

**CONTRACEPTIVE AND FAMILY PLANNING EXPERIENCES, PRIORITIES, AND  
PREFERENCES OF WOMEN WITH SERIOUS MENTAL ILLNESS**

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## **ABSTRACT**

Over three million women of reproductive age residing in the United States are living with a serious mental illness (SMI). Compared to the general population, women with SMI have lower rates of contraceptive use, receive suboptimal reproductive care, and are at increased risk for unintended pregnancy. Few studies examine the factors associated with contraceptive nonuse/misuse and unintended pregnancy among this population or what women with SMI identify as important contraceptive and family planning counseling topics.

A systematic literature review was conducted in Study 1 to understand the current state of research regarding the contraceptive experiences, knowledge, and attitudes of women with SMI. Research quality, outcomes assessed, and findings varied, but many studies confirmed that women with SMI have disproportionately poorer contraceptive experiences. In Study 2, qualitative interviews were facilitated with women with SMI to understand factors influencing their contraceptive use/nonuse. Findings revealed that pregnancy intentions did not always align with contraceptive behaviors. Contributing factors to contraceptive nonuse/misuse included the influence of SMI symptoms, knowledge of and attitudes toward contraception, reproductive coercion, and sexual violence. Study 3 examined women's reproductive counseling preferences and priorities, which included consideration of SMI symptoms when making contraceptive decisions, SMI medication contraindications and teratogenicity, SMI symptom changes during

pregnancy/post-partum, and provider sensitivity. Additionally, these studies uncovered a more robust understanding of the differential reproductive experiences of women with bipolar, major depressive, and schizophrenia/schizoaffective disorders. Primary differences included variations in SMI symptoms and their influence on contraceptive use, with bipolar mania contributing to nonuse and fear of exacerbations in depressive symptoms impacting contraceptive method choice. Further, a higher proportion of women with schizophrenia/schizoaffective disorder experienced reproductive coercion, increasing their risk for unintended pregnancy.

This dissertation provides important information that can enhance the way reproductive services are delivered to women with SMI. All women deserve the opportunity to express their sexuality and realize their family planning goals, however they may be defined. To promote the reproductive health and rights of this population, it is of significant public health importance to ensure that women with SMI can safely and effectively prevent or experience pregnancy and achieve optimal fertility-related outcomes.

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## **PREFACE**

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## 1.0 INTRODUCTION

There are over three million women of reproductive age with serious mental illness (SMI) residing in the United States. Compared to the general population, women with SMI are more likely to experience contraceptive misuse/nonuse and negative reproductive outcomes. Little attention has been given to the contextual factors that contribute to the reproductive disparities experienced by this population. Further, only limited research regarding the pregnancy intentions, contraceptive decision making, and the family planning priorities and preferences of women with SMI exists.

The first section of this dissertation provides an introduction to and public health significance of the problem as well as current gaps in knowledge. Next, three distinct studies will be discussed, each of which fill an existing literature gap. Study 1 provides a comprehensive review of the literature regarding the contraceptive experiences, knowledge, and attitudes of women with serious mental illness. Study 2 provides a qualitative assessment of the factors that influence contraceptive use among women with SMI. In Study 3, women's narratives regarding their family planning priorities and preferences for who they would like to receive this information from are explored. The final section provides additional discussion and conclusions related to each paper and suggestions for future research.

## 1.1 BACKGROUND

Ten million adults in the United States are currently living with a serious mental illness (SMI),<sup>1,2</sup> and over three million of them are women of reproductive age (defined here as 18-45).<sup>2,3</sup> The Center for Behavioral Health Statistics and Quality defines SMI as a mental, behavioral, or emotional disorder (excluding developmental and substance use disorders) that: (1) is currently diagnosable or diagnosed within the past year, (2) is of sufficient duration to meet diagnostic criteria specified within the *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)*, and (3) results in serious functional impairment, which substantially interferes with or limits one or more major life activities.<sup>4</sup> Schizophrenia, bipolar, and major depressive disorders make up the majority of SMI diagnoses<sup>1</sup> and contribute to poorer health outcomes including increased physical and behavioral health comorbidity and an estimated 13-30 year decreased life expectancy.<sup>5</sup> Factors such as poverty, lack of social support, drug use, and inadequate health care contribute to the disparities experienced by this population, and this may be especially true for many women of child bearing age with SMI who can experience a myriad of challenges throughout their reproductive years.

Many earlier studies of the reproductive experiences of women with SMI focused on those living in institutions which often enforced strict regulations on the sexual practices of residents.<sup>6-8</sup> In recent decades, far fewer individuals experience institutionalization for mental health conditions. Thus, women with SMI are likely to have different patterns of sexual activity and reproductive experiences than cohorts that were previously residing in long-term inpatient treatment facilities.

Existing research focusing on the sexual and reproductive health experiences of women with SMI residing in community settings indicate that sexual relationships, pregnancy, and

motherhood are quite common among women with SMI.<sup>9-16</sup> The prevalence of motherhood among women with SMI varies across studies, but it is estimated to be between 40-60%, and they have 1.9 to 2.4 children,<sup>15</sup> which is similar to the rate of the general population.<sup>17</sup> Further, between 65-75% of women with SMI engage in sexual intercourse in a given year<sup>9,10</sup> and they typically have a greater number of lifetime sexual partners compared to women without SMI.<sup>18,19</sup> Despite the high rates of sexual intercourse and pregnancy among this population, distinct disparities exist and poor reproductive health and pregnancy outcomes are common.<sup>20-36</sup>

Existing research explores the disparate negative fertility-related outcomes of women with SMI compared to healthy controls.<sup>26,27</sup> For example, a meta-analysis of prenatal and perinatal outcomes found that women with schizophrenia had two times the risk of experiencing a miscarriage, congenital defect, preterm labor, multiple obstetrical complications, and lower Apgar score, and were less likely to take prenatal vitamins.<sup>26</sup> Similarly, a secondary data analysis conducted by Jablensky and colleagues revealed that women with schizophrenia, bipolar disorder, and major depressive disorder were more likely to experience placental abnormalities, hemorrhage, and fetal distress.<sup>27</sup> Much of the available literature focuses on the prenatal, postpartum, and parenting stages, which is of critical importance to understanding the range of experiences women with SMI may face during their reproductive years.<sup>26,27,30-34</sup> However, little attention, specifically qualitative, is given to the pre-pregnancy period to understand factors that influence pregnancy intentions, contraceptive decision making, and other family planning experiences of this population.

More research is needed to understand how to best serve women with SMI to ensure that their unique family planning needs are addressed. Effective contraceptive use and family planning counseling is critical to public health because these can decrease rates of unintended



pregnancy and reduce the physical, social, and emotional burden resulting from pregnancies that are mistimed and unwanted.<sup>37-43</sup> Further, sexually transmitted infections can be reduced with the use of effective barrier contraceptive methods,<sup>44,45</sup> and comprehensive family planning services can provide information about preconception and prenatal care, which is important to maintaining a healthy pregnancy.<sup>46-48</sup> The next section provides information about the contraceptive use, pregnancy intentions, and family planning research available pertaining to women with SMI as well as the societal, organizational, interpersonal, individual, and biological factors that may contribute to their differential experiences.

## 1.2 OVERVIEW OF THE PUBLIC HEALTH PROBLEM

**Women with SMI are at increased risk of experiencing unintended pregnancy.**<sup>19,49</sup> Overall, nearly 50% of pregnancies in the United States are considered unintended<sup>50</sup> meaning they occur at the wrong time, are unexpected, or are unwanted (i.e., the woman did not desire the current pregnancy or any pregnancy).<sup>50,51</sup> Unintended pregnancy can lead to negative health consequences for mothers, children, and their families<sup>37-43</sup> and unintended pregnancy is not an uncommon experience for women with serious mental illness.<sup>6,19,26,52-55</sup> Marengo and colleagues compared unintended pregnancy rates of 63 women with euthymic bipolar disorder to 63 healthy controls and found the rates of unintended pregnancy to be 67% and 22%, respectively.<sup>49</sup> Ozcan et al. assessed differences in rates of unintended pregnancy for Turkish women with schizophrenia, bipolar disorder, and major depression and found a high prevalence among all three groups with a diagnosis of major depression indicating the highest rate (45%).<sup>10</sup> Despite

these findings, sample sizes used to calculate unintended pregnancy risk and experiences among this population remain small.

No known population-based studies exploring abortion rates among women with SMI exist; however, some research suggests that abortion rates are higher among women with SMI.<sup>19,49</sup> A study conducted by Miller et al. revealed abortion rates of 44% among women with SMI compared to 20% among a control group without an SMI diagnosis.<sup>19</sup> Dickerson's 2004 study found that women with SMI have fewer pregnancies ending in live birth; however, information was not obtained as to how many of these pregnancies ended in spontaneous versus induced abortions.<sup>18</sup> It is well known that abortion typically does not lead to subsequent long-term psychiatric illness;<sup>56-58</sup> however, more research is needed to determine how SMI may influence a woman's abortion and pregnancy continuation decision-making process to ensure that she is in control of her fertility outcomes.

Adolescents with SMI participate in sexual risk behaviors, such as earlier onset of sexual intercourse (many before the age of 13), more sexual partners, and less condom use than their non-SMI counterparts, putting them at increased risk of unintended pregnancy.<sup>59,60</sup> Mental illnesses including affective, addictive, anxiety, and conduct disorders among teenagers are associated with teenage pregnancy, and adolescents experiencing affective disorder (which includes bipolar disorder and major depression) are over two times more likely to experience a pregnancy as a teenager compared to adolescents without a mental illness.<sup>60</sup> In the above referenced study, pregnancy intentions were not described in the available dataset;<sup>60</sup> however, it is known that youths between the ages of 15-19 experience a disproportionately higher number of unintended pregnancies compared to adult women,<sup>61</sup> so it likely that many pregnancies that occurred among the study sample were considered mistimed or unwanted.

As described above, the vast majority of existing research focuses on pregnancies that women with SMI view as unintended and very few studies explore the narratives and experiences of women whose pregnancies were desired, planned, and/or wanted, which perpetuates the notion that this population should avoid pregnancy and motherhood. Mowbray's qualitative explorations provide narratives from women with SMI who viewed motherhood as a highly valued role and an opportunity to grow and develop alongside a son or daughter who could provide them with love and companionship.<sup>15,62</sup> Additionally, women viewed children as a source of emotional support that they otherwise may not have given their higher likelihood for social isolation;<sup>15,62</sup> however, some also noted that their perception of personal inadequacy as a parent and the financial strain of raising a child contributed to psychological distress.<sup>15</sup>

These accounts of complex emotions and experiences with adversity during motherhood provide insights into factors that may contribute to the pregnancy intentions of women with SMI. A more robust understanding about the attitudes and behaviors of those who choose to avoid pregnancy altogether, want to become pregnant in the future, are currently planning a pregnancy, or have already had a child or children, is needed. Clarifying the thought processes surrounding the pregnancy intentions and goals among women with SMI can provide critical information needed to develop patient-centric family planning services that are understandable and relevant to this population.

**Women with SMI have low rates of contraceptive use and adherence.**<sup>6,26,53,63-66</sup> Avoidance of unintended pregnancy can be achieved by correct and consistent use of effective contraceptive methods.<sup>67,68</sup> Despite the benefits of contraception for those wanting to prevent pregnancy, women with SMI in both inpatient and outpatient settings report low use, and use does not

always increase as a result of a previous experience with unintended pregnancy, abortion, and/or child custody loss.<sup>65</sup> Further, women with SMI who have just given birth are less likely to report receiving contraceptive counseling post-partum, putting them at increased risk of unintended pregnancy and inadequate birth spacing.<sup>69</sup> A 2009 Chilean study found that, among a sample of 233 women with SMI, 90% disclosed recent sexual activity yet only 32% were using any form of contraception. Among those using contraception, 40 were sterilized and the remainder used oral contraceptives, condoms, or an injectable, such as Depo-Provera, to prevent pregnancy. However, 80% of women using non-permanent methods of contraception were using them incorrectly.<sup>53</sup> A small cross-sectional study conducted by Thomas, et al. found that among 82 women in an institutionalized setting, many of whom had an abortion (n=22) or relinquished guardianship of their child (n=28), only 32% were using any form of contraception.<sup>65</sup> Additionally, rates of contraceptive use at last intercourse among a sample of Turkish women with SMI remain low.<sup>10</sup>

Contraceptive use can also be assessed by exploring gaps in refills of oral contraceptives and the degree of contraceptive coverage over the course of an extended time period. For example, a retrospective analysis of women Veterans with mental illness (not all had SMI) who were prescribed hormonal contraception concluded that those with mental illness were more likely to experience refill gaps of longer than 30 days and had fewer months of contraceptive coverage in one year when compared to female Veterans without mental illness. Contraceptive gaps increased and coverage decreased further among women Veterans with co-occurring mental health and substance use disorder diagnoses,<sup>70</sup> indicating that substance use disorders, when coupled with mental illness, can further impact a woman's ability to maintain contraceptive adherence.

There is a dearth of information about dual and multimethod contraceptive use, which typically involves the use of condoms with another form of birth control, among women with SMI. According to an array of studies including national surveys, dual method use, or the use of two methods of contraception at the same time, ranges from about 6-13% among the general population of young women.<sup>71-73</sup> These data are not available for young women with SMI; however, a similar study conducted with women with psychological disorders, found that nearly 35% of the study sample used two methods of contraception. Positive predictors of increased multimethod use were multiple sexual partners, condom self-efficacy, and neighborhood cohesion; but adolescent women who experienced a previous pregnancy were less likely to use condoms along with another contraceptive method.<sup>74</sup> It is important to note, however, that adolescent women with severe psychotic disorders, such as schizophrenia, were omitted from the sample.<sup>74</sup> It is possible that a SMI diagnosis may decrease the likelihood of using multiple methods of contraception, but this has yet to be explored.

**Women with SMI may also experience the undue influence of others when making contraceptive decisions.** Tubal sterilization, a surgically performed and permanent method of contraception, is a procedure that is common among women with SMI.<sup>63,75</sup> However, some studies suggest that the patient is not always the one who makes the decision to sterilize. In a qualitative study conducted by Guedes et al., six sterilized women (15% of the sample) with SMI provided narratives of parents, physicians, or spouses making the sterilization decision for them.<sup>53</sup> Further, some health professionals promoted sterilization, indicating that it is the most appropriate method for women with SMI,<sup>53</sup> which may undermine a woman's autonomy related to fertility-related decisions. It should be noted, however, that the study referenced above was

not conducted within the United States, and American women with SMI may describe very different experiences regarding tubal sterilization decision making and consenting procedures.

**Family planning services for women with SMI are suboptimal, and they are not provided with adequate contraceptive use and fertility-related information that is sensitive to their unique situations and needs.**<sup>29,76-79</sup> Patient-centered effective contraceptive and family planning services are necessary to support informed decision making among women so they can most effectively achieve their reproductive goals. Many women with SMI are interested in receiving family planning consultation;<sup>76,77,80</sup> however, their experiences with providers and the healthcare system remains inadequate.<sup>29,76-79</sup> A qualitative study conducted by Chernomas, et al. revealed several topic areas that women were interested in discussing with their healthcare providers, but felt as though they were not provided with sufficient information about medication usage during pregnancy, parenting issues, and the impact of contraception on the menstrual cycle.<sup>76</sup> For example, one woman stated that, despite her emotional suffering during pregnancy, her provider would not engage with her in a conversation about the risks and benefits of restarting her medications.<sup>76</sup> Quantitative studies have demonstrated that women with SMI are not provided with adequate information about contraception or other fertility-related topics by their mental or physical health providers.<sup>78,81,82</sup> However, little is known about the specific contraception and family planning information women with SMI would like to receive from health care clinicians.

