be doing. So, honestly, I would say [this] group stripped all that. That’s not what it was about. We weren’t talking about that in there, at all. It was more like, wow, this is really tough, because I’d say, a lot of time, new mothers don’t talk about the ‘it was really tough’ part, they just – it’s just coffee shop talk.

Receiving the support of other women and hearing the stories of their experience, whether in person in a support group or online in a forum, was a theme throughout these interviews. It appeared to be a way for women to try on the experience of pregnancy and mitigate some of the uncertainty by walking in another woman’s shoes.

**On medication**

The experiences that these three women shared illustrates the lack of consensus in provider attitudes toward medications for bipolar disorder during pregnancy as well as the importance of consensus building in patient-provider decision-making. One participant endured a cycle of going on and off her mood stabilizing medication for nearly three years before becoming pregnant. She would discontinue her medication with the supervision of her psychiatrist, lasting as long as she could while undergoing fertility treatments, and then she would start her medication again when she felt she could not handle it anymore. This on-off cycle repeated for more times than she was able to quantify. While describing how difficult this
cycle was on her and on her husband, she also indicated her resolute support for her decision and her feeling that there was no way for her to be on any medication while trying to conceive because of the risk. In the overall context of her pregnancy, this destabilization caused by stopping her medication was something that she was willing and able to endure. Another participant remained on her psychotropic medications for the entirety of her pregnancy, with the support of her midwives, who did their own research on the medications. Her child was born without any complications. A third participant described being taken off all four of her psychotropic medications at 9 weeks of pregnancy and the resulting depression, anxiety and suicidiality that resulted in a hospitalization at 18 weeks. Of that time she said:

I felt like from the providers that, I felt like I was horrible for wanting to get back on something. I was begging them for any type of help. And I would’ve done anything, even if it was non-pharmaceutical, I would’ve done it if it would’ve helped….But it, it made me, like it made me, feel like I was putting myself before the baby, and it was like, it wasn’t that way at all, but that’s how it felt like I was being seen.

After moving to another state and seeking specialist care, she was put back on her medications at 25 weeks, her mental state improved considerably and she remained on medication for the remainder of her first pregnancy and her subsequent pregnancy. This woman spoke equally eloquently about her conviction, as well as her provider’s conviction, that staying on her medication was the safest option for her and her baby. In her own words: “the safety of my baby was always number one, but the thing is my baby wasn’t going to be safe if I wasn’t keeping myself safe”. In her current pregnancy she remains on all her medications.

Discussion
This project began with the intention of giving voice to individual experiences, and as this study progressed, wildly different patient experiences were indeed revealed. This was a surprising finding, as it was assumed that similar stories, linked by bipolar disorder would dominate the narrative. What was truly revealed was how unique each woman’s experience was, and how bipolar disorder – when managed carefully – became merely a piece of the puzzle rather that the overriding theme. For one participant, her pregnancy narrative was primarily about her fertility struggle and her self-identification as a “fertility patient”. For another, her experience was framed by her experience as a nurse and the support of her providers. For a third, her experience was a study in comparisons, with her first pregnancy dominated by medication issues, depression, hospitalization, and her second one relatively idyllic, with specialist medical care and with bipolar disorder as a bit player.

While the sample size is small and the experiences diverse, some commonalities of the patient experience emerged as data was analyzed. Codes fell predominantly into categories of internal, or relating to the patient’s inner life and sense of well-being, and external, or relating to those factors outside the patient herself. Codes also seemed to divide naturally into groupings of stabilizing and destabilizing. A theoretical matrix is useful for understanding the interplay of these categories - internal / external and stabilizing / de-stabilizing - and their influence on the pregnant patient with bipolar disorder:

<table>
<thead>
<tr>
<th>Stabilizing – Internal</th>
<th>De-stabilizing – Internal</th>
</tr>
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<tbody>
<tr>
<td>Emotional stability</td>
<td>Discontinuation of medication</td>
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<tr>
<td>Hopefulness/optimism</td>
<td>Emotional lability</td>
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<td>Educational level</td>
<td>Suicidality</td>
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<td></td>
<td>Depression</td>
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<td>Guilt</td>
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</table>
This matrix may prove beneficial to a clinician by helping the clinician to organize the forces in a patient’s life for the purposes of designing appropriate interventions. As nurses, this matrix is useful for helping us to identify appropriate nursing diagnoses and interventions. While for a patient with bipolar illness issues of internal stability may come most easily to mind, this matrix underscores the many external (or psychosocial) sources that are also at play.

