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

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Abstract

Background*:* Bipolar disorder often emerges in an individual's late teens and early twenties, thus women with bipolar 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, yet no research exists on this population's experience of pregnancy.
Design: This study utilized semi-structured telephone interviews to gather preliminary 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-led interventions to help manage illness during pregnancy and postpartum.
Method: A purposive sample of four English-speaking women, age 29-39, with a confirmed diagnosis of bipolar disorder I or II and who had given birth within the last eighteen months, was recruited nationally via the electronic and mass media, and postings on bulletin boards in a range of educational and related settings. One open-ended focused telephone interview was held with each client, and conducted by the first author. She was also responsible for doing the audiotaping, transcription, and coding of the data using a descriptive qualitative design.
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 healthcare provider as advocates, the importance of interdisciplinary care, education, community support and the mixed impact of medication.
Discussion & Conclusion*:* This research contributes to initiatives designed to improve healthcare for pregnant women with bipolar disorder, augment patient education materials, and inform the design of nurse-led interventions. 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 research

An estimated 0.5-1.5% of people in the United States are diagnosed with bipolar disorder (Yonkers et al., 2004). 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 pregnancy for women with chronic illness is established in the literature (Holton, Kirkman, Rowe, & Fisher, 2012; Meade, Sharpe, Hallab, Aspanell, & Manolios, 2012). and the experience of motherhood for women with serious mental illness has been extensively researched (Benders-Hadi, Barber, & Alexander, 2013; Blegen, Hummelvoll, & Severinsson, 2012; Montgomery, Tompkins, Forchuk, & French, 2006). 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.

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 for women with bipolar disorder. Nurses are uniquely positioned to positively impact patient care for this population due to their natural role as patient advocates (Allison, 2004; Lagan, Knights, Barton, & Boyce, 2009, Kralik, 2002). By focusing on the lived experiences of women with bipolar disorder from the nursing perspective, this study seeks to address the gap in the literature, identify themes to address with future patient education initiatives, and contribute to the discourse among healthcare providers regarding clinical care.

Bipolar illness during pregnancy

Pregnancy brings a unique set of challenges to women with bipolar disorder, including risk of relapse, teratogenicity of medications, and increased risk of postpartum psychosis. Pregnancy, particularly the postpartum period, is a time of increased risk of relapse for women with bipolar disorder (Freeman et al., 2002; Viguera et al., 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 to recommend 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 associated with a twofold greater risk of relapse compared to continuation of mood stabilizers in pregnancy (Viguera et al., 2007). Prophylactic pharmacologic treatment throughout pregnancy has been shown to reduce but not eliminate the risk of relapse (Bergink et al., 2012; Cohen, Sichel, Robertson, Heckscher, & Rosenbaum, 1995). Perinatal women with bipolar disorder participating in a partial hospitalization program reported more extensive psychiatric histories, including greater likelihood of taking psychotropic medications and prior suicide attempts, as well as a history of substance abuse (Battle, Weinstock, & Howard, 2014).

Women with bipolar illness are faced with an exceptional conundrum when considering conception and many are counseled not to become pregnant because of the risk to their mental stability and the risk to the unborn child (Cohen et al., 2010). 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), and recent research suggests sodium valproate exposure in utero has been linked to lowered IQ, behavioral problems and a potentially increased risk for autism spectrum disorders and ADHD in children (Gentile, 2014). Lithium exposure in utero has been associated with low birth weight, floppy baby syndrome, and an increased risk of cardiovascular anomalies, including Ebstein's Anomaly (Diav-Citrin et al., 2014; Yonkers et al., 2004). A study examining neuromotor function in 6-month-old infants with in-utero exposure to antipsychotics, antidepressants, or no psychotropic medication, found that infants exposed to antipsychotics had significantly lower scores on neuromotor performance (Johnson, LaPrairie, Brennan, Stowe, & Newport, 2012). However, research in this area is limited by a lack of randomized-controlled trials, and thus, the effects of medication are difficult to disentangle from the effects of bipolar disorder itself. 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).