The risk of SMI recurrence during pregnancy is common, potentially leading to hospital admissions and pregnancy complications. For example, women with bipolar disorder who discontinue medication have up to a 70% likelihood of being admitted at least once during pregnancy.<sup>23,24,83</sup> Given this, the topic of medication use during family planning conversations is

of critical importance because the risk of poor pregnancy outcomes among women who experience SMI symptom relapse during pregnancy is particularly high.<sup>32</sup> Arming women with SMI with updated and balanced family planning information improves their ability to better participate in the reproductive decision making process.<sup>82</sup>

Counseling about the effects of medication use during pregnancy can change a woman's intentions to conceive. A 2002 study explored women's family planning decisions after receiving services at a psychiatric program that specialized in perinatal and reproductive consultation. The program offered up-to-date information about the risks and benefits associated with SMI medication continuation/discontinuation during pregnancy. The majority of women receiving the specialized consultation stated that they had previously been counseled by a physical or mental health provider to avoid pregnancy due to their SMI diagnosis. However, after receiving specialty reproductive health psychiatric services, over half of the women attempted to conceive and many were successful within the first year. Among those who decided to avoid pregnancy, reasons such as fear of potential teratogenic risks of medications, SMI recurrence due to medication discontinuation during pregnancy, and genetic transmission of SMI were cited.<sup>82</sup> However, providers still often forego conversations about the teratogenic nature of certain SMI medications and the importance of effective contraceptive use to avoid pregnancy or plan pregnancy when taking these potentially harmful drugs.<sup>84,85</sup>

Several additional studies recognize that maintaining reproductive autonomy is essential, and women with SMI are in need of family planning services that may be different from those without SMI who do not experience the same psychosocial challenges.<sup>86-89</sup> For example, some genetic counselors and mental health professionals are integrating discussions about the genetic nature of SMI into their routine practice since many women express concerns about passing their

diseases onto their children if they decide to procreate.<sup>80</sup> Additionally, clinicians and researchers acknowledge that the ethical challenges of providing family planning services to women with SMI are complex due to symptoms that may alter their ability to make informed decisions independently.<sup>90,91</sup> As such, McCullough et al. proposed three approaches for the ethical pregnancy decision making of women with SMI based on their values, knowledge, symptom control, and decision-making capacity. These approaches include: (1) Autonomous decision making, in which the woman's SMI is well managed, she is in full control of the decision making process, and her decisions are not made by for her by family, spouses, or clinicians; (2) Assisted decision making which promotes the reversal of the factors that are preventing a woman from making an autonomous decision, such as finding more effective medications to improve symptoms and decisional capacity, enhancing a woman's communication skills so she can improve her self-advocacy and limit her experiences with coercion, increasing her knowledge about the clinical management of abortion and/or pregnancy taken to term, and helping her understand the impact of SMI on decision making; and (3) Surrogate decision making which involves asking women with SMI about their personal values and ensuring that surrogates maintain these values to the best of their ability when making reproductive health and family planning decisions.<sup>90</sup>

Additional guidelines that utilize findings from previous research have been suggested, including: involving spouses, significant others, and family members in the counseling process if possible,<sup>86,89</sup> looking for signs of IPV or pressure from family members that may impact a woman's ability to effectively use contraception or make family planning decisions,<sup>86</sup> providing repeat exposure to contraceptive efficacy requirements since women with SMI are less likely to maintain this information long-term,<sup>92</sup> discussing and modifying medication regimens to reduce



teratogenic risk,<sup>5,93,94</sup> and integrating family planning counseling into community mental health centers and not relying solely on gynecologist and family practitioners.<sup>89,94</sup> Despite the promise of these recommendations, little evidence exists indicating that the preferences of women with SMI were taken into account during their development. For example, there are no known studies that provide in-depth information about where women with SMI prefer to receive family planning counseling, the information that would be most useful and meaningful to them, their perception of shared decision making during the family planning process, how they use the information they have been given, and barriers to receiving the counseling they desire.

**Women with SMI who become pregnant are more likely to experience negative pregnancy outcomes.** Compared to the general population, women with SMI are at increased risk of hemorrhage, pulmonary embolism, gestational diabetes, and preeclampsia during pregnancy<sup>20-27</sup> and these disparities remained in several studies even after adjusting for covariates including age, marital status, education, race/ethnicity, and parity.<sup>21,27,33,95</sup> Fetal and neonatal morbidity and mortality are also more common among pregnant women with SMI as evidenced by higher rates of preterm birth, low birth weight, congenital malformations, decreased Apgar scores, and higher rates of stillbirth, infant death, and SIDS.<sup>26,28-30,32-36,96,97</sup> A recent population-based study explored whether or not these same issues are experienced by women with SMI who are no longer taking outdated antipsychotic regimens from the 1980's and 1990's, and whose mental health care is now community based rather than hospital based. This study revealed similar findings in that women with schizophrenia were at increased risk for gestational diabetes, venous thromboembolism, preeclampsia, and premature birth, and required more hospital resources for themselves and their infants, such as maternal and neonatal intensive care.<sup>20</sup> A lack of or delay in

prenatal care likely contributes some of the pregnancy outcome disparities experienced by women with SMI,<sup>31,98,99</sup> and other potential contributors include decreased use of prenatal vitamins, increased tobacco use, young (<20 years) or older (>34 years) maternal age during pregnancy, and lack of social support.<sup>26,27</sup> As evidenced above, poor outcomes experienced by pregnant women with SMI are vast, leading to their suggested designation by the American Psychiatric Association as a “health disparity population”.<sup>94</sup>

### **1.3 FACTORS THAT MAY CONTRIBUTE TO CONTRACEPTIVE USE AND FAMILY PLANNING EXPERIENCES**

Robust analyses of the contextual factors that contribute to pregnancy intentions, contraceptive use issues, and family planning among women with SMI are absent from existing literature. It is likely that the interplay of several factors, from the biological impact of disease symptomology on a woman’s ability to effectively use contraception, to mental illness-related stigma that causes feelings of parental inadequacy and lower rates of healthcare utilization among women with SMI contribute to poorer outcomes. The following section describes several potential factors organized using the social ecological framework that may help explain the contraceptive use and family planning disparities impacting women with SMI who are of reproductive age.

### 1.3.1 Societal factors

#### *Stigma*

Public stigma, or negative beliefs about or reactions to a group that is labelled as different from the majority population,<sup>100,101</sup> among individuals with SMI exists across all elements of society including policy, media, child and social services, and health care systems.<sup>102-106</sup> The media's focus on the mentally ill as violent and impulsive sustains societal beliefs that those with SMI should be feared and isolated.<sup>102,103</sup> Other misconceptions held by the public include the belief that individuals with mental illness are irresponsible and unable to care for themselves and others, requiring an authority figure to make decisions for them.<sup>64,102</sup> For example, mothers with SMI are far more likely to experience custody loss due to the perception that they are unfit to effectively raise a child,<sup>69,105,107,108</sup> and as a result, mental illness stigma may unduly increase the involvement of child and protective services.

When experiences with public stigma become internalized, self-worth may be diminished,<sup>103,104,109,110</sup> further relegating the individual to a perceived lower status than that of the "normal" population.<sup>103,110</sup> A decrease in self-esteem can contribute to social isolation, job loss or the inability to obtain gainful employment, and decreased likelihood of seeking health care.<sup>109,111</sup> Experiences with mental health stigma may also prevent disclosure of SMI, which may lead to increased internalization of negative stigma-related feelings.<sup>112,113</sup> Mothers in Diaz-Caneja's 2004 study were hesitant to disclose their SMI status for fear of rejection and judgement by other women. Their ability to make and maintain friends, develop a social network, and seek health care was limited by their perception that others may believe them to be unfit mothers who require help with child rearing.<sup>113</sup> Despite this, some research indicates that women with SMI view parenthood as an opportunity to uphold their place in society as a normal

member of the community.<sup>114</sup> The complexities of stigma warrant further investigation to understand how women deal with potentially conflicting experiences with the desire to bear children to affirm normalcy and their perceptions of society's belief that they are unable to successfully raise a child as a result of their mental illness.

Sexual and reproductive experiences can also be impacted by self-stigma, putting women with SMI at risk for contraceptive misuse/nonuse and unintended pregnancy. Decreased self-efficacy, which often results from the internalization of stigmatizing beliefs, may lead to poorer contraceptive adherence, such as the inability to remember to take a daily birth control pill.<sup>115</sup> Feelings of negative self-worth can also impact women's intimate relationships. Those who believe they are unworthy of a relationship may be more likely to settle for a partner that does not suit them, take part in unwanted intercourse to appease their partner, and may be less likely to advocate for safe-sex practices such as condom use.<sup>101,104,116</sup> Men's experiences with SMI-related stigma are not unlike women's, and their decreased self-confidence can lead to extreme measures to maintain a relationship. In Elkington's 2013 qualitative study, a male participant revealed that he was trying to impregnate his partner for fear that she would eventually leave him as a result of his mental illness. Neither he nor his partner wanted to become pregnant at this time, but he stated he was doing it "*Just to keep her*".<sup>101</sup> These experiences can all have potentially detrimental effects on a woman's fertility, reproductive health, and emotional well-being.

As stated above, the constant exposure to stigma may perpetuate feelings of decreased self-worth and self-efficacy and increase social isolation. For some, however, stigma has an opposite or a neutral effect. Corrigan and Watson posit that a paradox of self-stigma exists and that all experiences with stigma do not necessarily contribute to poorer outcomes. Some

individuals with SMI react to stigma with anger and/or a sense of empowerment.<sup>103,110</sup> As such, they are more likely to advocate for better healthcare, take part in shared decision-making practices, and become more active participants in their care. These individuals are more likely to have a strong peer group and bonds with others who are similar to them and who are also energized by the prejudice and discrimination they face.<sup>103,110</sup> Some with SMI may maintain a neutral stance in the face of adversity and are not internally impacted by the stigmatizing beliefs and/or actions of others.<sup>103,110</sup> Little is known about why certain individuals are more or less likely to have a particular response to stigma. Some research suggests that living with mental illness for an extended period of time, the ability to conceal the source of stigma, and the belief that mental illness is not one's fault may cause a person to respond more favorably to negative social-structural experiences and beliefs.<sup>103,110</sup> Identifying moderators related to stigma response may provide insights into the development of interventions that increase resiliency and empowerment among women with SMI.

### **1.3.2 Organizational factors**

#### ***Healthcare system inadequacies***

Integrating effective reproductive services for women with SMI into outpatient care settings has become a topic of importance in recent decades, but this was not always the case. Many women with SMI residing in psychiatric institutions were forcibly sterilized to ensure that their mental illness was not propagated throughout society via pregnancy and childbearing.<sup>89</sup> Further, strict limitations were placed on institutionalized women, limiting their opportunity to engage in sexual relations.<sup>6</sup> Women with SMI were viewed as unfit parents and, on many occasions, lost custody of their children or were provided with little or no visitation with their children if they

became institutionalized.<sup>6,89,105,113</sup> As deinstitutionalization became commonplace in the United States, women with SMI became part of a society that was not equipped to effectively tend to their reproductive needs.<sup>6,89,113,117</sup> While strides have been made in the delivery of reproductive health counseling for women with SMI, they still experience a lack of recognition within much of the healthcare system, and extensive work is required to promote their reproductive autonomy and improve family planning and pregnancy outcomes within today's healthcare system.<sup>6,117</sup>

A 1999 study conducted at Western Psychiatric Institute and Clinic in Pittsburgh, Pennsylvania found that of 120 women of childbearing age with SMI who had sexual intercourse, 75 were either not using contraception, or their birth control status was unknown. Of these 75 women, only 32 (43%) had information in their medical records indicating that their clinicians provided them with contraceptive counseling.<sup>78</sup> This information, along with several additional studies with similar findings<sup>55,105,118-120</sup> indicate that there are barriers that may be intrinsic within our health care system and/or provider training that contributes to the inability to adequately address the family planning needs of women with SMI. Integrating contraceptive counseling services into mental health hospitals has shown promise in early studies with regard to increased contraceptive uptake and continuation after discharge,<sup>54,121</sup> however, the outdated nature of this research does not translate into an effective model of contraceptive care that can be utilized with community dwelling women with SMI in which psychiatric hospitalization is now less common.

Negative experiences with seeking care and the internalized stigma faced by women with SMI have led to feelings of “invisibility” within the healthcare system, with some declaring that they are identified more by their disease rather than as a person.<sup>76</sup> A survey conducted by Benders-Hadi in a large psychiatric hospital found that many women with SMI had children, yet

the multidisciplinary teams caring for them conducted no formal assessments of parity and women's parenthood status was not always reflected in their medical charts. In other words, "Although acknowledged by some clinicians at the individual level, motherhood appears to remain a forgotten role systematically."<sup>122</sup> The sex-negative beliefs of some providers, their potential underestimation of sexual intercourse and pregnancy rates among women with SMI, and the lack of holistic health assessment, limits their ability of clinicians to effectively engage women with SMI in conversations about their sexual and reproductive needs.<sup>78,79,94</sup> Further, the topic of intimate partner violence, which is commonly experienced by women with SMI, is often inadequately addressed and/or goes unnoticed by many mental health providers, creating a missed opportunity to assess and potentially attend to a risk factor that is associated with poor reproductive health and pregnancy outcomes.<sup>123–125</sup>

### **1.3.3 Interpersonal factors**

Women with SMI are more likely to experience marital conflict and divorce, have difficulty maintaining long-term relationships, and more often have a spouse or partner who has also been diagnosed with a mental illness.<sup>15,90</sup> They have more lifetime sexual partners than women without SMI, and have an increased likelihood of engaging in sex exchange,<sup>6,9,18,19,126</sup> putting them at higher risk for unintended pregnancy and sexually transmitted disease. Conversations about contraception between sexual partners do not occur as often as they do among healthy women, with one Turkish study finding that 40% of schizophrenic and 50% of bipolar patients discussed contraception with their partner versus 90% of women in the control group.<sup>127</sup> Further, a small amount of dated research reveals great variability in who makes the decision to have children with only seven of eighteen women stating that decision making was a shared

responsibility between partners.<sup>55</sup> A better understanding of the extent to which women with SMI discuss contraception and family planning with their male partners is critical to effectively include both women and men in the development of fertility-related programming efforts.

### ***Intimate partner violence, domestic violence, and sexual abuse***

Several review articles describing rates of intimate partner violence (IPV), domestic violence (DV), and sexual abuse among women with SMI reveal staggering numbers with ranges of 21-70%,<sup>128</sup> 32-76%,<sup>126</sup> and 30-60%.<sup>129</sup> Variations in rates can be attributed to individual characteristics such as homelessness, being in an inpatient or community setting, involuntary commitment into an institution, and experiencing a high degree of activity limitations due to SMI.<sup>126,128,130</sup> Reporting sexual abuse or IPV may be a challenge for women with the most serious symptoms who may be unable to translate their experiences into a form of abuse and, therefore, it is likely that rates remain underreported.<sup>126</sup> It should be noted that for some cross sectional explorations, it was not possible to assess the temporal nature of SMI and abuse (e.g., if exacerbations in mental illness occurred after the abuse, or if women were already experiencing SMI prior to being abused);<sup>128</sup> however, qualitative inquiry could help to discern this information.

The most common perpetrator of IPV, DV, and sexual abuse against women with SMI are husbands and sexual partners,<sup>131,132</sup> and these unstable and tumultuous relationships can greatly impact a woman's contraceptive use and pregnancy outcomes. Compared to women in non-abusive relationships, women who experience IPV experience increased rates of forced sex, both decreased contraceptive use and forced contraceptive use, coerced pregnancy continuation



or abortion, social isolation, decreased ability to negotiate condom use, unintended pregnancy, and delayed prenatal care.<sup>133–138</sup>

Existing research makes the link between IPV and reproductive coercion among the general population,<sup>139–143</sup> but the extent to which women with SMI experience reproductive coercion has yet to be explored. Reproductive coercion, including contraceptive sabotage (e.g., flushing birth control pills, condom refusal), pregnancy promotion (i.e., the verbal or physical forcing of pregnancy), and control of pregnancy outcomes (i.e., coercing a woman to continue a pregnancy or obtain an abortion)<sup>142,144,145</sup> may contribute to the disproportionately high rates of unintended pregnancy and contraceptive misuse and nonuse among this population. More research is needed to understand the specific relationship experiences of women with SMI to explore the nuances of how intimate partner sexual abuse, violence, and reproductive coercion impact the fertility-related behaviors and reproductive experiences of this population.

Some women with SMI believe they are underserving of or unlikely to experience a healthy relationship with an intimate partner and they worry that their mental illness may impact relationship stability.<sup>77,101</sup> If someone does show sexual interest in them, women with SMI are at risk of giving in to their partner's sexual demands for fear of rejection.<sup>76,104</sup> They may continue a relationship even when experiencing IPV, and submitting to a partner is sometimes seen and the only option to avoid further abuse. As one woman stated in Davison's 2010 qualitative study:<sup>104</sup>

*"I actually feel that with the sexual abuse, I feel like I've got quite close to madness...And I found that if someone was attracted to me, it was almost an obligation to have to be in a relationship or to do something with them. It was like the impulse for my actions came from outside, not from me. I wasn't tuned*

*towards myself and my own needs or anything, I was tuned towards meeting the needs of others for survival.”*

Sexual relationships are sometimes viewed as a way to overcome loneliness and feel wanted, even if the nature of the relationships are unhealthy or abusive.<sup>76</sup> Cogan and colleagues found that women with SMI are largely interested in learning how to improve their self-esteem and communication with their partners to promote equity within relationships,<sup>79</sup> but the most effective ways to enhance negotiation skills and improve the confidence of women with SMI require further investigation.

### ***Childhood sexual abuse***

Outside of the context of relationships with intimate partners, women with SMI experience increased rates of childhood sexual abuse and rape,<sup>146,147</sup> which decreases their likelihood of seeking health care and undergoing disease prevention procedures.<sup>44</sup> Women who experience childhood abuse are less likely to obtain a mammogram and cervical cancer screening,<sup>148</sup> which translates to fewer visits with providers who can engage them in conversations about reproductive health. Finding approaches to overcome these missed opportunities by determining innovative ways to reach those with limited healthcare utilization is critical to improving the health of women with SMI.