This distinction is important when we return to the words of the participant who said, “I heard it was going to be really good or really bad”. This statement belies an assumption that there is something inherent to the experience that is unquantifiable and will lead to good or bad outcomes. What these women told me, however, was that there was not a good or bad experience in the end, but a series of experiences, factors and people who impacted them throughout their pregnancy. All women acknowledged at the time of interview that their pregnancy and postpartum experiences were continuing to evolve. Even in the face of challenge there was hope. The potential for internal instability with a patient with serious mental illness should not be understated, but there is always more we can do as providers and as a community to help those in
need of external support. Women entering into pregnancy with bipolar disorder need the external, stabilizing support of their family, their community and their providers to maintain and buttress their internal stability.

This matrix would benefit greatly from continued testing of its analysis, given its foundation rests on the preliminary results of three interviews. Recruitment for this study is ongoing and the theoretical framework will continue to be refined prior to publication.

**Strengths**

Strengths of this study include the exploratory nature of the work and the attempt to give a voice to women not previously heard from in the literature. This study was the first to explore women’s experiences of bipolar disorder during pregnancy in qualitative format.

By utilizing telephone interviews, we were able to recruit nationally, which contributed geographic diversity to our participant sample. Additionally our inclusion of pregnant women allowed us to explore a broader spectrum of patient experience and allowed for comparisons by the individual participant. As a result of this national sampling, we were able to speak with women who received care from a variety of providers from midwives to OBs to psychiatrists, in a variety of professional environments, from community hospitals to large teaching hospitals.

Another strength of this study is the semi-structured qualitative questionnaire that was developed through extensive research and consultations with experts in the field. This format provided great opportunity for discussion between the researcher and participants.

**Limitations**

The biggest unanticipated challenge in this study was recruitment of participants. We deliberately chose not to recruit at the UNC Center for Women’s Mood Disorders clinic or postpartum unit because they provide nationally-recognized, evidence-based, specialist care and
we wanted to speak to women with a diverse array of experiences. However the original recruitment method, a mass e-mail to UNC employees and students, yielded only one participant in two months. Attempts to institute additional recruitment methods were stymied by unanticipated challenges: the Facebook ad was held up for two months by technical challenges that required the help of the Facebook programming team. The Depression and Bipolar Support Alliance ad was delayed for a month and a half because it required the review of the medical director. Even with multiple additional recruitment methods, finding eligible participants who were willing and able to find the time to be interviewed proved difficult. These recruitment challenges translate to study limitations in the form of a small sample size and limited diversity. Additionally, the lack of racial and ethnic diversity in our sample means that our results are perhaps less generalizable to the general population.

Another limitation is posed by the recruitment methods chosen in this study – specifically, the primary contacts for the researcher were via e-mail and a web address, limiting participation to those with an e-mail address and Internet access. Lastly, phone interviews, while allowing for national recruitment, present a challenge to building rapport and may have changed the nature of the participants’ responses. The impact of meeting participants face-to-face cannot be underestimated when research involves delving into sensitive personal topics. However, this method was chosen in order to maintain privacy of the participants, clinic space limitations, as well as for safety of the researcher.

**Clinical implications**

Bipolar disorder is a multi-factorial mental illness with a broad range of associated medical and psychosocial effects and a high rate of medical burden (Soreca, Frank, & Kupfer, 2009). In-depth study of patient experience has the potential to positively impact future patient
care and reduce medical burden by contributing to effective patient-centered interventions. Given the interdisciplinary nature of clinical care for this population, psychiatrists, social workers, obstetricians and midwives may be involved in their care and would benefit from the understanding of this population’s experience of pregnancy. Speaking broadly, qualitative nursing research is important because it gives us insight into our patients’ experiences and helps us to improve their care both directly, by focusing our assessment and increasing our awareness of potential problems, and indirectly, by improving our ability to empathize with our patients and giving those patients a voice within the rarefied world of the health science literature.