Women with bipolar disorder, treated or untreated, are at increased risk for adverse pregnancy, birth, and neonatal outcomes including preterm birth, neonatal hypoglycemia and microcephaly (Boden et al., 2012; Jablensky, Morgan, Zubrick, Bower, & Yellachich, 2005; Judd et al., 2014). History of bipolar disorder is the biggest predictor of an episode of postpartum psychosis other than a previous history of postpartum psychosis (Munk-Olsen et al., 2009). Postpartum psychosis is a psychiatric emergency and a potential complication that can threaten the life of mother and infant (Wakil, Perea, Penaskovic, Stuebe, & Meltzer-Brody, 2013). The current clinical guidelines therefore suggest that women with bipolar disorder receive pharmacotherapy during and after pregnancy to prevent relapse (Yonkers, Vigod, & Ross, 2011).

Experiential accounts of bipolar illness

To our knowledge there have been no experiential accounts of pregnancy among women with bipolar disorder. Driscoll (2004), however, examined the lived experience of non-pregnant women with bipolar II disorder in a dissertation. Bipolar II disorder is distinguished from bipolar I disorder by the occurrence of hypomanic rather than manic episodes. The author, a psychiatric clinical nurse specialist, interviewed a sample of 11 women with bipolar II disorder using descriptive phenomenological methods (Driscoll, 2004). Themes that appeared in participant conversations about the clinical care they received for their bipolar disorder included the difficulties of being diagnosed and treated, lack of validation from healthcare providers, and poor results from pharmacotherapy (Driscoll, 2004). Another 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). More recently, a study in Australia suggested that women with bipolar disorder, compared to women with unipolar depression, expressed more concerns with how pregnancy would impact their disorder and the likelihood of their children inheriting their disorder

(Paterson, Parker, Fletcher, & Graham, 2013). Despite the great need for information regarding care for this patient population, minimal research has been published on this topic.

Method

Overview

The Institutional Review Board (IRB) at the University of North Carolina at Chapel Hill approved this research study including study protocol, recruitment methods, and study-related documents. Participants were provided with written consent forms that established that interviews would be audio recorded and data would be used in publication. The first author with supervision of two faculty advisors conducted recruitment, screening, and interviews.

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). We recruited women who were postpartum, as well as one woman who was pregnant and postpartum, in order to gather a more comprehensive, real-time assessment of the experience of pregnancy and motherhood in women with bipolar disorder. 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, community flyers, ResearchMatch.org, and via a Facebook advertisement, all of which contained a link to an online screening tool. 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 et al., 1998) to screen for current mania or psychosis. A website address was created to house the questionnaire: http://www.bpdpregnancy.com, and 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 contacted those who consented to participate using a standardized phone script. Participants were e-mailed copies of the consent form for their records. No participants utilized the option to conduct the screening over the phone.

Study Design

This study involved a brief online screening questionnaire, one scheduling phone call, and one 1-2 hour (allotted time) telephone interview. The interview included completion of a

demographic questionnaire, administration of sections A: Major Depressive Episode and Major Depressive Episode with Melancholic Features, B: Dysthymia, and C: Suicidiality of the M.I.N.I. clinical interview, and an original semi-structured interview (Appendix A). Sections A (over the phone) and D (online) of the M.I.N.I. were used to confirm diagnosis of bipolar disorder. A risk management protocol was developed to specify actions for the student 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 supervisor, who was on call for every telephone interview. Participants received their choice of a $15 gift card from Target or Wal-Mart for participating in the telephone interview.

Data Collection

The telephone interview, utilizing the original semi-structured interview guide, took 20-90 minutes depending on the participant. The researcher took notes throughout and audiotaped the interview using a pick-up microphone and voice recorder.

Qualitative interview guide

The interview guide 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, and medication. The guide was vetted by a variety of healthcare providers with relevant professional experience including a clinical psychologist with extensive experience working with women with bipolar disorder, a women's health nurse practitioner experienced in working with vulnerable populations, and a doctorally prepared nurse-researcher**.** These expert providers edited the interview guide, however due to time constraints the guide was not piloted before use in the study.

Open-ended questions were utilized deliberately, in keeping with the exploratory nature of the 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.

Data Analysis

The interviews were transcribed and compared to the original audio recording for accuracy. Data was coded using descriptive methods described by Charmaz in her grounded theory methodology (2006), in consultation with the faculty advisors. 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 (Charmaz, 2006). Throughout, the researchers 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 September 2014, 154 women started the online screening tool and 113 completed it. Six women met the eligibility criteria, and agreed to an interview. Two participants did not respond to phone calls and emails to schedule the interview. Four 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 two lived with partners. 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 two completed portions of their college degrees. The time between diagnosis of bipolar disorder and pregnancy ranged from one to twenty-two years. One participant dealt with significant fertility issues prior to her pregnancy. Other complications included gestational diabetes, preeclampsia and hyperemesis gravidarum. 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

The participant interviews featured recurring themes such as hopefulness, the importance of interdisciplinary care, the crucial advocacy of healthcare providers, the role of community resources and education, and the significant impact of medication management.