### 1.3.4 Individual factors

#### *Contraceptive knowledge, attitudes, and preferences*

Existing studies have found that women with SMI have decreased levels of knowledge about the variety of contraceptive methods available to them and misconceptions about birth control are common.<sup>55,64,127,149</sup> Methods such as IUDs and implants are less known.<sup>81</sup> Reasons for and attitudes related to contraceptive non-use provided by women with SMI include: not expecting to have sex, fear of or experiences with side-effects, not thinking that pregnancy is a possibility, desiring pregnancy, difficulty remembering to take birth control, partner's dislike of birth control, fear that someone would find their birth control, and inconvenience.<sup>81</sup> While this information provides a good basis as to why a woman with SMI might forego contraception, more details are needed surrounding the context of these reasons. For example, what is inconvenient about using contraception for these women, and are there methods that they would view as more user-friendly, such as long-acting reversible contraception (LARC)? Where does the fear of contraceptive side effects come from? Is it a result of personal experience or from second-hand accounts from friends or relatives? Why do some women's partners not like contraception - are they trying to promote pregnancy? Obtaining answers to these questions can aid in the development of family planning services that help to overcome women's barriers to and misconceptions about contraceptive use.

Little is known about the contraceptive preferences of women with SMI. Several studies suggest that LARC, such as the IUD or contraceptive implant, may be optimal for women with SMI because these methods increase adherence with little to no effort.<sup>6,75,86,150,151</sup> Twelve month continuation rates of IUDs versus the depot medroxyprogesterone acetate (DMPA) contraceptive injection were assessed for a cohort of 18-44 year old women with bipolar disorder. Women who

were provided with an IUD were significantly more likely to continue using it after one year (over 85%). Further, only 31% of women utilizing DMPA received the three or more annual injections necessary to reduce their risk of pregnancy.<sup>75</sup> However, one dated study revealed that some women with SMI feared the notion of a “foreign object” being inserted into their body and, as such, were averse to considering LARC.<sup>55</sup> The impact of SMI medications on the efficacy of hormonal contraceptive methods (described later), the possible decreased ability of women with SMI to remember to effectively take birth control pills or monitor menstrual cycles if using natural family planning, and contraindications of hormonal contraceptive method use among the high number of female smokers with SMI are all factors that necessitate consideration when determining what method is most appropriate for a woman with SMI,<sup>52</sup> all while still taking into account her personal preferences.

### *Substance use*

Nearly half of those diagnosed with SMI will also experience a co-occurrence of substance use disorder within their lifetime,<sup>152</sup> almost 25% experienced both within the last year,<sup>4</sup> and only a small number are likely to receive treatment for both conditions.<sup>153</sup> Drug and alcohol misuse can lead to an increase in sexual and reproductive risk taking.<sup>70,154–161</sup> Women who use illicit drugs are more likely to engage in sex exchange or prostitution to maintain a high, which puts them at increased risk for sexual violence which is associated with contraceptive misuse and unintended pregnancy.<sup>126,134,152,162</sup> A large study exploring the efficacy of a multi-site clinical trial of opioid treatment for pregnant women found that of the 946 women screened for participation, 817 reported that their pregnancies were unintended, which is nearly twice to three times the rate of the general population.<sup>160</sup> Among women with substance use disorder, inadequate prenatal care is three and a half times more likely, and they are five times more likely to initiate care later in

the pregnancy compared to women without the disorder.<sup>99</sup> Substance use disorder coupled with SMI poses serious sexual and reproductive risks to women. Determining ways to integrate SMI and substance use treatment alongside sexual and reproductive counseling and programming may improve women's health outcomes.

### ***Socio-economic status***

Many women with SMI are of low socio-economic status due to a lack of gainful employment and low annual household income. This can lead to impoverishment and homelessness<sup>163-166</sup> and can impact contraceptive use and receipt of family planning services.<sup>126,167</sup> The employment rate for individuals with SMI is about one-third to one-half that of those without SMI, despite the desire of many to find employment.<sup>163</sup> Women with SMI are less likely to have health insurance and, as a result, may not obtain adequate reproductive health care,<sup>167</sup> limiting their chances of being properly screened for reproductive health issues and provided with contraceptive counseling. Further, some women are not be able to afford contraception, such as condoms, to prevent pregnancy and sexually transmitted infections.<sup>126</sup> Poverty stricken women are more likely to participate in risky sexual behaviors, such as sex trading, for financial reasons unrelated to obtaining drugs,<sup>9</sup> and they are at increased risk of experiencing sexual assault.<sup>168</sup>

### **1.3.5 Biological factors**

#### ***SMI symptomology***

The symptoms experienced by women with SMI may be important contributors to contraceptive misuse/nonuse and family planning issues. Women with schizophrenia may experience disorganized thoughts and behaviors<sup>169</sup> making it difficult to adhere to effective contraceptive

use practices and limiting their ability to effectively communicate with providers or intimate partners about their family planning concerns.<sup>6,90</sup> Women with bipolar disorder, depending upon whether they are experiencing a manic or depressive state, may encounter a variety of symptoms that may make them more vulnerable to unintended pregnancy and/or lessen their adherence to contraceptive use, such as taking part in impulsive sexual and self-destructive behaviors, becoming easily distracted, lacking motivation, and experiencing memory problems and other cognitive impairments.<sup>63,90,170,171</sup> However, no known studies have examined the extent to which SMI symptoms, versus other social, emotional, and biological factors, impact contraceptive use and family planning.

#### ***Drug interactions between SMI medication and contraception***

Antipsychotic medications and antiepileptic drugs contraindicate the use of some hormonal methods of contraception.<sup>75,86,150,151,172</sup> Women with SMI taking certain mood stabilizers and antiepileptics (commonly used to treat schizophrenia) to control their symptoms can experience medication induced heightened liver metabolism of some contraceptive steroids. For example, synthetic estradiol (Ethinyl-Estradiol) found in some combination contraceptive methods (e.g., estrogen/progesterone containing pills, NuvaRing) may be metabolized too quickly, yielding the birth control pill less effective and increasing a woman's risk for unintended pregnancy.<sup>52,75,86</sup> Conversely, synthetic estradiol can decrease antiepileptic drug levels in the body, decreasing the effectiveness of the drugs and increasing the likelihood of severe disease-related side effects such as tremors, lethargy, and low blood pressure.<sup>86</sup>

While some SMI medications contraindicate the use of certain hormonal contraceptive methods, these same medications also have the potential to decrease a woman's knowledge of her own pregnancy risk. Amenorrhea, or the absence of a menstrual cycle for more than six

months, is a relatively common side effect of antipsychotic medication that may falsely contribute to a woman's belief that her pregnancy risk is greatly decreased.<sup>150,173,174</sup> Hence, she may be less likely to use contraception.<sup>150</sup> Hyperprolactinemia, or an increase in prolactin levels which most often impacts the functioning of the reproductive system, can cause a cadre of reproductive side effects, including anovulation and decreased fertility,<sup>175,176</sup> which clinicians may assume is an effective way for women with SMI to avoid pregnancy.<sup>87,177</sup> Consequently, clinicians may forego counseling SMI patients about the availability and use of other, more effective, methods of contraception.

## **1.4 THEORETICAL FRAMEWORKS**

As described above, societal, system, interpersonal, individual, and biological experiences likely contribute to negative fertility-related outcomes among women with SMI. However, little is known about the extent to which each impacts and interacts with one another or the primary determinants that contribute to these disparities.

### **1.4.1 Ecosocial theory**

Ecosocial theory is a framework that may begin to explain these associations across multiple domains. Ecosocial theory posits that an individual's biology and health outcomes are impacted by macro-level conditions and experiences across the life course and vice versa. This framework has been used to describe the pathways in which racism leads to inequities in health,<sup>178,179</sup> occupational health disparities,<sup>180</sup> and differential health experiences related to sex and gender.<sup>181</sup>

**Embodiment**, the primary construct of ecosocial theory, refers to the incorporation of past and current social, political, and interpersonal experiences into one's internal being. Causal mechanisms for embodiment are described via *pathways of embodiment* including history, social-ecological contextual factors, and the biological strengths and weaknesses that impact a public health phenomenon. The *life course* is taken into account because it helps to describe exposure and resistance to the causal factors related to negative health outcomes across the spectrum of lived experiences. The final construct, **accountability and agency** refers to the responsibility of researchers, social systems, and others to understand and acknowledge the complexity of health inequities and ensure that analyses conducted to explore the causal mechanisms of these disparities appropriately address the benefits and limitations of the analytic methods and measures used.<sup>178,179</sup> One potential rendering of the ecosocial framework as it relates to contraceptive use and family planning among women with SMI may include the embodiment of mental health public/self-stigma and subsequent reproductive health outcomes related to the worsening of symptoms (biological factor), decreased self-efficacy and substance use (individual factors), lack of social support (interpersonal factor), and authoritarian healthcare systems and practices (organizational factor). However, the link between several additional factors, such as childhood sexual abuse and IPV, and the embodiment of stigma remains unclear.

#### **1.4.2 Grounded theory and framework development**

A grounded theory, or one that is “grounded” in the data, utilizes an inductive and iterative process to lead to the development of a conceptual framework that can be applied to a complex issue. It is especially useful when exploring concepts in which no framework currently exists.<sup>182–</sup>

<sup>184</sup> People's perspectives and experiences are rigorously explored using a variety of qualitative



methodologies to conceptualize the complexities of their unique situations. During the development of a conceptual framework, both purposive and theoretical sampling are used to obtain adequate information to describe the unique experiences of individuals.<sup>182-185</sup> For example, Montgomery's 2006 qualitative study purposively sampled participants based on SMI diagnosis and parity and then theoretically sampled additional women who no longer lived with their children to gather information regarding differing motherhood situations and perspectives.<sup>186</sup> A few additional studies have utilized a grounded theory approach to develop frameworks related to SMI and fertility; however, they typically focus on the postnatal period and parenting issues/needs of women with SMI.<sup>187-189</sup> They do not explore issues such as access to quality family planning, the gamut of factors associated with contraceptive use, and/or the impact of male partners on family planning and contraceptive decision making. This, or a similar approach, could potentially lead to the development of a robust conceptual model that could become the basis for future qualitative and quantitative explorations.

## **1.5 SUMMARY OF RESEARCH GAPS**

Much of the existing research that focuses on the contraceptive use and family planning needs and experience of women living with SMI is outdated, utilizes quantitative methodologies, and does not provide an in-depth exploration of the unique contextual factors that contribute to the reproductive health disparities faced by this population. Studies that do begin to expand their scope from a description of the problem to the identification of risk factors associated with poorer reproductive outcomes only do so superficially, making it difficult to determine the nuances of each risk factor, barrier, and/or experience. Much of the available research is

internationally-based and likely reflects socio-cultural, political, and healthcare experiences that differ from those in the United States. In addition, no known studies provide a conceptual framework that encompasses many of the potential contributors to disparities in contraceptive use and family planning experiences among women with SMI.

Several additional research questions have not been answered or have only been explored to a limited extent. Critical questions that remain include:

- What are the pregnancy intentions and related contraceptive use and family planning behaviors of women with SMI? How does SMI influence these intentions and behaviors?
- What impact do intimate partners have on fertility-related behaviors such as contraceptive use and pregnancy?
- How do women with SMI choose to use/not use a contraceptive method? What information would be helpful in making this decision?
- Where do women with SMI want to obtain contraceptive counseling and family planning services? How can physical and mental health providers best support the reproductive health of women with SMI?
- How do contraceptive use and family planning experiences differ by SMI diagnoses?

Supporting the reproductive rights of this particularly vulnerable population is of utmost importance. All women deserve the opportunity to express their sexuality and realize their family planning goals, however they may be defined. To promote the reproductive health and rights of this population, it is of significant public importance to ensure that women with SMI can safely and effectively prevent or experience pregnancy and achieve optimal fertility-related outcomes.

## 1.6 DISSERTATION OVERVIEW AND SPECIFIC AIMS

This dissertation seeks to examine the breadth and depth of factors that contribute to contraceptive use/nonuse and pregnancy planning experiences and priorities of women with SMI. Three studies were conducted, one systematic review of the literature and two qualitative explorations, each aimed at addressing important gaps in the scientific literature. Study 1 consisted of a comprehensive review of existing literature focusing on the contraceptive experiences, knowledge, and attitudes of women with SMI. For Study 2, qualitative interviews were conducted with 28 women with SMI to understand contributors to their contraceptive use experiences. Study 3 utilized qualitative data to identify the contraceptive use and family planning counseling priorities and preferences of women with SMI. In addition, Studies 2 and 3 began to uncover a more robust understanding of how family planning experiences and priorities differ among women with bipolar disorder, major depressive disorder, and schizophrenia/schizoaffective disorder.

### 1.6.1 Study 1: Primary aim

*Primary Aim:* To identify the scope of academic literature focusing on the contraceptive use experiences, knowledge, and attitudes of women with SMI.

### 1.6.2 Study 2: Primary and secondary aims

*Primary Aim:* To examine the contextual factors related to the contraceptive use experiences of women with SMI.

- **Secondary Aim:** To explore how contextual factors related to contraceptive use and family planning experiences differ by SMI diagnosis.

### **1.6.3 Study 3: Primary and secondary aims**

**Primary Aim:** To understand the contraceptive and family planning counseling priorities and preferences of women with SMI.

- **Secondary Aim:** To explore how contraceptive and family planning counseling priorities and preferences differ by SMI diagnosis.

## 2.0 CONTRACEPTIVE EXPERIENCES, KNOWLEDGE, AND ATTITUDES OF WOMEN WITH SERIOUS MENTAL ILLNESS: A LITERATURE REVIEW

### 2.1 ABSTRACT

**Background:** Nearly half of pregnancies in the United States are unintended and women with serious mental illness (SMI) experience disproportionately high rates of pregnancies that are mistimed or unwanted. Effective use of contraception can prevent unintended pregnancy; however, little is known about the current state of the literature regarding contraceptive experiences, attitudes, and knowledge of women with SMI. A comprehensive review of existing literature was conducted to address this gap.

**Methods:** Databases including PubMed, CINAHL, Embase, PsycInfo, Social Sciences Abstracts, and Population were searched to identify relevant literature published between 1980-2017 that met the following inclusion criteria: a portion of the study sample included women of reproductive age with a serious mental illness, availability of the article in English, and contraceptive attitudes and/or experiences were evaluated as a study outcome. Two reviewers assessed all abstracts and full-text articles to determine inclusion in the final report. A single reviewer extracted pertinent information from and appraised the scientific rigor of each included article.

**Results:** Outcomes assessed, country of study origin, and scientific rigor varied greatly across existing literature. Three primary outcome categories were identified including contraceptive use, contraceptive information and access, and contraceptive knowledge and attitudes. Higher quality studies demonstrated that women with SMI have disproportionately poorer contraceptive experiences, including contraceptive nonuse, misuse, and gaps in coverage. In addition, this population experienced suboptimal access to contraceptive care and less knowledge about available contraceptive methods.

**Conclusion:** Additional research is needed to obtain a more expansive understanding of the contraceptive experiences of women with SMI to allow healthcare providers and public health practitioners to more effectively meet the reproductive needs of this vulnerable population.

## 2.2 BACKGROUND

Nearly 50% of pregnancies in the United States are considered unintended,<sup>50</sup> meaning they occur at the wrong time, are unexpected, or are unwanted,<sup>50,51</sup> however, effective use of contraception can prevent unintended pregnancy.<sup>190,191</sup> Over 60% of women in the United States who are of child bearing age use contraception, with some of the most common methods including the pill, condoms, sterilization, and long-acting reversible contraception.<sup>192</sup> Despite the widespread availability of most contraceptive methods, unintended pregnancy rates remain disproportionately high among certain subpopulations, including women with serious mental illness (SMI).<sup>26,49,52,193</sup>

Existing studies conducted both within and outside of the United States (U.S.) reveal that women with SMI, including those with schizophrenia, schizoaffective disorder, bipolar disorder,

and major depressive disorder, may be particularly vulnerable to mistimed or unwanted pregnancies.<sup>6,10,19,26,49,52,54,55</sup> Marengo and colleagues compared unintended pregnancy rates of 63 Argentinian women with euthymic bipolar disorder to 63 healthy controls and found the rates of unintended pregnancy to be 67% and 22%, respectively.<sup>49</sup> Research also suggests that abortion is more common among U.S. women with SMI with one study finding an abortion rate of 44% among women with SMI compared to 20% of women in the control group.<sup>19</sup> Unintended pregnancy can lead to negative physical health, emotional, and social consequences for mothers, children, and their families,<sup>37-43</sup> and women with SMI may require more extensive contraceptive counseling and services to decrease the rate of unintended pregnancy among this population.<sup>86</sup>

Healthcare for individuals with SMI residing in the U.S. changed drastically in the late 1970's and early 1980's with the passage of legislation to improve outpatient treatment for individuals with mental health conditions, which shifted comprehensive mental health treatment from residential psychiatric institutions to community mental health centers.<sup>194,195</sup> As a result, more women with SMI began receiving and continue to receive care in community settings, necessitating research to determine the best methods of providing effective outpatient reproductive healthcare to those living with chronic mental health conditions. Despite the increase in studies focusing on the family planning needs and experiences of this population, no known review of the literature has been conducted to examine their commonly used or preferred methods of contraception, knowledge about existing methods, or access to contraception. To address this need, this review identifies existing literature focusing on the contraceptive experiences, knowledge, and attitudes of women with serious mental illness who are not residing in long-term psychiatric institutions. This information will provide insights about potential gaps in family planning care experienced by women with SMI and reveal important information for

healthcare clinicians to consider during the provision of contraceptive counseling services to reduce the risk of unintended pregnancy among this population.