This study validates the lived experience of this population and provides a way for these women to contribute to their own healthcare in an indirect way (Driscoll, 2004). This research will contribute to the on-going conversation about provision of healthcare services and advocacy for pregnant women with serious mental illness by documenting patients’ subjective impressions of their healthcare experiences (Lagan, Knights, Barton, & Boyce, 2009). With women and specifically pregnant women being historically under-studied, this study also contributes to the larger body of scientific research.

During any health event, particularly during pregnancy when the life of the patient and the life of the child are going to be impacted, a history of mental illness deserves the same attention and quality of care that a history of chronic physical illness deserves. Patients with complex histories challenge us in the best possible ways as providers: by compelling us to make use of our interdisciplinary team, call in referrals and consults, recall knowledge outside our chosen specialty and utilize active listening skills to hear what our patients have to teach us. This research has the potential to contribute to a variety of clinical care initiatives to improve outcomes for pregnant patients with bipolar disorder and other serious mental illness and is
unique in its inclusion of patient interviews. Previous research by Hauck et al. (2008) contributed to an Australian initiative that created “a framework for community mental health clinicians to improve the reproductive health outcomes for women with SMI [serious mental illness]” (p. 384). This Australian initiative involved discussions with physicians, community leaders, clinic managers, nursing directors and midwives, and an extensive literature review but no patient interviews. Another aspirational example is the nurse-led Intensive Psychiatric Community Care Program, developed for veterans with serious mental illness and their young children, which utilizes small-group psychotherapy and case management to intervene in the re-hospitalization cycle and to promote adaptation to motherhood (Mohit, 1996).

All participants in this study indicated support for online and in-person postpartum support groups and further indicated that they would like more support throughout pregnancy. This indicates a need for a perinatal support group for women with mental illness, perhaps even something similar to the Centering model of prenatal care, but all the women in the group would share a diagnosis of bipolar disorder or other mental illness. In addition to the midwives present at each visit, perhaps a psychiatrist or psychiatric nurse practitioner could see the group to help lead the educational portion of the session. An initiative such as this could lead to increased trust, communication and support, and hopefully better outcomes for mother and baby.

Another idea for a nurse-led intervention is to make nursing care managers available to pregnant patients with bipolar disorder or other mental illness. One participant in this research spoke highly of the nurse who called her each week as part of an initiative through her health insurance provider and the stabilizing impact that those weekly phone calls had on her, as well as the role the nurse’s advocacy played in prompting her to recognize a medical emergency and get the care she needed. What if a nurse-led initiative was started to partner nurses with psychiatric
training with patients with bipolar disorder during their pregnancies to monitor them, start patient education early and provide support? This kind of initiative acknowledges the comments of participants who both linked their excellent outcomes to the consistency and availability of their providers.

As previously mentioned, qualitative nursing research doesn’t simply benefit patients, it benefits nurses by increasing education and empathy. Mixed attitudes endure among mental health nurses caring for patients with mental disorders during the perinatal period and this research can be utilized to contribute to education and training initiatives for nursing staff (McConachie, & Whitford, 2009). An anecdote by way of illustration: during a clinical post-conference on my labor and delivery clinical rotation, I heard a story from a classmate who explained that she and her preceptor were sent to the psych unit where she encountered a floridly psychotic female patient who was pregnant and in labor, in restraints in her room because she was spitting and trying to bite the nurses on the unit. My classmate and her preceptor were sent to put a fetal monitor on this mother because the psychiatric nurses did not have the tools or the knowledge to monitor the pregnancy. What my classmate commented on so articulately in her re-telling of this incident was the way the nurses just stood there – both the psychiatric nurses and the labor and delivery nurses. No one knew what to do for this patient and how to engage with the problem presented by her complex care needs. This is an extreme case, but it’s important because it exemplifies the challenges of caring for patients requiring cross-specialty care.

Now imagine if there was a quick protocol for working with pregnant patients with mental illness available on both floors. What if in the process of training nurses on each floor, there was a primer on how to work with patients with mental illness and pregnancy? One of the
main implications for this research is the fact that it begins to bridge that gap across specialties and identifies concrete strategies for nursing education.