Hopefulness: Wanting to share a positive experience. While not glossing over the challenges, all women spoke of their experiences with a sense of hopefulness and 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. She spoke of gravitating to external sources of hopefulness:

> I liked my mom's advice because she talked to a doctor who specializes in exactly what I needed, like, you know a women's specialist…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 the participants used included *hopeful*, *awesome*, *calm*, *content*, and *stable*. One participant spoke directly of wanting to advocate for women with bipolar disorder following her experience.

More than a diagnosis: the importance of interdisciplinary care. All four women described the 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 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, what I would've given anything for. Just someone who could've helped me with both pregnancy and the psychiatric aspect. You know, that could…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…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 healthcare 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 smooth communication between healthcare providers, particularly the psychiatrist and fertility specialist. Another woman worked closely with her psychiatrist and her midwives. One woman mentioned her obstetrician, doula, and labor and delivery nurses as the members of her team who had the biggest impact on her care. A fourth 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 always equal teamwork:

> 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…they just wouldn't come to an understanding…

Healthcare Providers: Advocating versus Silence. All participants spoke of the importance of responsiveness and clear communication with their healthcare providers. One said,

> You know, I feel like I have a really close relationship with my doctor…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 and she's quick to reply. She spends the quality time at the office visits when I go to see her.

Responsiveness, advocacy, and a history of good communication with healthcare providers build a trusting relationship that relieves some of the uncertainty of pregnancy with bipolar disorder. The importance of healthcare provider as advocate was frequently underscored by participants, and in many cases, a nurse or licensed clinical social worker filled this role. As one participant explained, "The nurses…were the same way as the therapist…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, both for their expert management of medications and their personal enthusiasm for the patient's pregnancy, born of a lengthy patient-provider relationship.

Preparation, Resources, & Education. Important sources of education and support that these women identified included online forums, community support groups, literature reviews and healthcare providers, particularly midwives. Resources that were identified as needed but lacking included medical specialists, pamphlets, and perinatal (in addition to postpartum) support groups.

The dual nature of online resources as both a comfort and source of anxiety was frequently underscored; one participant commented, "Yeah, I did end up going to lots of forums and sites about the hyperemesis…That was all super worrying, but….they [the forums] alleviated concerns for the most part."

One 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 in the postpartum period, in contrast to the competition that can sometimes be fostered in an environment with 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….I would say [this] group stripped all that. That's not what it was about….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.

Support of other women, and hearing stories of experience, whether in person via a support group or online via a forum, was a theme throughout these interviews. Hearing others' narratives appeared to be a way for women to mitigate some of the uncertainty of pregnancy and the postpartum period.

On medication. These four women disclosed experiences that illustrated a lack of consensus and continuity in healthcare provider attitudes toward medication management of 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 several 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, then start her medication again when she felt she could not tolerate it anymore. While describing how difficult this cycle was, she also indicated her resolute support for her decision, feeling that there was no way for her to be on any medication while trying to conceive because of the risk to the fetus. In the overall context of her pregnancy, the 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 woman stopped her anti-anxiety medication abruptly once she discovered she was pregnant and tapered her other mood-stabilizing medications over the first trimester with the support of her obstetrician. She was not seeing a psychiatrist at the time, and reported experiencing intermittent anxiety for the remainder of her pregnancy. A fourth participant described being taken off all four of her psychotropic medications abruptly at 9 weeks of pregnancy. Her subsequent depression, anxiety, and suicidiality resulted in an emergent hospitalization at 18 weeks. Of that time she said,

> I felt like from the providers that…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….it made me feel like I was putting myself before the baby…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. This woman spoke of her conviction, and her healthcare 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 study, begun with the intent to investigate the experiences of women linked by a common diagnosis, in the end revealed was how unique each woman's experience was. Bipolar disorder – when managed carefully – became merely one strand of the larger narrative thread. For one participant, her pregnancy narrative was primarily about her fertility struggle and experience as a "fertility patient." For another, her experience was framed by her work as a nurse and the support of her healthcare providers. For a third woman, many of her memories of pregnancy were primarily defined to her hyperemesis gravidarum diagnosis. For a fourth, her experience was a study in contrasts, with a first pregnancy dominated by medication issues, depression, and hospitalization, while her second was relatively idyllic, under the supervision of specialist care.