## **2.3 METHODS**

### **2.3.1 Literature search**

Databases including PubMed, CINAHL, Embase, PsycInfo, Social Sciences Abstracts, and Popline were searched by an experienced research librarian to identify literature published between the years of 1980-2017. Search terms related to the following concepts were used to identify relevant articles. Diagnosis-related terms included: serious mental illness, serious and persistent mental illness, schizophrenia, schizoaffective disorder, bipolar disorder, and major depression/major depressive disorder. Terms related to contraception, birth control, contraceptive ring, vaginal ring, intrauterine device, contraceptive implant, long-acting reversible contraception, contraceptive injection, birth control pill/oral contraceptives, birth control patch, condom, male condom, female condom, diaphragm, cervical cap, contraceptive sponge, spermicide, withdrawal, natural family planning, coitus interruptus, Essure, tubal ligation, and tubal sterilization were used to search for articles describing information about the full spectrum of available contraceptive methods. The specific PubMed search strategy can be found in Appendix A. Two additional abstracts were identified via other means: one via Google Scholar search and another, which was published after the database abstract identification process was completed, was provided by a topic area expert.



### 2.3.2 Article screening

Articles were included in the full text review if they met the following criteria: (1) the study sample included women in their childbearing years between the ages of 15-49, (2) the study sample included women with a serious mental illness (e.g., schizophrenia, schizoaffective disorder, bipolar disorder, major depressive disorder), (3) the article was available in English, (4) the article was published in or after 1980, and (5) contraceptive attitudes and/or experiences were assessed as a study outcome. Attitudinal outcomes included thoughts, feelings, fears, or perceptions related to the value/benefits of contraceptive methods or the perceived efficacy of contraception. Experience-related outcomes included: use of contraception, types of methods used, contraceptive knowledge, contraceptive behaviors (e.g., misuse, gaps in use, discontinuation), contraceptive access, influence from others (e.g., partners, providers, family members) on contraceptive use, perceptions of contraceptive symptoms, and sources of contraceptive information. Studies utilizing quantitative, qualitative, or a mix of research methodologies were included if they measured at least one outcome relevant to this review.

Studies were excluded if they were intervention studies, systematic reviews, guidelines, case studies, commentaries, or conference papers/posters; focused on condom use to prevent sexually transmitted infections rather than pregnancy; or focused on contraceptive method use as a potential *cause* of SMI symptoms. In addition, one of the goals of this review was to understand the contraceptive experiences of women receiving care in outpatient settings; therefore, studies focusing only on women whose primary residence was a long-term psychiatric treatment facility were not included. All abstracts and full-text articles were assessed for inclusion/exclusion by two independent reviewers. Disagreements between reviewers were discussed until a conclusion was made about article inclusion/exclusion. DistillerSR,<sup>196</sup> a

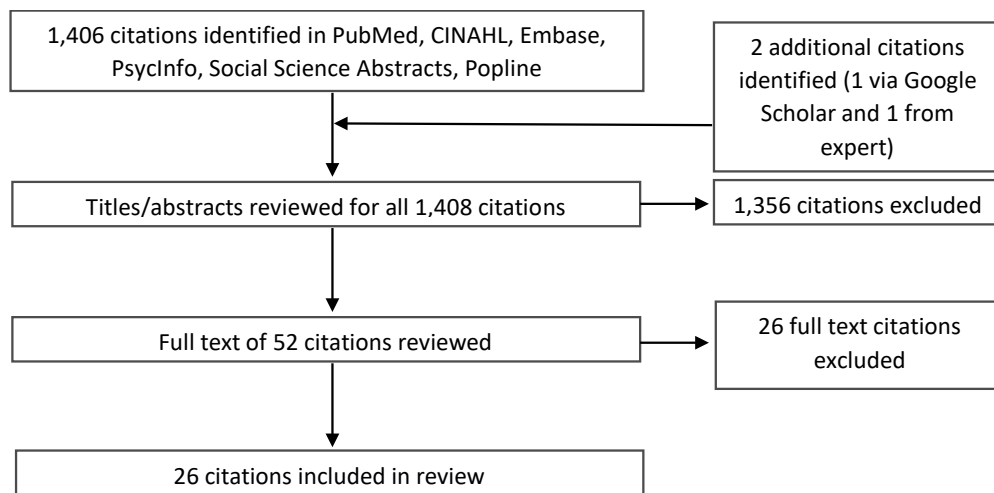
systematic review data collection and organization software, was used to support the abstract and full text screening process.

### **2.3.3 Data extraction, synthesis, and quality assessment**

A single reviewer extracted information about each study's purpose, outcomes assessed, participant characteristics, geographic study setting, methods, and findings and synthesized the data into tabular format. A second reviewer read a portion of the articles (20%) and confirmed that the appropriate data was systematically being abstracted by the primary reviewer. The National Institutes of Health Quality Assessment Tool for Observational and Cross-Sectional Studies<sup>197</sup> was used to critically appraise the scientific rigor and potential sources of bias of each study. Extracted data was compared across studies to determine the breadth, depth, and quality of available research and allow for an assessment of existing research gaps. To do so, a comprehensive list of all study outcomes related to the aims of the review was generated. Outcomes were then combined into major themes and subthemes which are represented in the Results section below. Research gaps were identified in relation to article quality (e.g., Were the methodologies used in existing research adequate to understand the full scope of the issues?), country of article origin (e.g., Were studies conducted within or outside of the U.S. and what is the potential impact of country of article origin on generalizability?), and outcomes assessed (e.g., Are there other important contraceptive attitude, knowledge, and experience outcomes that have not been adequately assessed?). To assess the current landscape of contraceptive experiences and attitudes of women with SMI, all relevant articles were included in this review and none were excluded based on quality.

## 2.4 RESULTS

Figure 2.1 provides a flow diagram of the articles that were identified, screened, deemed eligible, and included in this literature review. After the removal of duplicate articles, 1,406 citations were abstracted from the six reference databases. Abstract review led to the exclusion of 1,356 citations and the full text of the remaining 52 citations were reviewed. Common reasons for full-text citation exclusion included: a lack of focus on women with serious forms of mental illness or no categorization of mental illness by severity (i.e., depression not differentiated between mild, moderate, and severe), women of reproductive age were not included in the analysis, or an article focused on condom use as a means of sexually transmitted disease prevention rather than the relationship between condom use on pregnancy. After full text review, 26 articles met the inclusion criteria.



**Figure 2.1. Identification and review of citations**

### **2.4.1 Study characteristics**

Of the 26 articles included in this review, the majority (n=22) were cross sectional studies<sup>10,49,53,63,74,79,81,84,127,198–209</sup> and the remainder were cohort studies (retrospective cohort: n=3; prospective cohort: n=1).<sup>70,75,210,211</sup> Three studies had a qualitative component<sup>53,79,81</sup> and one study utilized latent class analysis.<sup>209</sup> Country of study origin varied with 11 conducted in the U.S.<sup>66,74,81,199,202,206,210,212–215</sup> and 15 conducted internationally.<sup>10,53,63,200,203–205,207–209,211,216–218</sup> Three studies focused on the female Veteran population<sup>199,210,213</sup> and most studies recruited participants from outpatient mental healthcare settings.<sup>49,53,63,74,79,81,127,198,201,203,206,207,209,215</sup> Study sample sizes ranged from 25<sup>79</sup> to 50,000+.<sup>199,202</sup>

### **2.4.2 Summary of key findings**

Findings related to the contraceptive experiences, knowledge, and attitudes of women with SMI varied greatly based on study design, country of study origin, and study population. The exploratory nature of all studies included in this literature review provides the groundwork for hypothesis generation; however, many gaps in existing research remain. Reported below is a summary of information identified related to three primary themes of interest: contraceptive use, contraceptive information and access, and contraceptive knowledge and attitudes, among women with SMI. In addition, any existing research regarding differences in these three primary themes by SMI diagnosis was assessed and the quality of existing literature is also described. Additional details regarding country of study origin, study design, outcomes assessed, and study findings can be found in Table 2.1.

## *Contraceptive use*

### *General use of contraception (n=14)*

Any studies reporting that women were either using or not using contraception within a given timeframe were classified within the theme of “general use of contraception”. These studies varied in terms of time point of interest, including: current use,<sup>63,199,204,207–209,211,215</sup> use at last intercourse,<sup>66,127,200</sup> use in previous three months,<sup>49</sup> use in past 12 months,<sup>66,203</sup> or ever used.<sup>10,207</sup> Few studies utilized a control group to understand the magnitude of which contraceptive use in the study sample compared to women without SMI and vast differences exist in the observed outcomes.

Six studies exploring rates and/or odds of contraceptive use among women with SMI compared to a control group were identified.<sup>49,127,199,200,204,211</sup> A sample of female U.S. Veterans, some diagnosed with depression or anxiety and others with a serious mental illness, were just as likely as controls to have a contraceptive method prescription; however, women with a mental health condition and substance use disorder had 20% lower odds of having a [prescription](#).<sup>199</sup> A study of Turkish women with schizophrenia were also significantly less likely to be using contraception and relied on less effective [methods](#),<sup>211</sup> and a Brazilian study found vastly lower odds of current contraceptive use among women with bipolar disorder compared to controls as well as other women with a mild to moderate psychiatric [diagnosis](#).<sup>204</sup> Pehlivanoglu and colleagues discovered non-significantly lower rates of contraceptive use at last intercourse among Turkish women with bipolar disorder, schizophrenia, and major depressive [disorder](#).<sup>127</sup> Conversely, a study based in Argentina found no difference in the rates of contraceptive use for women with bipolar [disorder](#)<sup>49</sup> compared to controls.

#### *Contraceptive failure/misuse/gaps (n=4)*

Two studies assessed pregnancy resulting from contraceptive failure or misuse/nonuse. An Australian study determined that of the 257 pregnancies that occurred among the study sample of women with schizophrenia and atypical psychosis, 52% were considered unplanned and 24 and 110 of these unplanned pregnancies resulted from contraceptive failure and contraceptive nonuse, [respectively](#).<sup>198</sup> In the second study, Kazerooni et al. sought to understand differences in pregnancy rates between female U.S. Veterans with mental health conditions compared to controls after oral contraceptive initiation. Women with a diagnosed mental health condition were significantly more likely to experience a pregnancy during the study [period](#).<sup>210</sup> Similarly, misuse of reversible contraception was high in a Brazilian study that found that of the 35 women using some form of reversible contraception, 77.2% were not using it correctly, increasing their risk of [pregnancy](#).<sup>53</sup>

Gaps in contraceptive coverage were evaluated among a large retrospective cohort of female U.S. Veterans by Callegari and colleagues. Those with mental health conditions, including depression, PTSD, anxiety, bipolar disorder, schizophrenia, and adjustment disorder, experienced more gaps in contraceptive coverage greater than 30 days and were less likely to have a full 12 months of contraceptive coverage compared to female Veterans without a mental health diagnosis. These findings were amplified for women with a mental health condition coupled with substance use [disorder](#).<sup>70</sup>

#### *Discontinuation/continuation of contraception (n=2)*

A retrospective cohort study of 849 U.S. women assessed method continuation of two forms of intrauterine device (i.e., CuT380A and LNG-IUS) and the depot medroxyprogesterone acetate

injection. Finding showed that women with bipolar disorder who had an IUD were significantly more likely to continue method use after one year compared to those utilizing the contraceptive injection which requires booster injections every three [months](#).<sup>75</sup> Only one study conducted in Nigeria assessed reasons for method discontinuation among a small sample of women (n=100) with SMI who were previously using contraception. The most common reason included fear of contraception; however, no additional information was provided regarding the context behind women's [fears](#).<sup>207</sup>

#### *Contraceptive methods used (n=12)*

In a large study of female U.S. Veterans with mental health conditions and a control group of female Veterans without a diagnosed mental health condition or substance use disorder, rates of highly effective method use (e.g., IUDs, contraceptive implants) were lower among women with mental health conditions both with and without concomitant substance use disorder compared to [controls](#).<sup>199</sup> Only one additional study, a U.S.-based cross-sectional survey, that also included qualitative interviews conducted with women of child bearing age with schizophrenia and schizoaffective disorder, assessed variations in chosen contraceptive methods. Findings revealed that women with schizophrenia/schizoaffective disorder were most likely to rely on tubal sterilization, followed by condoms, which were also the two most common methods utilized by those in the control [group](#).<sup>81</sup>

The heterogeneity of the participant samples in terms of diagnosis type and country of study origin did not allow for a direct comparison of method use by SMI diagnostic category.<sup>10,49,53,63,74,81,199,201–203,205,208,215</sup> A Turkish study found that women with varying SMI conditions had similarly high rates of reliance on coitus interruptus and IUD [use](#).<sup>10</sup> A

longitudinal cohort study conducted in the U.S. that utilized weekly journal entries documenting intercourse and contraceptive use found that women with moderate/severe depression were significantly more likely to use condoms and less likely to use long-acting reversible contraceptive (LARC) compared to oral [contraceptives](#).<sup>215</sup> In Argentina, Marengo et al. reported that condoms were the method of choice for bipolar women in the study sample followed by the [IUD](#).<sup>49</sup>

Only two studies included multi-method contraceptive use as an outcome. Hall et al. found that women with moderate/severe depression were significantly less likely to use nearly all combinations of methods compared to women with low-level or no [depression](#),<sup>215</sup> and Lang and colleagues found that among adolescent women with mental health conditions, one-third used two methods of [contraception](#).<sup>74</sup>

#### *Reasons for contraceptive use/nonuse (n=3)*

Three cross-sectional studies: one survey,<sup>207</sup> one secondary data analysis of national Behavioral Risk Factor Surveillance System data,<sup>202</sup> and another mixed methods survey and qualitative interview study,<sup>81</sup> revealed very different reasons for contraceptive use/nonuse among women with SMI. A Nigerian study found that fear of contraceptive side effects, cultural and/or religious reasons, and spousal opposition limited contraceptive use. This was the only identified study that also explored specific reasons why women with SMI chose to use contraception, which included the completion of childbearing and the desire to increase time intervals between [births](#).<sup>207</sup> Miller's 1998 examination of U.S. women with schizophrenia and schizoaffective disorder determined that participants were significantly more likely to admit "not getting around" to using contraception and considering it "too hard to take" compared to women without SMI. In



addition, participants were more likely to have delusional thoughts or beliefs about contraception, contributing to its [nonuse](#).<sup>81</sup> A U.S.-based study of over 50,000 women with frequent mental distress, which was indicative of major depressive disorder,<sup>219</sup> found that commonly reported reasons for contraceptive nonuse included not thinking about the possibility of pregnancy, pregnancy ambivalence, and [cost](#).<sup>202</sup>

#### *Experiences with tubal sterilization (n=1)*

A single study based in Brazil included qualitative data about women's experiences with forced sterilization. In this sample, 40 women (15.7%) were sterilized; however, six revealed that it was not their personal decision to have the procedure. One study participant with bipolar disorder stated, "When I woke up I was told I had been sterilized. During delivery the doctor asked me how many children I had and performed the tubal sterilization." Husbands, mothers, and sisters were also mentioned by participants as individuals who made sterilization decisions on participants' [behalf](#).<sup>53</sup>

#### ***Contraceptive information and access***

##### *Sources of contraceptive information/discussion (n=6)*

Women with SMI reported relying on a variety of sources for information about contraception. Contraceptive advice and information was received from providers in all countries represented in existing literature (i.e., United States, Turkey, Scotland, Australia, Nigeria),<sup>10,81,84,127,203,209</sup> although there is variation in the prevalence of these discussions among study samples with a range of 5% of women with SMI in a Nigerian [sample](#)<sup>207</sup> to 75% among a sample of women with schizophrenia/schizoaffective disorder in the [U.S.](#)<sup>81</sup> Other sources women relied on for

contraceptive discussions and information included sexual partners/spouses,<sup>127,207</sup> neighbors and friends,<sup>10,203</sup> and the internet.<sup>203</sup>