With further interviews to identify additional patient concerns and improve this stabilizing/destabilizing matrix, I hope the results of this study can be used to guide future quantitative research and the development of measures that may expedite assessment and provide quality, individualized treatment for pregnant women with bipolar disorder. Empirical research findings become even more valuable tools for improving patient care when paired with the voices of patients themselves. I am inspired by the honesty and eloquence with which these three women spoke about their experiences and feel honored that I was trusted to relay their words to my own community. I want to honor their experiences by doing what I can to improve nursing care for future patients in similar circumstances.
References


EXPERIENCE OF PREGNANCY WITH BIPOLAR DISORDER

*Archives of General Psychiatry, 66*(2), 189–195.


Appendix A

Text of UNC Mass E-mail and NAMI, DBSA, Craigslist Ads

Are you a new mom with bipolar disorder or manic depression?

We are recruiting women who:

- Are at least 18 years old
- Are within 18 months postpartum of their most recent pregnancy
- Have a history of bipolar disorder or manic depression

You may qualify for a research study that could help researchers at the University of North Carolina-Chapel Hill Nursing School better understand the experience of pregnancy for women with bipolar disorder. If you qualify, this research project involves a 1-2 hour telephone interview where we will ask you about your most recent pregnancy experience and a short online questionnaire about your emotions. If you would like to participate in this study, please complete this brief online screening tool http://bpdpregnancy.com, or e-mail erin_richardson@med.unc.edu to complete it over the phone. Compensation for this study is a $15 Target or Wal-Mart gift card.
Appendix B - Flyer

Are you a new mom with bipolar disorder or manic depression?

We are recruiting women who:

- Are age 18 or older
- Are within 18 months postpartum of their most recent pregnancy
- Have history of bipolar disorder or manic depression

You may qualify for a research study that could help researchers at the UNC-Chapel Hill Nursing School better understand the experience of pregnancy for women with bipolar disorder.

- 1-2 hour telephone interview about your most recent pregnancy experience
- A short online questionnaire about your emotions
- Compensation is a $15 Target or Wal-Mart gift card

Visit http://bpdpregnancy.com to complete a brief online screening tool to determine if you might be eligible. E-mail erinrich@email.unc.edu with questions.

IRB #13-2852 approved 1-23-14 by the Biomedical Institutional Review Board.
Appendix C

Research Match Initial Message

A research team with University of North Carolina at Chapel Hill in Chapel Hill, NC, believes you might be a good match for the following study:

Are you a new mom with bipolar disorder or manic depression?
We are recruiting women who:
- Are age 18 or older
- Are within 18 months postpartum of their most recent pregnancy
- Have history of bipolar disorder or manic depression

You may qualify for a research study that could help researchers at the UNC-Chapel Hill Nursing School better understand the experience of pregnancy for women with bipolar disorder.

- 1-2 hour telephone interview about your most recent pregnancy experience
- A short online questionnaire about your emotions
- Compensation is a $15 Target or Wal-Mart gift card

If you are interested in this study and having the research team contact you directly, please select the "Yes, I'm interested" link below. By clicking the "Yes, I'm interested" link, your contact information will be released to the research team. If you select the "No, thanks." link or do not respond to this study message, your contact information will not be released to the research team.

Yes, I'm interested! No, thanks.

You are receiving this email message since you have registered in the ResearchMatch registry. Should you wish to edit your profile or remove your contact information from this registry, please login here.
Appendix D

Facebook Advertisement

Study for new moms!
wpdnpregnancy.com

New moms with a history of bipolar disorder. Phone interview, $15 gift card

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Here is the actual ad, which will run in the right column of Facebook and will link to our screening tool at our new web address: http://www.wpdpregnancy.com

Social activity will NOT show up next to the ad.
Appendix E

Screening Questionnaire (Online/Phone)

This research study is examining the experience of pregnancy for women with bipolar disorder. The study will involve one 1-2 hour interview for eligible participants. We’ll be glad to tell you more about the research, but first we would like to ask you for some information about your health and past pregnancies to see if you meet admission criteria. We are recruiting a very specific population of women for this study. Some of the questions are personal; however, all the information you share is confidential. You don’t have to answer any questions you don’t want to, and you can stop at any time. By answering these questions, you are consenting to participate in this screening process.