While the sample size is small and the experiences diverse, some commonalities of the patient experience emerged. Codes fell predominantly into categories of "internal" or relating to the patient's inner life, and "external" or relating to those factors outside the patient herself. Codes also seemed to divide naturally into categories of stabilizing and destabilizing. A theoretical matrix is useful for understanding the interplay of these categories, internal/external and stabilizing/destabilizing, and their influence on the patient with bipolar disorder during pregnancy (Table I).

Table 1: Influences on Experience of Pregnancy with Bipolar Disorder

Stabilizing – Internal	**De-stabilizing – Internal**
Emotional stability Hopefulness/optimism Education Community resources Medication	Discontinuation of medication Emotional lability Suicidiality Depression Anxiety Guilt
Stabilizing – External	**De-stabilizing – External**
Support of family and providers Interdisciplinary care Established relationships with healthcare providers Responsiveness of healthcare providers Healthcare providers with access to research Medical specialists Hospitalization	Discontinuation of care Judgment of providers or family Complications of conception and pregnancy (fertility issues, gestational diabetes) Lack of community resources/support Hospitalization

While conducting a diagnostic evaluation and treatment planning for a patient with bipolar illness, internal–destabilizing factors may come most easily to mind, yet 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, leading to good or bad outcomes. What these women described, however, was not a good or bad experience in the end, but a series of experiences, factors, and people who impacted them throughout their pregnancy, and which continued to evolve, even at the time of interview. The potential for internal instability with a patient with serious mental illness should not be understated, but women entering into pregnancy with bipolar disorder need the external, stabilizing support of their family, community and healthcare providers to maintain and buttress their internal stability.

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. Telephone interviews allowed for recruitment across the United States, which contributed geographic diversity on a national level. As a result of this national sampling, we were able to speak with women who received care from a variety of healthcare providers, in a variety of professional environments. Inclusion of pregnant women allowed exploration of a broader spectrum of patient experience and participant-generated comparisons. Another strength of this study is the original semi-structured 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. We deliberately chose not to recruit locally at the UNC Center for Women's Mood Disorders Perinatal Psychiatry outpatient clinic or inpatient unit because they provide nationally-recognized, evidence-based, specialist care, and we wanted to speak to women with a diverse array of experiences. However, even with multiple recruitment methods, finding eligible participants who were willing and able to be interviewed proved difficult. Recruitment challenges translated to study limitations of a small sample size and limited diversity. The lack of racial and ethnic diversity in this sample leads to results that are 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 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.

This preliminary study does not achieve data saturation and has not produced a theory to explain these women's experiences. Instead it is one of the first to describe these women's experiences and forms a foundation for future qualitative work. Recruitment was ended in spite of a lack of saturation, due to the time constraints imposed by the nature of this project as an undergraduate honors thesis. Thus, these results need replication in future research.

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, a variety of healthcare providers may be involved in the care of women with bipolar disorder and would benefit from understanding this population's experience of pregnancy.

This study validates the lived experience of this population and, as Drisoll (2004) states, can provide a way for women to contribute to their own healthcare in an indirect way. This research will contribute to the on-going conversation about provision of healthcare services for pregnant women with serious mental illness by documenting patients' subjective impressions of their healthcare experiences, which has been advocated by Lagan, Knights, Barton, and 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 healthcare providers: by compelling us to make use of our interdisciplinary team, to recall knowledge outside our chosen specialty and to utilize active listening skills to hear what our patients have to teach us. Previous research by Hauck, Rock, Jackiewicz, & Jablensky (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, but no patient interviews. Our exploratory research has the potential to contribute to a variety of clinical care initiatives to improve outcomes for pregnant patients with serious mental illness and is unique in its inclusion of patient interviews**.**

All participants in our 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 or home visit service for pregnant and postpartum women with serious mental illness. In the United Kingdom, the Perinatal Support Project (PSP) paired women with mild-to-moderate mental health issues with a volunteer for home visits or a targeted support group. This relationship lasted through the

duration of pregnancy and during the first year of the child's life. Qualitative data suggests this program was valued by healthcare providers and participants and was helpful to women with mild-to-moderate depression (Coe & Barlow, 2013). Another alternative would be something similar to the Centering model of prenatal care (Rising, 1998), where all the women in the group would share a diagnosis of bipolar disorder or other mental illness. With the Centering model of prenatal care, women are placed into small groups based on their due dates. They complete their prenatal visits together, in group visits supported by midwives that combine education, assessment, and support (Rising, 1998). For women with serious mental illness, in addition to the midwives present at each visit, perhaps a psychiatrist or psychiatric nurse practitioner could see the group at each visit. An initiative such as this could lead to increased trust, communication and support, and better outcomes for mother and baby.