**Table 2.1. Summary of evidence**

Author, year, country	Design	Population	Outcomes assessed	Findings
Barkla, 2000, Australia <sup>198</sup>	Cross-sectional survey	Women ages 21-80 with diagnosis of schizophrenia, atypical psychoses, affective psychoses receiving outpatient mental health treatment (n=110)	Pregnancy resulting from failed contraception or contraceptive nonuse	Of 257 pregnancies, 134 (52%) considered unplanned, 24 resulted from contraceptive failure, 110 resulted from contraceptive nonuse
Berenson, 2011, United States <sup>212</sup>	Retrospective cohort	Women ages 18-44 with diagnosis of bipolar disorder who received an IUD (LNG-IUS, CuT380A), depot medroxyprogesterone acetate, or sterilization between 2001-2005 (n=849)	Rate of contraceptive continuation (12 months)	86% and 87% of women with an intrauterine device (CuT380A and LNG-IUS, respectively) were using method in 12 months compared to 31% receiving injection (p<0.0001)
Bursalioglu, 2013, Turkey <sup>211</sup>	Cross-sectional survey	Women ages 15-49 with schizophrenia, bipolar disorder, and depressive disorder (n=136) who were admitted to hospital and control group (n=60)	Use of reliable, unreliable and no contraception; opinions about contraception	No significant difference in opinions about contraception between patients and controls; Women with schizophrenia and bipolar disorder less likely to use contraception and use of unreliable methods higher in schizophrenia and control groups (p<0.05)
Callegari, 2015, United States <sup>70</sup>	Retrospective cohort	Female Veterans ages 18-45 with depression, PTSD, anxiety, bipolar disorder, schizophrenia, adjustment disorder, substance use disorder (n=5,181) and control group (n=4,599) with a hormonal contraceptive prescription in the first week of FY 2013	Hormonal contraceptive adherence and continuation	Women with mental illness and substance use disorder (SUD) experienced increased number of contraceptive gaps (IRR 1.13, CI: 1.04-1.22, p<0.01); Women with mental illness with and without SUD experience gaps >30 days (aOR 1.35, CI: 1.19-1.52, p<0.001 and aOR: 1.46, CI: 1.19-1.79, p<0.0001, respectively); Both groups experienced fewer months of contraceptive coverage compared to controls (mental illness only: coefficient -0.39, CI: -0.56 to -0.23, p<0.001; mental illness and SUD: coefficient -0.90, CI: -1.20 to -0.62, p<0.001); Women with mental illness and SUD significantly less likely to have 12-month coverage (OR 0.76, CI: 0.63-0.93, p<0.001)
Callegari, 2014, United States <sup>199</sup>	Cross-sectional secondary data analysis	Female Veterans ages 18-45 with depression, PTSD, anxiety, bipolar disorder, schizophrenia, adjustment disorder, substance use disorder (n=39,856) and control group (n=54,259) with at least one visit to primary care or women's health clinic during FY 2008	Prescription for contraception	No significant difference between women with mental illness only and control group for having any contraceptive method (aOR: 1.04, CI: 1.00-1.08, p=0.06); women with mental illness and SUD had significantly lower odds of having a contraception prescription (aOR=0.79, CI: 0.73-0.86, p<0.001); women with mental illness only and mental illness + SUD significantly less likely to use highly effective methods (aOR 1.17, CI: 1.08-1.27, p<0.001 and aOR 1.30, CI: 1.10-1.54, p=0.002, respectively)
Cogan, 1998, United States <sup>79</sup>	Cross-sectional survey and qualitative interviews	Women ages 18-65 with serious mental illness (diagnosis not specified) receiving community-based mental health treatment (n=25)	Access to contraception and/or information about contraception	60% had difficulty accessing information about contraception; however, most believed that help was available to access this information (mean score 7 on 1-10 scale, 1= help not at all available and 10 = help very available, SD: 3.1)
Cole, 2000, United Kingdom <sup>208</sup>	Cross-sectional retrospective medical	Women ages 16-45 discharged from inpatient psychiatric ward (n=56)	Mention of contraceptive use in medical record from most recent inpatient admission	Three women (5%) were using contraceptive pills or the contraceptive injection, three had hysterectomies, and one was sterilized; majority of notes had no mention of contraception (80.3%); Eight patients taking lithium did not have information about contraception in medical record

**Table 2.1 Continued**

	record review			
Coverdale, 1997, New Zealand <sup>200</sup>	Cross-sectional survey	Women ages 18-50 with schizophrenia, bipolar disorder, major depression, and other mental illnesses (n=66) and a matched control group (n=66)	Use of contraception at last intercourse	35 (55.4%) of psychiatric patients had heterosexual intercourse in the previous 12 months and only one who reported wanted to avoid pregnancy did not using contraception at last intercourse; No similar information provided for control group
Coverdale, 1989, United States <sup>201</sup>	Cross-sectional survey	Women ages 18-40 receiving services for schizophrenia, schizoaffective disorder, bipolar disorder, major depression, and other mental health issues receiving services at a county mental health clinic (n=80)	Contraceptive method used at last intercourse; contraceptive nonuse in the previous 12 months	Among women not desiring pregnancy, tubal ligation most common method used during last intercourse in previous (n=9), followed by IUD (n=5), condom (n=5), pill (n=4), and other methods (n=7), 14 (33%) did not use contraception; no relationship found between diagnosis type and use of contraception at last intercourse ( $\chi^2=0.28$ , $df=1$ , $p>0.05$ ); five women who used contraception at last intercourse did not use it at some point in the previous 12 months
Farr, 2011, United States <sup>202</sup>	Cross-sectional secondary data analysis	Sexually active women ages 18-44 with frequent mental distress who are at risk for pregnancy and who provided information about contraception currently being used/not used in the BRFSS (n=53,255)	Use of permanent or highly/moderately effective reversible contraception	Lower odds of contraceptive use among women with frequent mental distress (aOR: 0.89, CI: 0.77-1.03) and higher odds of using permanent methods over highly effective (aOR: 0.54, CI: 0.36-0.80) and moderately effective (aOR: 0.60, CI: 0.39-0.92) reversible methods; Among those not using contraception, reasons mentioned were similar for all women including: not thinking about the possibility of pregnancy, thinking partner was too old to become pregnant, pregnancy ambivalence, and cost
Guedes, 2009, Brazil <sup>53</sup>	Cross-sectional survey and qualitative interviews	Sexually active women age 12-49 with a diagnosis of mood disorder, schizophrenia/paranoid disorder, neurotic disorder, or personality disorder attending a psychosocial treatment facility (n=255)	Correct/incorrect use of contraception	13.7% of the sample used some form of reversible contraception and (n=35) and of those using reversible contraception, 77.2% were not using it correctly; 40 women (15.7%) were sterilized and of these women, six (15%) stated that sterilization was not their personal decision; Qualitative information provided about contraceptive use included knowledge of the potential interaction between contraception and psychotropic medications and instances of sterilization being made by someone other than the participant (i.e., mother, husband, doctor)
Hall, 2013, United States <sup>220</sup>	Longitudinal cohort study	A random sample of women ages 18-20 with moderate/severe depression residing in the state of Michigan (n=689)	Weekly contraceptive use	Women with moderate/severe depression: had greater odds of contraceptive nonuse (OR: 2.23, $p=0.04$ ), used methods less effective than oral contraceptives including condoms (RR: 1.17, CI: 1.00-1.34), $p=0.02$ ) and withdrawal (RR 1.29, CI: 1.10-1.51, $p<0.001$ ) and were less likely to use long-acting reversible methods compared to oral contraceptives (RR 0.52, CI: 0.40-0.68, $p<0.001$ ); relative risk of all multi-method combinations compared to single method use lower among women with moderate/severe depression with the exception of a combination of a noncoital method and withdrawal (RR: 1.21, CI: 0.85-1.71, $p=0.29$ )
Hauck, 2015, Australia <sup>203</sup>	Cross-sectional survey	Women ages 18-50 with anxiety, schizophrenia, bipolar disorder, personality disorder, and eating disorder attending outpatient mental health clinics (n=220)	Current contraceptive use and source of contraception advice	Of the 145 women confirming intercourse in previous 12 months, 104 (71.6%) used contraception; Of all sexually active women, 51% used less effective methods (e.g., condoms, withdrawal, oral contraceptive pill) and 38.6% used long-acting methods (e.g., implant, IUD, sterilization); Most common sources of contraceptive advice in previous 12 months included general practitioner (66%), friends (11.8%), and the internet (11.8%)

**Table 2.1 Continued**

Kazerooni, 2015, United States <sup>210</sup>	Retrospective cohort	Female Veterans ages 18-44 with depression, anxiety, PTSD, adjustment disorder, bipolar disorder, schizophrenia (n=1,347) and a control group (n=819) who newly started hormonal contraception between October 2008-September 2012	Pregnancy rates among hormonal contraception users	Women diagnosed with a mental health disorder significantly more likely to experience a pregnancy during the study period (OR: 1.69, CI: 1.15-2.58, p<0.001)
Lang, 2011, United States <sup>74</sup>	Cross-sectional survey	Sexually active adolescent women (mean age 15.29) with oppositional defiant disorder, ADHD, conduct disorder, generalized anxiety disorder, mania, PTSD, and hypomania receiving treatment in inpatient or outpatient settings (n=288)	Predictors of multi-method contraceptive use	100 women (34.7%) reported multi-method use (condoms and another method) in past three months; Predictors of multi-method use included: condom use self-efficacy (aOR: 1.07, CI: 1.02-1.12), multiple sex partners (aOR: 2.87, CI: 1.27-6.48), previous pregnancy (aOR: 0.41, CI: 0.17-1.00), communication with parents about sex (aOR: 0.97, CI: 0.94-0.99), parental sexual norms (aOR: 1.08, CI: 1.02-1.14), and neighborhood cohesion (aOR: 1.91, CI: 1.03-3.55)
Langan, 2013, Scotland <sup>84</sup>	Cross-sectional retrospective medical record review	Women age 16-50 with a psychiatric indication (e.g., bipolar disorder, depression, schizoaffective disorder, schizophrenia) for the use of valproate, lamotrigine, carbamazepine, or topiramate (n=172)	Evidence of teratogenic risk and contraceptive counseling	Teratogenic risk counseling was low among the four anticonvulsants studied (carbamazepine (40%), valproate (22%), lamotrigine and topiramate (0%); When teratogenic risk was discussed, 67% on valproate and 43% on carbamazepine had a documented contraception discussion
Magalhaes, 2009, Brazil <sup>63</sup>	Cross-sectional survey	Women (medium age 38) with bipolar disorder who were enrolled in an outpatient bipolar treatment program (n=136)	Prevalence of contraceptive use; types of methods used; demographics related to use/nonuse	58.8% of women in the sample were using any form of contraception; Contraceptive use was associated with being married (OR: 2.41, CI: 1.07-5.46, p=0.034), older (OR: 3.95, CI: 1.65-9.42, p=0.002), having 1-2 pregnancies (OR: 3.96, CI: 1.20-13.11, p=0.024), and having more than 2 pregnancies (OR: 2.73, CI: 1.02-7.31, p=0.046); Women using oral contraceptives were younger than those relying on sterilization (p<0.001) or not using any method (p=0.01)
Marengo, 2015, Argentina <sup>49</sup>	Cross-sectional survey	Women ages 18-55 both with bipolar disorder receiving services at an outpatient bipolar disorder treatment program (n=63) and a matched control group (n=63)	Contraceptive use in previous three months; Current contraceptive method being use	Use of any effective method in previous three months 90.7% for women with bipolar disorder and 91.8% for controls (p=1.00); 77.8% (n=49) women with bipolar disorder reported current use of contraception with most common methods including: condoms (57.1%), IUD (12.2%), multiple methods (12.2%), and oral contraceptives (8.2%)
Miller, 1998, United States <sup>81</sup>	Cross-sectional survey and qualitative interviews	Women ages 18-45 with schizophrenia or schizoaffective disorder who were not actively psychotic from inpatient and outpatient treatment settings (n=44) and control group without a mental health condition (n=50)	Knowledge about contraceptive methods; perceptions of obstacles to obtaining or using contraception	Tubal sterilization most common methods used by both groups followed by condoms. Women with schizophrenia could name fewer contraceptive methods (p<0.01), heard of fewer methods including long-acting reversible methods and injections (p<0.01); Approximately 75% of women in both groups ever discussed contraception with a health professional (p=1.00); Women with schizophrenia less likely to discuss contraception with a sexual partner (p=0.01); Significantly different reasons for contraceptive nonuse between the two groups include "didn't get around to it" (n=13 schizophrenia group versus n= 6 controls; $\chi^2$ : 3.9, p=0.05) and "too hard to take birth control" (n=11 schizophrenia group versus n=0 controls; $\chi^2$ : 11.8, p<0.01); Schizophrenia group more likely to have delusional beliefs about contraception

**Table 2.1 Continued**

Moreno, 2012, Brazil <sup>204</sup>	Cross-sectional survey	Women with bipolar disorder being treated at a mood disorders unit of a hospital with at least one child age 6-18 (n=34) and controls (n=53 with mild to moderate psychiatric diagnoses; n=53 without psychiatric diagnosis)	Past and current contraceptive use	Groups did not differ in past contraceptive use; Chance of current contraceptive method use lower for women with bipolar compared to controls without a psychiatric diagnosis (OR: 0.17, CI: 0.06-0.52, p=0.002) and controls with a mild to moderate psychiatric diagnosis (OR: 0.21, CI: 0.07-0.61, p=0.004)
Nguyen, 2017, Australia <sup>209</sup>	Cross-sectional survey and exploratory latent class analysis	Women ages 18-50 attending outpatient mental health clinics (specific diagnoses not specified) (n=220)	Seeking contraceptive advice from a general practitioner	Women who were sexually active and health seeking (57% of sample) had highest rate of contraceptive use (probability: 0.92) and were most likely to seek advice from general practitioner (GP) (probability: 0.72); Low sexual activity health seeking women (26% of sample) had low probability of contraceptive use (0.08) but likely to seek advice from GP (0.62); Low sexual activity and non-health seeking women (17% of sample) very low probability of contraceptive use (0.03) and least likely to seek GP advice (probability: 0.30)
Ozcan, 2013, Turkey <sup>10</sup>	Cross-sectional survey	Women ages 18-49 with schizophrenia, bipolar disorder, depression, and other mental health conditions being treated in an acute inpatient psychiatric ward (n=292)	Contraceptive use during sexual intercourse; types of methods used, source of contraceptive information	70.5% (n=206) of women who ever had sexual intercourse used some form of contraception, in order of most common: coitus interruptus (29.8%), IUD (29.3%); 42.8% reported that source of contraceptive knowledge was neighbors and friends and 21.9% talked with a health professional about contraception; 47% reported using contraception at last intercourse: 25.4% used coitus interruptus, 23.4% had IUD, and 14.9% use condoms
Pehlivanoglu, 2007, Turkey <sup>127</sup>	Cross-sectional survey	Women ages 15-49 with schizophrenia, bipolar disorder, and depression receiving outpatient psychiatric care (n=50) and control group (n=50)	Contraceptive knowledge; contraceptive attitudes; contraceptive use at last intercourse, discussion about contraception with partner; discussion contraception with psychiatrist	Women with schizophrenia more likely to report no knowledge of contraception, women with depression and controls more likely to report having enough contraceptive knowledge compared to schizophrenia group (p=0.004); Schizophrenia group less knowledgeable about all contraceptive methods, women with bipolar disorder and depression had similar rates of knowledge as controls with most known methods including oral contraception, condoms, IUDs, and tubal sterilization; Schizophrenic group opinion about tubal sterilization significantly less positive compared to other groups (p=0.003); Non-significant, but lower rates of women with bipolar disorder (60.5%), schizophrenia (68.6%), and depression (75.5%) used contraception at last intercourse compared to controls (81.4%, p=0.185); Depressed women and controls more likely to talk with partner about contraception compared to schizophrenic and bipolar patients (p=0.001); Few women in patient groups discussed contraception with psychiatrists (≤13%)
Raja, 2003, Italy <sup>205</sup>	Cross-sectional survey	Men (n=60) and women (n=57) <50 years of age with schizophrenia, schizoaffective disorder, and bipolar disorder who were admitted into a psychiatric intensive care unit	Contraceptive method used in previous three months	Of the 40 patients reporting sexual intercourse in three-months prior, two use oral contraceptives, five had an IUD, eight relied on coitus interruptus, 17 used condoms, one used spermicides, and 14 did not use a contraceptive method
Ritsher, 1997, United States <sup>206</sup>	Cross-sectional survey	Men (mean age 37, n=59) and women (mean age 41, n=107) with affective disorder or schizophrenia receiving services in rural, urban,	Receipt of contraceptive care	35% of female respondents reported not receiving regular birth control care