Would you be willing to answer questions to see if you might be eligible? YES (continue) / NO (end)

How old are you? _________ (if >18, continue, if <18, end)

Have you ever received a diagnosis of bipolar disorder? YES (continue) / NO (end)

Are you currently pregnant? YES (continue) / NO (continue)

Have you given birth in the last year? YES (continue) / NO (end)

On what date did you give birth? ________________

Did you have a diagnosis of bipolar disorder at the time of your most recent pregnancy? YES (continue) / NO (end)

When was your bipolar disorder diagnosed? ________________

Now I’d like to ask you a series of questions about your emotions.

Are you currently feeling up or high or full of energy? YES / NO

Are you currently feeling persistently irritable? YES / NO

If you are feeling high, full of energy or irritable, do you:
  • Feel that you can do things other cannot do, or that you are an especially important person? YES / NO
  • Need less sleep? YES / NO
  • Talk too much without stopping, or so fast that people have difficulty understanding? YES / NO
  • Have racing thoughts? YES / NO
  • Become easily distracted so that any little interruption could distract you? YES / NO
  • Become so active or physically restless that others were worried about you? YES / NO
• Want so much to engage in pleasurable activities that you ignored the risks or consequences (for example, spending sprees, reckless driving, or sexual indiscretions)? YES / NO
→ Current manic or hypomanic episode: Are 3 or more coded yes? YES (end) / NO (continue)

Have you ever believed that people were spying on your or that someone was plotting against you, or trying to hurt you? YES / NO
   IF YES, do you currently believe these things? YES / NO

Have you ever believed that someone was reading your mind or could hear your thoughts or that you could actually read someone’s mind or hear what another person was thinking? YES / NO
   IF YES, do you currently believe these things? YES / NO

Have you ever believed that someone or some force outside of yourself put thoughts in your mind that were not your own or made you act in a way that was not your usual self? Have you ever felt that you were possessed? YES / NO
   IF YES, do you currently believe these things? YES / NO

Have you ever believed that you were being sent special messages through the TV, radio, or newspaper, or that a person you did not know personally was particularly interested in you? YES / NO
   IF YES, do you currently believe these things? YES / NO

Have your relatives or friends ever considered any of your beliefs strange or unusual? YES / NO
   IF YES, do they currently consider your beliefs strange? YES / NO

Have you ever heard things other people couldn’t hear, such as voices? YES / NO
   IF YES, did you hear a voice commenting on your thoughts or behavior or did you hear two or more voices talking to each other? YES / NO
   IF YES, did you hear these things in the past month? YES / NO

Have you ever had visions when you were awake or have you ever seen things other people couldn’t see? YES / NO
   IF YES, have you seen these things in the past month? YES / NO

→ Current psychotic episode: Are 2 or more coded yes? YES (end) / NO (continue)

<table>
<thead>
<tr>
<th>Eligible</th>
<th>Ineligible</th>
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Eligible Script/Screen: See Text for Online Consent Form.
Ineligible Script/Screen (END): It seems that you don’t meet the criteria for this particular research study. Thank you for your interest in our research!
Appendix F

Website: http://bpdpregnancy.com

This research study is examining the experience of pregnancy for women with bipolar disorder. The study will involve one 1-2 hour interview for eligible participants. We'll be glad to tell you more about the research, but first we would like to ask you for some information about your health and past pregnancies to see if you meet admission criteria. We are recruiting a very specific population of women for this study. Some of the questions are personal, however, all the information you share is confidential. You don't have to answer any questions you don't want to, and you can stop at any time. By answering these questions, you are consenting to participate in this screening process.

If you have any questions about this survey, please contact emrich@email.unc.edu.
Appendix G

Research Personnel

**Erin C. Richardson.** Erin Richardson, BA, was the principal investigator and is a nursing student. Prior to entering nursing school she was a full-time project coordinator and clinical interviewer at the UNC Center for Women's Mood Disorders, where she regularly administered the M.I.N.I. and informed consent. She is currently a research assistant for Dr. Crystal Schiller, PhD, on her study on the neurophysiology of postpartum depression. She wrote the IRB application, recruiting and screened participants, obtained informed consent, administered the M.I.N.I., interviewed participants, and transcribed, coded and analyzed the data.