Another initiative suggested by our work is to make nursing care managers available to pregnant patients with serious mental illness. One study participant 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 seek care. An excellent example of the innovative care that patients with interdisciplinary diagnoses deserve is a recent nurse-led Perinatal Dyadic Psychotherapy pilot study that provided nursing home visits comprised of home visits to mothers with postpartum depression to explore their infant's behavior using supportive psychotherapy techniques. This intervention resulted in clinically significant decreases in depression and anxiety scores, and increased self-esteem scores (Goodman, Guarino, & Prager, 2013). More initiatives are needed to partner specially trained nurses with women with mental illness during their pregnancies to provide monitoring, early patient education, and support.

Although preliminary, the matrix (Table 1) will prove beneficial to nurses and other clinicians by providing a framework to organize the internal and external destabilizing forces in a patient's life for the purpose of tailoring interventions to individual patients, thereby contributing to individualized medicine. For example, a patient choosing to discontinue medication will benefit from more frequent check-ins with healthcare providers to monitor affective instability and suicidiality. Those with pregnancy complications will benefit most from interdisciplinary care administered by a well-integrated medical team, including an obstetrician, psychiatrist, and general practitioner or nurse to coordinate care. Those with a lack of community resources or support will require case management to identify resources and support both for the mother and for the infant. Moreover, the internal and external stabilizing forces may be leveraged to promote emotional stability and positive pregnancy outcomes for this vulnerable population. Cultivating a sense of hopefulness and optimism, which contribute to feelings of self-efficacy, can be powerful in any circumstance that requires health behavior change (Schwarzer, 1994), and leveraging the other stabilizing forces, such as the support of family members or healthcare providers or access to specialists, may be particularly helpful.

With further interviews to identify additional patient concerns and improve this matrix, this study can be used to guide future quantitative research and the development of measures that may expedite assessment and treatment of 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.

References

Allison, S. (2004). Psychotropic medication in pregnancy: Ethical aspects and clinical management. *Journal of Perinatal & Neonatal Nursing*, *18*(3), 194. doi: 10.1097/00005237-200407000-00003

Battle, C. L., Weinstock, L. M., & Howard, M. (2014). Clinical correlates of perinatal bipolar disorder in an interdisciplinary obstetrical hospital setting. *Journal of Affective Disorders*, *158*, 97–100. doi: 10.1016/j.jad.2014.02.002

Benders-Hadi, N., Barber, M., & Alexander, M. J. (2013). Motherhood in women with serious mental illness. *The Psychiatric Quarterly*, *84*(1), 65–72. doi: 10.1007/s11126-012-9227-1

Bergink, V., Bouvy, P. F., Vervoort, J. S. P., Koorengevel, K. M., Steegers, E. A. P., & Kushner, S. A. (2012). Prevention of postpartum psychosis and mania in women at high risk. *The American Journal of Psychiatry*, *169*(6), 609–615. doi: 10.1176/appi.ajp.2012.11071047

Blegen, N. E., Hummelvoll, J. K., & Severinsson, E. (2012). Experiences of motherhood when suffering from mental illness: a hermeneutic study. *International Journal of Mental Health Nursing*, *21*(5), 419–427. doi: 10.1111/j.1447-0349.2012.00813.x

Boden, R., Lundgren, M., Brandt, L., Reutfors, J., Andersen, M., & Kieler, H. (2012). Risks of adverse pregnancy and birth outcomes in women treated or not treated with mood stabilisers for bipolar disorder: population based cohort study. *BMJ*, *345*(nov07 6), e7085–e7085. doi: 10.1136/bmj.e7085

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Thousand Oaks, CA: Sage Publications.

Coe, C., & Barlow, J. (2013). Supporting women with perinatal mental health problems: the role of the voluntary sector. *Community Practitioner*, *86*(2), 23–7.