**Table 21 Continued**

		and suburban psychiatric rehabilitation centers and matched controls (n=104)		
Tunde-Ayinmode, 2013, Nigeria <sup>207</sup>	Cross-sectional survey	Women ages 18-52 with schizophrenia, depression, bipolar disorder, unclassified psychotic disorder, and severe obsessive-compulsive disorder who were attending an outpatient psychiatric facility (n=100)	Contraceptive knowledge; contraceptive use; reasons use contraceptive use, nonuse, and discontinuation	88% of women had knowledge about any contraceptive method and 61% were interested in using it, 27% were using some form of contraception and 51% had never used it; Women knew least about tubal sterilization (16%) and IUDs (37%) and most about male condoms (68%), injectables (64%), and oral contraceptive pills (56%); Most common methods being used included condoms (37%), injectables (22%), oral contraceptive pills (22%), and IUDs (7%); 48% of women discussed family planning with spouse, 5% received family planning information from a clinic (though 81% wanted family planning information); Reasons for contraceptive nonuse included fear of side effects (39.7%), desire for children (33.3%), cultural and/or religious reasons (14.3%), indecision (3.2%), opposition from spouse (1.6%); Reasons for use included not wanting more children (88.2%), birth spacing (29.6%), and limiting family size (7.4%); Reasons for discontinuation included fear of the method (72.7%), pregnancy (13.6%), and ending a sexual relationship (9.1%)

### *Access to and receipt of contraceptive care (n=3)*

Access to and receipt of contraceptive care was reported as suboptimal in the three studies assessing these outcomes. Despite 81% of women with SMI in a Nigerian sample desiring information about contraception, only 5% received this information from a family planning [clinic](#).<sup>207</sup> Sixty percent of 25 U.S. women with SMI in a qualitative study revealed that they experienced difficulty accessing [contraception](#)<sup>79</sup> and over a third of the 107 U.S. women with schizophrenia or affective disorder completing a cross-sectional survey reported not receiving regular contraceptive [care](#).<sup>206</sup>

### ***Contraceptive knowledge and attitudes***

#### *Knowledge about contraceptive methods (n=3)*

Three studies, one focusing solely on women with schizophrenia/schizoaffective disorder, and two others including women with a variety of SMI diagnoses, assessed contraceptive knowledge. Women with schizophrenia could name fewer methods of contraception, were less knowledgeable about long-acting reversible contraception compared to controls,<sup>81</sup> and were more likely to report not having enough contraceptive knowledge.<sup>127</sup> In Miller's 1998 study, only 43% of women with schizophrenia had heard of the contraceptive implant compared to 88% of controls, and a similar difference in knowledge was found for injectable contraception (30% and 74% for women with schizophrenia and controls, [respectively](#)).<sup>81</sup> These same disparities in contraceptive knowledge were not evident among women with other SMI diagnoses, including bipolar disorder and major depression, according to one Turkish [study](#).<sup>127</sup>



### *Contraceptive attitudes/interest (n=3)*

Few studies focused on substantive outcomes related to attitudes about or interest in contraception among women with SMI, and the only three existing explorations were all conducted outside of the United States.<sup>127,207,211</sup> Pehlivanoglu and colleagues found that their sample of Turkish women with schizophrenia had significantly less positive opinions about tubal sterilization compared to women with bipolar disorder, depression, and healthy [controls](#).<sup>127</sup> Tunde-Ayinmode's Nigerian study determined that 88% of women in the study sample were interested in using contraception, but only 27% were actually using a [method](#).<sup>207</sup> The third study from 2013 found no significant difference in opinions about contraception between Turkish patient and control groups; however, no additional information was provided about the questions asked and the contraceptive methods [assessed](#).<sup>211</sup>

### **2.4.3 Study quality**

Among the 26 articles included in this review, 18 utilized a convenience sample to identify potential participants,<sup>10,49,53,63,66,74,81,127,198,200,203–207,209,211,214</sup> seven conducted retrospective analyses of institutional databases, medical record reviews of all available research subjects, or national representative survey data,<sup>70,75,84,199,202,208,210</sup> and one study identified a random sample of participants using a state driver's license/personal identification card registry.<sup>215</sup> Findings from those implementing convenience sampling procedures are likely not representative of the larger population limiting generalizability of study findings.

Few studies stratified their analysis by diagnostic category, making it challenging to discern the degree to which specific SMI diagnoses impacted outcomes of interest. Four studies looked only at women with bipolar disorder,<sup>49,63,75,204</sup> one focused on women with

schizophrenia/schizoaffective disorder,<sup>81</sup> and one focused only on those with depression.<sup>215</sup> The remaining studies all included participants with a mix of SMI (and sometimes non-SMI) diagnoses and, of these studies, only two assessed differences in outcomes by diagnosis.<sup>127,211</sup> Overall, only 11 studies included a control group<sup>49,70,81,127,199,200,202,204,206,210,211</sup> making it challenging to understand if contraceptive experiences, knowledge, and attitudes varied for the study population compared to women without mental health conditions for the remaining 15 studies.

Several studies did not use validated tools to assess outcomes of interest<sup>66,198,200,203–205</sup> or they did not provide specific details about the measures used.<sup>127,207</sup> Only two studies provided a sample size justification<sup>53,206</sup> and five did not assess and/or report statistical significance of all findings.<sup>53,84,203,207,208</sup> Of the three studies using qualitative research methods,<sup>53,79,81</sup> only one provided a detailed analytic plan for the assessment of interview data.<sup>79</sup>

## 2.5 DISCUSSION

Contraceptive use, method choice, knowledge, and attitudes of women with SMI varied greatly across the articles included in this literature review. In the majority of studies with control groups, women with SMI were less likely to use any form of contraception, were more likely to use less effective methods, and experienced increased odds of method misuse and gaps in coverage. Existing research demonstrates that comprehensive discussions about contraception between patients and providers do not take place as often as they should, potentially increasing women's risk for unintended pregnancy and/or negative pregnancy outcomes. Thus, information regarding provider's perceptions of barriers and facilitators related to contraceptive counseling

practices and an in depth understanding of the family planning priorities and preferences of women with SMI and are needed to inform clinical guidelines for the provision of effective and patient-centered reproductive care.

A distinct lack of qualitative research has been conducted to understand the nuances of the experiences women with SMI face when accessing, learning about, communicating about, or using contraception. Notably, only three existing studies, two of which had little information about their qualitative methodology, reported any qualitative data related to topics discussed in this review. Questions remain about how women with SMI choose to use/not to use contraception, how they make decisions about which method to use, who is involved in these decisions, and what information would be helpful in making these decisions. Studies specifically tailored to obtain an in-depth understanding of the contextual factors related to the contraceptive use and family planning experiences of women with SMI can help to move beyond describing the issue to inform interventions to improve fertility-related outcomes for this vulnerable population.

The high rates of contraceptive misuse or gaps in coverage reported in some existing studies highlight the potential benefit of promoting LARC or permanent methods of contraception for women who wish to delay or cease childbearing. However, ensuring that the decision to have an IUD/implant inserted or go through with tubal sterilization is that of the patient and not an unwelcome proxy is critical to avoid situations similar to those described in Guedes qualitative study highlighting women's experiences with sterilization decisions that were not their own.<sup>53</sup> Furthermore, women with SMI, specifically those with schizophrenia and schizoaffective disorder, revealed a disparate lack of knowledge about LARC<sup>81</sup> and less positive attitudes about tubal sterilization compared to women with other SMI diagnoses.<sup>127</sup> A better

understanding of the differential experiences with, knowledge about, and attitudes toward long-acting and permanent contraception for each diagnostic category is critical to ensuring that all women with SMI can be part of a patient-centered shared-decision making process when determining their reproductive goals.

Much of the research identified in this review was conducted in other countries where cultural norms and beliefs about contraception may be different than those of women with SMI residing in the U.S. For the three primary themes discussed in this literature review, few studies conducted in the U.S. focused on themes: “Contraceptive information and access” and “Contraceptive knowledge and attitudes”. While the inclusion of studies that were conducted both within and outside the U.S. provided interesting information on an international scale, it should not be assumed that these findings are generalizable to populations of women outside of the country of study origin. Regional differences related to health care infrastructure, contraceptive policies and practices, and attitudes about contraception may lead to differential experiences for women with SMI. Thus, more U.S.-based research is needed to increase understanding of the contextual factors related to contraceptive use among U.S. women to inform domestic reproductive healthcare delivery and decrease disparities in unintended pregnancy.

There are several limitations worth noting that may impact the findings of this review. First, only six literature databases were searched for relevant citations and the final citation extraction occurred in January 2017. Some relevant articles may have been missed if they were only available in a different database or if they were published after the final citation extraction took place. Second, while a vast array of terminology was used to extract references related to the gamut of available contraceptive methods and the full scope of SMI diagnostic categories,

some terms may not have been included in the search and, thus, citations may have been inadvertently excluded. Third, to identify as many articles as possible describing the contraceptive experiences of community-dwelling women with SMI, a relatively large time frame (1980-2017) was included in the search criteria. This may date some of the findings given continual advancements in available contraceptive methods that could impact method attitudes, knowledge, and use. Finally, while the study findings summarized in this review provide important descriptive information regarding what is currently known about the topic of interest, it was not possible to make detailed comparisons across studies given the heterogeneity of study populations, differences in the use of standardized measures, analytic techniques utilized, and data reported.

## **2.6 CONCLUSION**

This comprehensive literature review summarizes experiences related to contraceptive use, knowledge, and attitudes among women with SMI who are at greater risk for unintended pregnancy. Proper use of contraception is the primary way to avoid mistimed and/or unwanted pregnancy. Although findings included in existing literature vary for our outcomes of interest, most higher quality studies utilizing a control group and larger sample sizes demonstrate that disparities remain. Most studies that begin to expand their scope from a description of the problem to the identification of risk factors associated with disparate contraceptive experiences only do so superficially, making it difficult to understand the nuances of the contextual factors that may influence these experiences. Arming women with knowledge and resources to make patient-centered contraceptive choices should be a top priority for researchers studying and

clinicians providing family planning services to women with SMI to reduce the burden of unintended pregnancy experienced by this population. Additional research, specifically qualitative, is needed to obtain a more expansive understanding of the contraceptive experiences and desires of women with SMI to allow healthcare providers and public health practitioners to more effectively meet their reproductive needs.

### 3.0 FACTORS INFLUENCING CONTRACEPTIVE USE AND FAMILY PLANNING AMONG WOMEN WITH SERIOUS MENTAL ILLNESS

#### 3.1 ABSTRACT

**Background:** Women living with a serious mental illness (SMI) can experience a myriad of challenges throughout their reproductive years including suboptimal contraceptive use and unintended pregnancy. Little is known about the contextual factors that influence the contraceptive use (or nonuse) of women with SMI. To address this gap, qualitative interviews were conducted with women with SMI to understand their pregnancy intentions, current contraceptive use, and factors that influence their contraceptive use behaviors and experiences.

**Methods:** Twenty-eight semi-structured in-depth interviews were conducted with women bipolar disorder (n=10), major depression (n=12), and schizophrenia/schizoaffective disorder (n=6) who were sexually active and between the ages of 18-45. Transcripts were analyzed by two coders using Crabtree and Miller's editing approach to identify major themes and subthemes.

**Results:** Most women (89%) wanted to avoid pregnancy; however, their contraceptive use behaviors did not always align with these intentions putting them at risk for unintended pregnancy. Factors that affected contraceptive use among participants included SMI symptoms, which influenced sexual behaviors and contraceptive choice, contraceptive knowledge and

attitudes, substance use, reproductive coercion, intimate partner violence, and sexual assault/abuse. A larger proportion of women with schizophrenia/schizoaffective disorder experienced reproductive coercion, compared to other SMI diagnoses categories.

**Conclusion:** The delivery of contraceptive counseling to women with SMI should assess factors beyond contraceptive choice that can influence a woman's ability to avoid unintended pregnancy.

### 3.2 BACKGROUND

Serious mental illnesses (e.g., bipolar disorder, major depressive disorder, schizophrenia, schizoaffective disorder) are chronic and can result in serious functional impairment and limitations in major life activities.<sup>4</sup> Ten million adults in the United States are currently living with a serious mental illness (SMI),<sup>1,2</sup> and nearly three million are women of reproductive age (defined here as 18-45 years of age).<sup>3,4</sup> Women with SMI can experience a myriad of challenges throughout their reproductive years, such as suboptimal family planning counseling,<sup>29,76-78,214</sup> higher rates of negative pregnancy outcomes,<sup>20-22,24-27,32-34</sup> and an increased likelihood of child custody loss.<sup>69,105,107,108</sup> In addition, unintended pregnancy, or a pregnancy that is mistimed, unexpected, or unwanted, is common among this population<sup>50,51</sup> and can result in negative health and social consequences for mothers, children, and families.<sup>37-43</sup>

While the avoidance of unintended pregnancy can be achieved with correct and consistent use of effective contraceptive methods,<sup>190,191</sup> women with SMI often report low use or inconsistent contraceptive use.<sup>70,199,204,211</sup> Existing studies show that women with SMI and other mental health conditions may be less likely to use any form of contraception,<sup>204,211</sup> more likely to



rely on less effective methods such as condoms and pills,<sup>199,211</sup> and more likely to experience a pregnancy after initiating contraceptive use.<sup>210</sup> For example, Guedes et al. found that of 255 Brazilian women with SMI, only 13.7% (n=35) were using a form of reversible contraception, and of these 35 women, 77.2% were not using these methods effectively.<sup>53</sup> A study of a random sample of young adult women residing in Michigan observed that those with moderate/severe depression were over two times more likely to forego contraceptive use during intercourse than those without depression.<sup>215</sup>

A growing body of research has also begun to explore reasons for contraceptive nonuse among women with SMI. Miller's study of women with schizophrenia and schizoaffective disorders found that participants were significantly more likely to admit "not getting around" to using contraception, consider it "too hard to take", and were more likely to have delusional thoughts about contraception compared to women without SMI.<sup>149</sup> Farr et al.'s research of over 53,000 women who were at risk for pregnancy found that women with major depressive disorder commonly reported reasons such as cost, not thinking about the possibility of pregnancy, and pregnancy ambivalence as contributors to contraceptive nonuse.<sup>202</sup>

Few studies provide information about contraceptive knowledge and attitudes of women with SMI. Existing research reveals that women with schizophrenia or schizoaffective disorder are knowledgeable about fewer contraceptive methods, including long acting reversible contraception (LARC), than women with other forms of SMI, such as bipolar disorder and major depressive disorder, as well as those without SMI.<sup>127,149</sup> Work by Bursalioglu found no significant differences between contraceptive attitudes of participants with SMI and controls among a sample of Turkish women; however, no information was provided about what

contraceptive methods were assessed and the specific questions that were asked to understand women's attitudes.<sup>211</sup>

There is a distinct lack of qualitative literature providing a more in-depth lens into the nuances and contributors to the contraceptive experiences, knowledge, and attitudes of women with SMI. Specifically, studies designed to understand the contextual factors, including biological, individual, interpersonal, and social-structural determinants, that influence the contraceptive use (or nonuse) of women with SMI are needed so we can move beyond describing the problem, to informing and developing interventions to improve reproductive health and family planning outcomes for this vulnerable population. To address this existing knowledge gap, semi-structured qualitative interviews were conducted with women of child-bearing age with bipolar, major depressive, and schizophrenia/schizoaffective disorders to begin to understand their pregnancy intentions, current contraceptive use, and the factors that influence their contraceptive behaviors and experiences. In addition, we sought to determine if contraceptive experiences differed by SMI diagnosis type.

### **3.3 METHODS**

#### **3.3.1 Data collection**

Qualitative interviews were conducted from December 2016 to May 2017 and lasted an average of 56 minutes. Several recruitment strategies were utilized to identify and enroll eligible participants including displaying study flyers in outpatient mental health treatment facilities, conducting brief study overview presentations during intensive outpatient treatment program

sessions, and provider referrals. Eligible women were diagnosed with bipolar disorder, major depressive disorder, or schizophrenia/schizoaffective disorder; were between the ages of 18-45; spoke English fluently; and had sexual intercourse within the previous year. Interviews were conducted in a private room at the outpatient location where participants received mental health treatment services and were audiorecorded for accuracy of data.

Women provided information about their current pregnancy intentions in response to the question: “What would it be like if you got pregnant right now?” Contraceptive use was assessed by asking: “Are you currently using any form of contraception/birth control? If yes, what method are you using?” and follow-up questions were asked about why they chose to use (or not use) a method of contraception. In addition, women were asked questions regarding their attitudes about several contraceptive methods, experiences with reproductive coercion, relationship experiences, and pregnancy planning, which can be found in Appendix B. To decrease the risk of discomfort for participants, specific questions regarding substance use and sexual abuse/assault were not asked; however, these topics often came up organically through conversation. At the completion of their study interview, each participant completed a brief demographic questionnaire and received a \$25 gift card to thank them for their time. Prior to starting this study, the protocol received expedited approval by the University of Pittsburgh Human Research Protection Office.