**Catherine I. Fogel.** Catherine I. Fogel, PhD, WHCNP, FAAN is a Research Professor in the UNC-CH School of Nursing. Dr. Fogel has over 30 years of supervising MSN and PhD students with Master's Theses and Doctoral Dissertations and more than 5 years supervising BSN Honors Projects including one which has been published in a national medical journal. In addition, Dr. Fogel's clinical practice has included conducting a prenatal clinic for women at risk for pre-term delivery, and a women's health clinic for women prisoners at NCCIW. Dr. Fogel has conducted 2 NIMH funded grants with women prisoners including one with pregnant prisoners and 2 CDC funded grant, one of which was with women prisoners and another with HIV+ women. She supervised the development of the study, including obtaining IRB approval, conducting the study and data analysis. She was available for phone consultation for problems if/when they arose.

**Crystal Schiller.** Crystal Schiller, Ph.D. is an Assistant Professor in the Department of Psychiatry, and she has ten years of experience conducting psychological assessments and performing studies that examine the effects of reproductive hormones on mood and behavior in
women. She supervised recruitment, screening, and interviewing of participants. She was also available for phone consultation and evaluation in the event that a participant had active manic symptoms, suicidal ideation, or experienced distress during the interview.

**Samantha Meltzer-Brody.** Samantha Meltzer-Brody, M.D. is an Associate Professor of Psychiatry and the Director of the Perinatal Psychiatry Program in the UNC Center for Women's Mood Disorders. She has published numerous manuscripts in the field of women’s mental health, currently participates in clinical trials research, and serves as the mental health consultant for the North Carolina Women’s Health Report Card. Her research investigates the biological markers of perinatal mood disorders including genetic, neurosteroid and other neuroendocrine biomarkers in cohorts of women recruited during pregnancy and followed longitudinally. Additionally, she investigates new treatment options for depression in perinatal women. Dr. Meltzer-Brody's was consulted in the development of hypotheses, recruitment efforts, and assisting in the interpretation and dissemination of results.

**David Rubinow.** David R. Rubinow, M.D. is chairman of the Department of Psychiatry and leads the UNC Center for Women’s Mood Disorders. He has over 30 years experience in reproductive endocrinology and psychiatry. During Dr. Schiller's maternity leave (approx. February 12 – May 8), he supervised recruitment, screening, and interviewing of participants. He was also available for phone consultation and evaluation in the event that a participant had active manic symptoms, suicidal ideation, or experienced distress during the interview.
Appendix H

IRB# 13-2852:
The experience of pregnancy for women with bipolar disorder Interview Guide

In as much detail as possible, please tell me what it was like to be pregnant with bipolar disorder.

What was your mood like during pregnancy?

Was your pregnancy planned or unplanned?

What do you wish you had known?

→ Prompt: What surprised you about pregnancy?

Can you give me an example of the kind of resource you would have liked to have during your pregnancy?

→ Prompt:
- Websites Y/N
- Blogs Y/N
- Pamphlets Y/N
- Books Y/N
- Medical specialist Y/N
- Support group Y/N

How would you describe the interactions you had with your healthcare providers during your pregnancy?

→ Prompt:
- Which healthcare providers did you find to be the most influential on your quality of care during your pregnancy?
- Did you get the same information from all your doctors or did they give you conflicting or different opinions?

Did you feel judged by your doctor, friends or family, for becoming pregnant even though you had bipolar disorder?

How did you feel supported during your pregnancy? How did you feel unsupported?

→ Prompt:
- How were your friends and family supportive of your pregnancy? How were they not?
- What advice did they give you regarding pregnancy and bipolar disorder?
- How were your healthcare providers supportive of the pregnancy? How were they not?

How would you describe the advice you received during your pregnancy? It can be medical advice or advice from family and friends.

→ Prompt:
- Whose advice did you trust?
- Whose advice did you take?
- Which of this advice was helpful?

Is there anything else you wish I had asked you?