Cohen, L. S., Sichel, D. A., Robertson, L. M., Heckscher, E., & Rosenbaum, J. F. (1995). Postpartum prophylaxis for women with bipolar disorder. *The American Journal of Psychiatry*, *152*(11), 1641–1645. doi: 10.1097/00006254-199606000-00002

Cohen, L. S., Wang, B., Nonacs, R., Viguera, A. C., Lemon, E. L., & Freeman, M. P. (2010). Treatment of mood disorders during pregnancy and postpartum. *The Psychiatric Clinics of North America*, *33*(2), 273–293. doi: 10.1016/j.psc.2010.02.001

Diav-Citrin, O., Shechtman, S., Tahover, E., Finkel-Pekarsky, V., Arnon, J., Kennedy, D., … Ornoy, A. (2014). Pregnancy outcome following in utero exposure to lithium: A prospective, comparative, observational study. *The American Journal of Psychiatry*, *171*(7), 785–794. doi: 10.1176/appi.ajp.2014.12111402

Driscoll, J. (2004). *The experience of women living with bipolar II disorder* (Unpublished doctoral dissertation). University of Connecticut, Storrs, CT.

Freeman, M. P., Smith, K. W., Freeman, S. A., McElroy, S. L., Kmetz, G. E., Wright, R., & Keck, P. E., Jr. (2002). The impact of reproductive events on the course of bipolar disorder in women. *The Journal of Clinical Psychiatry*, *63*(4), 284–287. doi: 10.4088/JCP.v63n0403

Gentile, S. (2014). Risks of neurobehavioral teratogenicity associated with prenatal exposure to valproate monotherapy: a systematic review with regulatory repercussions. *CNS Spectrums*, *19*(04), 305–315. doi: 10.1017/S1092852913000990

Goodman, J. H., Guarino, A., & Prager, J. (2013). Perinatal dyadic psychotherapy: Design, implementation, and acceptability. *Journal of Family Nursing*, *19*(3), 295–323. doi: 10.1177/1074840713484822

Hauck, Y., Rock, D., Jackiewicz, T., & Jablensky, A. (2008). Healthy babies for mothers with serious mental illness: A case management framework for mental health clinicians. *International Journal of Mental Health Nursing*, *17*(6), 383–391. doi: 10.1111/j.1447-0349.2008.00573.x

Holton, S., Kirkman, M., Rowe, H., & Fisher, J. (2012). The childbearing concerns and related information needs and preferences of women of reproductive age with a chronic, noncommunicable health condition: a systematic review. *Women's Health Issues: Official Publication of the Jacobs Institute of Women's Health*, *22*(6), e541–552. doi: 10.1016/j.whi.2012.08.001

Jablensky, A. V., Morgan, V., Zubrick, S. R., Bower, C., & Yellachich, L.-A. (2005). Pregnancy, delivery, and neonatal complications in a population cohort of women with schizophrenia and major affective disorders. *American Journal of Psychiatry*, *162*(1), 79–91. doi: 10.1176/appi.ajp.162.1.79

Johnson K.C., LaPrairie J.L., Brennan P.A., Stowe Z.N., & Newport D. (2012). Prenatal antipsychotic exposure and neuromotor performance during infancy. *Archives of General Psychiatry*, *69*(8), 787–794. doi: 10.1001/archgenpsychiatry.2012.160

Judd, F., Komiti, A., Sheehan, P., Newman, L., Castle, D., & Everall, I. (2014). Adverse obstetric and neonatal outcomes in women with severe mental illness: To what extent can they be prevented? *Schizophrenia Research*, *157*(1–3), 305–309. doi: 10.1016/j.schres.2014.05.030

Kralik, D. (2002). The quest for ordinariness: transition experienced by midlife women living with chronic illness. *Journal of Advanced Nursing*, *39*(2), 146–154. doi: 10.1046/j.1365-2648.2000.02254.x

Lagan, M., Knights, K., Barton, J., & Boyce, P. M. (2009). Advocacy for mothers with psychiatric illness: A clinical perspective. *International Journal of Mental Health Nursing*, *18*(1), 53–61. doi: 10.1111/j.1447-0349.2008.00576.x