### **3.3.2 Data analysis**

Verbatim transcripts were created for all audiorecorded study interviews; however, all identifiable information, such as names of participants or their friends, family members, or providers, were omitted to ensure confidentiality. Crabtree and Miller’s editing approach<sup>221</sup>

provided the analytic framework from which the qualitative data was assessed. Most codes were developed inductively by reviewing several transcripts and identifying themes and subthemes. In contrast, pregnancy intentions were coded based on the findings of Borrero et al.'s qualitative analysis of low-income women's pregnancy categorizations which included: wanting to avoid pregnancy, desiring pregnancy, ambivalence about pregnancy desires, and lacking intention.<sup>222</sup> To assess current contraceptive use, contraceptive methods being used by participants were divided into three primary categories that are commonly used to describe their pregnancy prevention effectiveness, including: low effectiveness (e.g., condoms, withdrawal), moderate effectiveness (e.g., pill, patch, ring, injection), and high effectiveness (e.g., intrauterine device, contraceptive implant).<sup>190</sup> A sampling of codes pertaining to the findings reported in this manuscript can be found in Appendix C.

During the analysis process, transcripts were organized into segments of text in which unique codes relating to the topics being discussed were applied. Qualitative analysis software (Dedoose)<sup>223</sup> was used to support the coding and organization of study data. To promote intercoder reliability, a portion of the study narratives were coded by two independent analysts. Following this process, the analysts met to discuss their coding decisions and discrepancies, and edit the codebook as needed. Remaining narratives were then coded independently and the two coders then reconvened to discuss coding decisions and talk through any disagreements until a final code was applied to each portion of the text being analyzed.

### 3.4 RESULTS

Twenty-eight interviews were conducted with women with bipolar disorder (n=10), major depressive disorder (n=12), and schizophrenia/schizoaffective disorder (n=6). Participants had an average age of 28.4, 70% were white, all had either a high school diploma or GED, and 65% took at least some college classes. Over 50% of participants had an income of less than \$20,000/year and 68% were covered by public insurance. The majority (82%) were single, 14% were married, 4% were divorced, and 32% were currently living with a male sexual partner. Slightly over half of the study sample (54%) were never pregnant and of the remaining 46% who conceived one or multiple times, only 25% continued a pregnancy to term. The themes discussed below provide information about participants' current pregnancy intentions and contraceptive use, and the factors that influence their use or nonuse of contraception.

#### 3.4.1 Current pregnancy intentions and rationale

All but three women indicated that they wanted to avoid pregnancy. Women wanted to avoid pregnancy for several reasons, including (1) other priorities: *"I think it would be hard to go to school and have a child at the same time."* (ID 106, age 20, major depressive disorder), (2) financial instability: *"I'd want to be good financially and be able to provide my child with, not even luxuries, but basic needs."* (ID 120, age 20, bipolar disorder), and (3) not having a spouse: *"It obviously has to be after marriage. I wouldn't want to start a family without a husband."* (ID 108, age 18, bipolar disorder).

Women also mentioned reasons for wanting to avoid pregnancy that were directly related to their SMI symptoms and experiences. Some felt as though their SMI symptoms may not allow

them to effectively care for a child, as one woman with major depressive disorder and obsessive-compulsive disorder (OCD) stated:

*“I don’t think I can mentally handle having a child, because with the OCD, a lot of the thoughts are about children sometimes. Like harming them...I just don’t think I can go through that again. It’s like, I have habituated to my son...so I don’t have to worry about that at all. But if I had another kid or adopted a baby, all the thoughts would come back and it would be like opening a fresh wound. And then when I get depressed and I don’t want to do anything, I can’t just leave a young child to fend for themselves, so I’d have to force myself. I just don’t think I would be good for it mentally.”* (ID 102, age 40, major depressive disorder)

Other participants mentioned that they were hesitant about having or adamantly did not want to have children because they feared their SMI was hereditary. As two women shared: *“I don’t want to have the potential of even passing on bipolar.”* (ID 105, age 30, bipolar disorder) and *“I don’t want kids. I don’t want to pass on what I have to another living being. I would never want somebody to live the life that I’m living, and I just don’t think I’d be a good mom.”* (ID 123, age 36, major depressive disorder) Finally, other women wanted to be sure that their SMI symptoms were under control prior to conceiving: *“I’m not ready for that...I want to be stable. I want to have been stable for a while and I want to have the blessings of my doctors. I also want to be on meds that are known not to mess up a kid...I would want to be stable on medicine.”* (ID 121, age 26, bipolar disorder)

Of the three women who were not trying to avoid pregnancy, one desired pregnancy, one was ambivalent, and one was lacking any pregnancy intention. The participant who was certain

that she wanted to become pregnant initially stopped using contraception because she was over the age of 35 and a smoker, both factors that contraindicate the use of several hormonal methods of birth control. After considering her current pregnancy intentions, she explained: *“I feel like I’m at a point in my life where I can give a lot to a child if I were to become pregnant. I want a child. That is my angle, to bring life into this world. I would be so happy...I got a lot of wisdom to impart. I know a lot of things.”* (ID 118, age 38, schizophrenia) Pregnancy ambivalence was only felt by one woman who had been trying for almost a year to become pregnant again, however, she had mixed emotions: *“I was thinking of going back on birth control but then whenever it gets to the point of actually doing it, I wimp out. ‘Cause I want a kid and then the other part – and there’s times that I don’t want a kid. Like, right now, I want a kid, but then I know I have to wait ‘cause I have a lot of stuff going on. All that stress can hurt the fetus.”* (ID 128, age 19, bipolar disorder) Finally, one woman did not desire to become pregnant or avoid pregnancy, nor was she ambivalent about having a child. She realized that it was a possibility, but felt that pregnancy was ultimately outside of her control and, hence, lacked any sort of pregnancy intention:

*“I don’t think about it. I just know that being as though me and [partner’s name] are having unprotected sex, I know that, you know, it’s a possibility that one day it could possibly happen...I wouldn’t be mad, I would just be like, ‘Wow, I’m about to have a baby again after all this time. But I really don’t think God has that for me though. I really don’t. It’s been 10 years and we’ve never ever got pregnant.”* (ID 125, age 37, major depressive disorder)

### 3.4.2 Current contraceptive use

Twenty women (71.4%) were using some form of reversible contraception. Of these women, 10 (50%) reported using methods with lower effectiveness rates (e.g., condoms, withdrawal), seven (35%) relied on moderately effective methods (e.g., pill, patch, ring, injection), and three (15%) were using long-acting reversible contraception (LARC) including the intrauterine device (IUD) or contraceptive implant. Two women had a hysterectomy, one woman’s partner had a vasectomy, and two were not using contraception to prevent pregnancy because their current relationships did not pose a pregnancy risk (one participant was a transgendered female, and another was in a relationship with a transgendered male). Table 3.1 provides an overview of contraceptive use for each SMI diagnosis category.

**Table 3.1. Current contraceptive use by SMI diagnosis**

Diagnosis → ↓Method	Bipolar Disorder N (%)	Major Depressive Disorder N (%)	Schizophrenia/Schizoaff ective Disorder N (%)	Total N (%)
None	2 (20.0%)	1 (8.3%)	0 (0.0%)	3 (10.7%)
Low effectiveness	5 (50.0%)	2 (16.7%)	3 (50.0%)	10 (35.7%)
Moderate effectiveness	0 (0.0%)	5 (41.7%)	2 (33,3%)	7 (25.0%)
High effectiveness	2 (20.0%)	1 (8.3%)	0 (0.0%)	3 (10.7%)
Other	1 (10.0%)	3 (25.0%)	1 (16.7%)	5 (17.9%)

Contraceptive use did not always align with women’s pregnancy intentions. Seven of the 10 women relying on condoms and withdrawal were not using these methods consistently which increased their pregnancy risk. Three women were not using any form of contraception. Through conversations with participants, several factors that influenced contraceptive use beyond each woman’s personal pregnancy intentions were identified and separated into the themes described below.



### 3.4.3 Relationship between SMI symptoms and contraceptive use

SMI symptoms were associated with varying contraceptive use/nonuse behaviors among women with bipolar and major depressive disorders. Women with bipolar disorder were more likely to experience symptoms of mania, which led to increased sexual risk-taking and contraceptive nonuse. Women with depression were more concerned about the impact of contraception on depressive symptoms which, at times, impacted method choice and continuation.

Experiences with mania was a common reason for contraceptive nonuse among women with bipolar disorder. Women related occurrences of extreme emotional highs with condom nonuse:

*“I think if I would be more manic then I would be more likely not to use a condom or just, you know, just not think that much about it because I think it makes things faster. One of the symptoms of being a little more manic than normal would be taking dangerous sexual risks...I think your judgement is a little bit impaired when you’re manic.”* (ID 104, age 20, bipolar disorder)

Another woman described the impact of her fluctuating emotions and bipolar symptoms on sexual experiences and risk taking: *“I think when I’m feeling manic, I’m more likely to not use one [a condom]. When I’m depressed, I just don’t have sex.”* (ID 109, age 38, bipolar disorder). This participant recalled having at least 12 past pregnancies, none of which resulted in a live birth.

The perceived or suspected impact of contraception on SMI symptoms also influenced some women’s choice of birth control, especially women with major depressive disorder. One

participant was considering the contraceptive implant, but chose a less effective method after contemplating its potential effect on her symptoms:

*“I was originally thinking of getting the implant, the arm one. But then I talked to my doctor and, like, because it’s an implant, it’s a little harder to take out. And we don’t know if it was going to impact my depression or not. So, the choice of the NuvaRing was [because] it’s localized. So it’s less likely to impact my depression.”* (ID 110, age 20, major depressive disorder).

Another participant stopped using contraception because she thought the birth control pills she was taking increased her depression symptoms: *“When I first got diagnosed, I was like, ‘What if it’s the pills causing me to be depressed?’ So I was like, you know what, let me stop taking these pills...but it didn’t change my depression...It’s obviously not the pills.”* She had since started using birth control pills again, but periodically “takes breaks” and relies only on condoms for several months due to a fear that *“If I keep taking them [birth control pills] all of my life, then I won’t be able to have children or something.”* (ID 106, age 20, major depressive disorder)

#### **3.4.4 Contraceptive knowledge**

Most participants stated that they had at least some knowledge about the various methods of contraception available to them, including the birth control pill, morning after pill, contraceptive injection, condoms, IUD, and contraceptive implant. However, two women, one with schizophrenia and one with schizoaffective disorder, stated that they had very little knowledge about contraceptive methods when they first became sexually active and that this directly

resulted in an unintended pregnancy. One woman feared that she would be permanently hospitalized because of her diagnosis and sought a partner to have sex with so she could “*experience [sex] in case I ended up in the hospital again.*” She continued to describe her first sexual experience: “*Well, I did have a condom and I was trying to put it on...I didn’t really know how to use them, but he tried putting it on and then we tried doing it but then it didn’t work so I tried again, but it still didn’t work so he got fed up with it and just took it off.*” (ID 116, age 32, schizophrenia) Similarly, a participant with schizoaffective disorder explained how little she knew about pregnancy prevention methods prior to her first pregnancy:

*“I had no idea about anything. So when it came to condoms, I had no idea about that...I had no idea that sex got you pregnant...I mean, if I had known that sex without condoms could lead to a baby, I would have made different choices...It was actually after I got pregnant that my ex-husband started becoming abusive. So after I had the baby, I started researching and gaining more knowledge so that I could make sure that I didn’t have another baby.”* (ID 127, age 32, schizoaffective disorder)

The least commonly known contraceptive methods among the study sample included IUDs and contraceptive implants, both forms of LARC. Three women had no knowledge about IUDs and nine women stated that they were unaware that a contraceptive implant was an available method. Variations in contraceptive knowledge by diagnosis category was also evident. The largest proportion of participants with schizophrenia/schizoaffective disorder (three of six women) had never heard of the implant, followed by 30% of bipolar women (n=3), and 35% (n=3) of women with major depression.

### 3.4.5 Attitudes about long acting reversible contraception

Despite the proven effectiveness of LARC in preventing pregnancy, participants were most vocal about their apprehension related to the use of these methods. Fear of pain and/or bodily harm were primary reasons women did or would not choose to have an IUD or implant inserted. Sentiments like the following quote were echoed by several women: *“It scares me because I’m afraid that it will slip and puncture something. That’s why I never went on it, but I had a doctor suggest it to me. I was like, no, because I don’t want to take that risk.”* (ID 102, age 40, major depressive disorder) Another woman questioned whether the IUD could impact her ability to become pregnant in the future: *“Let’s say it was to break or if it was to rip any lining or cause damage to the uterus. Then eventually you want to get pregnant but you can’t because that has caused damage to your uterus and then you’re screwed. So it scares me.”* (ID 127, age 32, schizoaffective disorder)

The perceived intrusiveness of IUDs and implants was mentioned by several women who stated that they did not want a foreign object inside of their uterus. One woman with schizophrenia described her feelings about the IUD:

*“I don’t like things being put up in my vagina because it’s painful. I believe it’s not part of something that should be, like, inside of you if it doesn’t belong there...Condoms are the least intrusive, and the intrauterine devices are, for me, too intrusive. The thought of having to stick something up there and pull it out every once in a while. You can remove it after seven years. Like, seven years with...a foreign object in your body just didn’t strike me as very practical or very safe...Maybe you can contract a disease, maybe the chemicals or whatever they use can affect your body or hormones...I hear all these stories.”* (ID 116, age 32, schizophrenia)

This participant's attitudes about IUDs and her belief that, once inserted, a woman had to continue to rely on the IUD for the full duration of its effective lifespan, contributed to her not considering a longer-term method. Hence, she used only condoms (albeit inconsistently) for pregnancy protection.

Three women with bipolar disorder and two with schizophrenia/schizoaffective disorder (none with major depressive disorder) shared that the concept of having an "implant" was undesirable, leading them to not consider using this form of LARC. Some participants made general statements like: *"I don't think I would want that just because it's an arm implant. I don't think I would want an implant of anything."* (ID 104, age 20, bipolar disorder). One woman with bipolar disorder feared the implant's hormonal makeup and likened it to science fiction:

*"I don't like the word "implant". I don't want anything implanted. The word bothers me – implant – and then also the hormones in there, the hormones that are in it. I would be afraid of just because I had an adverse reaction to it. And then it seems like suck a, like, major thing to do with your body to be like in a month, 'Oh I have to get it out.'...It's like sci-fy-y, like a robot and I don't want anything to do with that."* (ID 109, age 38, bipolar disorder)

One woman with schizoaffective disorder directly linked her thoughts about the contraceptive implant to her SMI symptoms: *"It has to do with my delusions. Um, implants being, like, trackable by the government and that goes way deep. Implants, anything underneath the skin...I wouldn't do."* (ID 127, age 32, schizoaffective disorder)

Of all participants, only three women possessed generally positive attitudes towards IUDs and seven felt similarly about the contraceptive implant. Primary reasons women advocated for

the use of LARC included increased effectiveness: *“I think it would be more effective because not everybody remembers to take the pills.”* (ID 117, age 43, major depressive disorder) and convenience/duration of LARC: *“I was interested in that because for five years, you wouldn’t have to worry about birth control. ‘Cause it was a small incision in your arm and I was getting my Depo shots in my arm anyway. So, what would be a little sliver of something for five years?”* (ID 118, age 38, schizophrenia).

### **3.4.6 Substance use**

Six women revealed that substance use was associated with their sexual and contraceptive behaviors and experiences, including contraceptive nonuse and unintended pregnancy. One participant stated: *“I’ve had unprotected sex in the past. I think a lot of that has to do with the alcoholism and drug use.”* (ID 112, age 29, major depressive disorder) When prompted to describe why she used condoms with some sexual partners and not others, another participant stated: *“It can depend on the influences, is there drugs or alcohol involved?”* (ID 104, age 20, bipolar disorder) A third woman discussed her experiences with substance use that contributed to her experience with unintended pregnancy:

*“I was doing drugs at the time. Um, marijuana, I was drinking, underage drinking, going to parties, having sex with random guys and, like, it started affecting me. I was getting sick, I wasn’t eating right. So when I went to the doctor, they’re like, ‘You’re pregnant,’ and I was like, ‘So, what do I do?’”* (ID 128, age 19, bipolar disorder)

The sexual risk-taking behaviors associated with substance use resulted in some participants being vulnerable to unintended pregnancy and sexually transmitted infections.

### 3.4.7 Sexual violence and abuse

Overall, 18 of 28 study participants (64%) disclosed that they had experienced some form of intimate partner violence (including reproductive coercion), childhood sexual abuse, or sexual assault/rape and some women shared information about their experiences with multiple forms of abuse in their lifetime. Women with major depressive disorder and bipolar disorder experienced similar rates of abuse and assault (58% and 50%, respectively); however, 100% (n=6) of participants with schizophrenia or schizoaffective disorder experienced physical and/or sexual violence.