Lim, L., Nathan, P., O'Brien-Malone, A., & Williams, S. (2004). A qualitative approach to identifying psychosocial issues faced by bipolar patients. *The Journal of Nervous and Mental Disease*, *192*(12), 810–817. doi: 10.1097/01.nmd.0000146734.39501.57

Meade, T., Sharpe, L., Hallab, L., Aspanell, D., & Manolios, N. (2012). Navigating motherhood choices in the context of rheumatoid arthritis: Women's stories. *Musculoskeletal Care*. doi: 10.1002/msc.1031

Montgomery, P., Tompkins, C., Forchuk, C., & French, S. (2006). Keeping close: Mothering with serious mental illness. *Journal of Advanced Nursing*, *54*(1), 20–28. doi: 10.1111/j.1365-2648.2006.03785.x

Munk-Olsen, T., Laursen, T. M., Mendelson, T., Pedersen, C. B., Mors, O., & Mortensen, P. B. (2009). Risks and predictors of readmission for a mental disorder during the postpartum period. *Archives of General Psychiatry*, *66*(2), 189–195. doi: 10.1001/archgenpsychiatry.2008.528

Newport, D. J., Wilcox, M. M., & Stowe, Z. N. (2001). Antidepressants during pregnancy and lactation: Defining exposure and treatment issues. *Seminars in Perinatology*, *25*(3), 177–190.

Paterson, A., Parker, G., Fletcher, K., & Graham, R. (2013). Beyond the baby blues: Perspectives of women diagnosed with a mood disorder on children, pregnancy and medication. *Australasian Psychiatry*, *21*(2), 160–164. doi: 10.1177/1039856212465346

Rising, S. S. (1998). Centering Pregnancy: An interdisciplinary model of empowerment. *Journal of Nurse-Midwifery*, *43*(1), 46–54. doi: 10.1016/S0091-2182(97)00117-1

Schwarzer, R. (1994). Optimism, vulnerability, and self-beliefs as health-related cognitions: A systematic overview. *Psychology & Health*, *9*(3), 161–180. doi: 10.1080/08870449408407475

Sheehan, D. V., Lecrubier, Y., Sheehan, K. H., Amorim, P., Janavs, J., Weiller, E., … Dunbar, G. C. (1998). The Mini-International Neuropsychiatric Interview (M.I.N.I.): The development and validation of a structured diagnostic psychiatric interview for DSM-IV and ICD-10. *The Journal of Clinical Psychiatry*, *59 Suppl 20*, 22–33;quiz 34–57.

Soreca, I., Frank, E., & Kupfer, D. J. (2009). The phenomenology of bipolar disorder: What drives the high rate of medical burden and determines long-term prognosis? *Depression and Anxiety*, *26*(1), 73–82. doi: 10.1002/da.20521

Viguera, A. C., Nonacs, R., Cohen, L. S., Tondo, L., Murray, A., & Baldessarini, R. J. (2000). Risk of recurrence of Bipolar Disorder in pregnant and nonpregnant women after discontinuing lithium maintenance. *American Journal of Psychiatry*, *157*(2), 179–184. doi: 10.1176/appi.ajp.157.2.179

Viguera, M. D., Whitfield, S. D., Baldessarini, M. D., Newport, M. D., Stowe, M. D., Reminick, B. A., … Cohen, M. D. (2007). Risk of recurrence in women With Bipolar Disorder during pregnancy: Prospective study of mood stabilizer discontinuation. *American Journal of Psychiatry*, *164*(12), 1817–1824. doi: 10.1176/appi.ajp.2007.06101639

Wakil, L., Perea, E., Penaskovic, K., Stuebe, A., & Meltzer-Brody, S. (2013). Exacerbation of psychotic disorder during pregnancy in the context of medication discontinuation. *Psychosomatics*, *54*(3), 290–293. doi: 10.1016/j.psym.2012.07.003

Yonkers, K. A., Wisner, K. L., Stowe, Z., Leibenluft, E., Cohen, L., Miller, L., … Altshuler, L. (2004). Management of bipolar disorder during pregnancy and the postpartum period. *The American Journal of Psychiatry*, *161*(4), 608–620. doi: 10.1176/appi.ajp.161.4.608

Yonkers, K. A., Vigod, S., & Ross, L. E. (2011). Diagnosis, pathophysiology, and management of mood disorders in pregnant and postpartum women. *Obstetrics and Gynecology*, *117*(4), 961–977. doi: 10.1097/AOG.0b013e31821187a7

Appendix A

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?