#### *Intimate partner violence and reproductive coercion*

Eight women disclosed being physically or emotionally abused by an intimate partner and ten described experiences with reproductive coercion, specifically contraceptive sabotage (e.g., condom refusal, flushing birth control pills) and pregnancy pressure (e.g., pressuring a woman to become pregnant when she does not want to).<sup>140,144,145</sup> Several women described experiences with condom refusal, including: *“I had met some guy in a bar...and I had brought a condom. And he was like, ‘No, I am not going to use this.’”* (ID 102, age 40, major depressive disorder) and *“When I got pregnant, he refused to use a condom. He just said, ‘Oh don’t worry about it, don’t use it.’ And he threw it to the ground.”* (ID 116, age 32, schizophrenia) Experiences with condom refusal ranged from male partners preferring the feeling of sexual intercourse without a condom to men who were actively promoting pregnancy.

Six women experienced pressure from sexual partners to become pregnant with one woman obtaining a protection from abuse order because of her partner’s pregnancy insistence and anger: *“He said, ‘Oh I want kids.’ And part of that anger, I think, is because I kept saying no*

*to him about kids...He wouldn't accept that. He was getting mad.*" (ID 115, age 29, schizophrenia) Three women of the 10 who experienced any form of reproductive coercion became pregnant because of their partner's pregnancy pressure or condom refusal. One woman with schizoaffective disorder became pregnant at age 16 by her 21-year-old partner: *"He did it on purpose...Because of his level of love or care for me and wanting to start a family and be with me...He actually proposed or wanted to propose and become engaged and get married and start a family."* She continued to explain that her partner's coercive behaviors did not result in one, but three pregnancies: *"He did not want me to be on it [birth control] because his goal was to impregnate me. And that's when I got pregnant twice the following year at the age of 17."* (ID 103, age 25, schizoaffective disorder).

Another participant utilized a risk-reduction approach to avoid becoming pregnant by her abusive former husband:

*"My ex-husband was abusive and he wanted me to get pregnant again. And so I ran to the clinic one day and I knew he was coming right after me and I just ran in and told them my husband's abusive and I need something right now to make sure I don't get pregnant and they gave me the Depo shot. Because, it was like, he would never know. He would find the pills, you know, that's why I ended up getting it [contraceptive injection]."*

(ID 127, age 32, schizoaffective disorder)

Her choice to use a hidden method of contraception allowed her to remain protected from pregnancy as she determined a way to escape her abusive relationship.

The entire sample (n=6) of women with schizophrenia/schizoaffective disorder were included in the ten total women who disclosed personal experiences with pregnancy pressure



and/or birth control sabotage. Of these six women, three experienced an unintended pregnancy resulting from reproductive coercion. No participants with bipolar disorder or major depressive disorder attributed an unintended pregnancy to coercive behaviors committed by a sexual partner.

### ***Childhood sexual abuse and sexual assault***

Childhood sexual abuse and sexual assault/rape were common among study participants. Four women (two with bipolar disorder, one with major depressive disorder, and one with schizoaffective disorder) revealed experiences of sexual abuse during their childhood or teenage years. One woman described sexual experiences forced by her brother: *“I was raped by my brother. Um, I was 15 when he raped me. He would tie me down to the bed, tell me to be quiet and if I ever told anyone he would hurt me. And when I got pregnant with his kid, I told my mom...She didn’t want to believe me and then whenever I went and got a DNA test done, she kicked me out and not him.”* (ID 128, age 19, bipolar disorder) Another participant was unable to continue using the vaginal ring for contraception because of her childhood sexual abuse experiences: *“I did try the NuvaRing for one month and I didn’t like it cause...like, I have PTSD from early age trauma...The NuvaRing is triggering.”* (ID 109, age 38, bipolar disorder)

Five additional participants described experiences of sexual assault and rape with one woman obtaining emergency contraception to prevent pregnancy after her non-consensual sexual encounter: *“This happened last October and it was a sexual assault. I didn’t want to go to the hospital or anything right away and I didn’t want to have to deal with any consequences, so I used that [emergency contraception] and that was almost an immediate thought that I needed to get that.”* (ID 111, age 21, major depressive disorder). Another participant who was repeatedly

raped by her husband stated: *“He wanted sex and I didn’t. We fooled around a little bit, but I couldn’t do it ‘cause he started getting angry, um, frustrated with himself...And he basically pulled me open with his fingers and held the pillow down. I mean, it wasn’t totally over my face...He cut me with his fingers and he just did his job.”* (ID 117, age 43, major depressive disorder) This participant stated that she did not consider that she was being raped by her husband until she talked about these experiences with her therapist who confirmed that her husband was, in fact, sexually abusing her.

These unwanted and often violent sexual experiences faced by participants increased their risk for unintended pregnancy and sexually transmitted infections, and sometimes influenced the method of contraception that they used or discontinued.

### **3.5 DISCUSSION**

The desire to avoid a pregnancy or become pregnant does not always align with a woman’s use of effective contraception or successful pregnancy planning.<sup>222</sup> Most study participants wanted to avoid pregnancy; however, several reported relying on contraceptive methods with lower effectiveness, were using these methods inconsistently, or were not using any form of contraception. These qualitative interviews illuminated several important factors that affected the contraceptive use and family planning experiences of women with SMI.

LARC is highly effective at preventing unintended pregnancy.<sup>224</sup> In fact, IUDs and contraceptive implants can have a lower failure rate than tubal sterilization and vasectomy.<sup>224</sup> The majority of the study sample wanted to avoid pregnancy while dealing with other life events such as finishing their education, finding a partner, becoming financially stable, and achieving

optimal SMI symptom management. Existing literature supports these,<sup>225–227</sup> and other reasons for delayed childbearing including desire for smaller family sizes.<sup>226</sup> Thus, it seems logical that LARC may be the best contraceptive option for many women who wish to delay or avoid childbearing. However, our findings show that the many participants held negative attitudes towards LARC, such as fear of pain during insertion, adverse reactions to concept of having an implant, and anxiety about the potential for bodily damage. Further, many women’s attitudes about LARC were generated from stories that they had heard from friends and relatives, rather than from their healthcare providers. These findings support research conducted with women without SMI who also received much of their information about LARC from non-professionals<sup>228</sup> and whose views of IUDs and implants were largely negative due to fear of or discomfort with the insertion procedure, side effects, and/or perceived risks to fertility.<sup>228–231</sup> Ensuring that women have evidence-based and comprehensive information about these methods may help them overcome some of their negative beliefs, potentially increasing LARC acceptability.

Over a third of participants (36%) in this study had a sexual partner who tried to pressure them to become pregnant or in some way refused to use or sabotaged contraception to promote pregnancy. Twenty-five percent of these women experienced pregnancy pressure and 21% experienced birth control sabotage (some women experienced both). Comparatively, Miller’s 2010 study of a sample of women ages 16-29 from the general population receiving services in California family planning clinics found that 19% and 15% of study participants experienced pregnancy pressure and birth control sabotage, respectively. Although our sample is small, our findings reveal a 6% increased prevalence of both forms of reproductive coercion among our study sample of women with SMI.

Further, all six women with schizophrenia/schizoaffective disorder in the study sample described personal experiences with reproductive coercion and, of the three women that became pregnant as a result of reproductive coercion, all fell into the same diagnosis category. Although these findings may suggest that women with schizophrenia/schizoaffective disorder may be particularly vulnerable to coercive experiences, it should be noted that five of the six participants with these disorders were women of color, a population that has also been shown to be at increased risk for reproductive coercion.<sup>145,232</sup> Two known studies provide data about the prevalence of and experiences with reproductive coercion by race/ethnicity. Miller's study referenced above found that African American women were two times more likely to experience pregnancy coercion than white women, and four times more likely to experience birth control sabotage.<sup>232</sup> In a qualitative study assessing risk factors for unintended pregnancy among 66 low-income African American and white women, 25 participants described experiences with reproductive coercion (53% of African American participants, 20% of white participants), and more African American disclosed experiencing an unintended pregnancy resulting from reproductive coercion.<sup>233</sup> Given the array of factors that likely contribute to male pregnancy control and contraceptive sabotage, it is difficult to discern whether SMI diagnosis, race, or a combination of these and/or other variables contributed to increased odds of experiencing reproductive coercion among participants with schizophrenia/schizoaffective disorder. Additional population-based studies are needed to explore these associations with increased accuracy.

Many women disclosed heartbreaking experiences of intimate partner violence, sexual abuse, assault, and rape. In addition to the lasting trauma that can often result from sexual violence, these experiences contributed to an increased risk of, or a personal experience with,

unintended pregnancy among study participants. This corresponds closely with existing literature which shows that women who experience abuse also experience increased rates of negative reproductive outcomes including forced sex, unintended pregnancy, and delayed prenatal care.<sup>133–138</sup> Several review articles describing experiences of intimate partner violence, domestic violence, and sexual abuse among women with SMI reveal staggering rates ranging from 21-76%.<sup>126,128,129</sup> Disclosing sexual abuse or IPV may be a challenge for women with serious SMI symptoms who may be unable to translate their experiences into a form of abuse and, therefore, it is likely that rates remain underreported.<sup>126</sup>

Screening women with SMI for IPV and sexual abuse is critically important to gauge if they may be at increased risk for adverse reproductive experiences. However, a qualitative study conducted by Rose et al. found that mental health clinicians cite inadequate training to support effective screening and fear of re-traumatization as contributors to avoidance of sexual abuse screening.<sup>234</sup> A psychiatrist interviewed for Rose's study also provided the following narrative, questioning the role of mental health providers in IPV screening: *"It's not on my list of things I have to cover...I suppose my first response to that is, should we be addressing this? Because I think so many things are coming under the role of psychiatry to sort out when actually they are not mental health problems."*<sup>234</sup> Existing research indicates, however, that victimization can increase mental health symptom severity and suicidal ideation,<sup>136,235,236</sup> making mental health treatment settings ideal locations for IPV assessment. Further investigation is needed to determine how to train mental health treatment staff to most effectively detect IPV in a manner that minimizes patient discomfort when disclosing this sensitive information.

Several limitations should be considered, as they may impact study findings. First, while our data show that women with schizophrenia and schizoaffective disorder may have less

knowledge about LARC and may be more vulnerable to reproductive coercion, the study sample only included six women with these diagnoses and, hence, it is unlikely that thematic saturation was achieved. Additional interviews with participants with schizophrenia/schizoaffective disorder may have resulted in different conclusions. Next, other factors such as race, education, and poverty status may contribute to women's contraceptive use and family planning experiences in combination with SMI diagnosis or in lieu of SMI diagnosis; however, the sample was not large enough to stratify by each of these variables to determine how they may correlate with our outcomes of interest. More research is needed to understand how these, and other social-structural factors such as stigma, are associated with the reproductive experiences of women with SMI. Finally, all participant data, including SMI diagnosis, was collected via self-report and was not compared with medical record information. Given this, it is possible that some women were included in the incorrect diagnosis category. However, it should be noted that interviewees displayed a high degree of awareness of their mental health diagnoses as well the medications that they were currently using or had previously used.

### **3.6 CONCLUSION**

This is the first known study to obtain in-depth participant narratives about the factors that impact the contraceptive use of women with SMI. Findings support existing research indicating that contraceptive use/nonuse is not always something that a woman can control and that pregnancy intentions may not align with contraceptive use. Symptoms of serious mental illness, along with contraceptive knowledge and substance use, can impact the ability of women with SMI to effectively use contraception. Further, reproductive coercion, sexual abuse, and intimate

partner violence are significant issues among this population and may increase their risk for experiencing unintended pregnancy. While comprehensive contraceptive counseling is critical for women with SMI, clinicians should assess for factors beyond contraceptive choice that can influence a woman's ability to avoid unintended pregnancy.

## **4.0 A QUALITATIVE EXPLORATION OF THE CONTRACEPTIVE AND FAMILY PLANNING COUNSELING PRIORITIES AND PREFERENCES OF WOMEN WITH SERIOUS MENTAL ILLNESS**

### **4.1 ABSTRACT**

**Background:** Women with SMI have lower rates of contraceptive use and adherence and experience disproportionately high rates of unintended pregnancy. Patient-centered services tailored to meet the fertility-related needs of women with SMI are critical; however, no known studies provide information about what contraceptive and family planning topics are most important to this population. To address this need, qualitative interviews were conducted with women with SMI to understand their contraceptive use and family planning counseling preferences and priorities.

**Methods:** Semi-structured interviews were conducted with women with major depression (n=12), bipolar disorder (n=10), and schizophrenia/schizoaffective disorder (n=6). Women were recruited from outpatient behavioral health treatment facilities, were between the ages of 18-45, and were sexually active. Using Crabtree and Miller's editing approach, two qualitative coders analyzed participant narratives to identify major themes and subthemes.

**Results:** Women revealed several topics that were unique to women with SMI including the potential impact of contraception on SMI symptoms, the relationship between SMI symptoms



and sexual risk-taking behaviors, medication interactions and management, SMI symptom exacerbations during and after pregnancy, and the importance of provider sensitivity when discussing family planning. Several topics of importance unrelated to living with SMI were also described. Women felt comfortable talking with their primary and reproductive care providers about these topics and most were willing to discuss these concepts with their behavioral health providers.

**Conclusion:** Women with SMI have unique priorities and preferences that must be taken into consideration to provide patient-centered contraceptive and family planning counseling services to a population that is vulnerable to poorer reproductive outcomes.

## 4.2 BACKGROUND

Sexual relationships, pregnancy, and motherhood are common experiences for women living with serious mental illness (SMI).<sup>9-17,55,64</sup> Nearly three million women of reproductive age in the United States are currently living with one or more SMI (e.g., schizophrenia, schizoaffective disorder, bipolar disorder, major depression).<sup>2,3</sup> Between 65-75% of women with SMI engage in sexual intercourse in a given year,<sup>9,10</sup> they typically have a greater number of lifetime sexual partners compared to women without SMI,<sup>18,19</sup> and the rate of childbearing among women with SMI is similar to that of the general population.<sup>15,17</sup> Women with SMI have lower rates of contraceptive use and adherence<sup>6,26,53,63-66</sup> and several studies have found that they experience disproportionately high rates of unintended pregnancy<sup>6,10,26,53,55,217</sup> putting them at increased risk for negative physical health and psychosocial outcomes that may result from a pregnancy that is mistimed or unwanted.<sup>37-43</sup>

Patient-centered contraceptive and family planning services are necessary to support informed decision making among women with SMI so they can most effectively achieve their reproductive goals and maintain their reproductive autonomy. Guidelines have been developed to support pregnancy decision making of women with SMI based on their values, knowledge, symptom control, and decision-making capacity.<sup>90</sup> Additional guidelines suggest providing repeat exposure to contraceptive options and efficacy information,<sup>86</sup> modifying medication regimens to reduce teratogenic risks,<sup>5,86,93,94</sup> and integrating family planning counseling into behavioral health treatment.<sup>5,89</sup> Despite the promise of these recommendations, little evidence exists indicating that input from women with SMI informed their development.

While many women with SMI receive or are interested in receiving family planning and contraceptive consultation,<sup>76,77,80</sup> their interactions and experiences with providers and the healthcare system remain inadequate.<sup>29,76-79</sup> Qualitative and quantitative studies reveal that women with SMI are given insufficient information about the risks and benefits of psychiatric medication usage during pregnancy,<sup>76</sup> they desire more information about available contraceptive methods,<sup>78,81,82</sup> and family planning topics outside of the context of contraception are not always discussed.<sup>77</sup> Further, there are no known studies that provide in-depth information about where women with SMI prefer to receive family planning counseling or their perceptions of the information that would be most useful and meaningful to them.

To address this need, qualitative in-depth interviews were conducted with women of child-bearing age with bipolar disorder, major depressive disorder, and schizophrenia/schizoaffective disorder to understand their family planning counseling priorities and preferences. Additional analysis was conducted to understand if and/or how these priorities and preferences differed by SMI diagnosis type.

## 4.3 METHODS

### 4.3.1 Data collection

Participants were recruited between December 2016 and May 2017 via several mechanisms including flyers in outpatient behavioral health treatment clinics, provider referral, and study information sessions during outpatient group therapy classes. Women were eligible if they were diagnosed with bipolar disorder, major depressive disorder, or schizophrenia/schizoaffective disorder; were between the ages of 18-45; spoke fluent English; and had sex with a male partner in the previous 12 months. Interviews were audiorecorded and conducted in a private room at two outpatient behavioral health facilities in Pittsburgh, Pennsylvania where most participants received psychiatric treatment.

During the interviews, women were asked questions about the information that they would find most helpful/important related to contraception, family planning, and sexual relationships. They were prompted for feedback about special considerations that providers should account for when counseling women with SMI about these topics. In addition, information was collected regarding the types of providers they have spoken with about reproductive health and contraception, the provider(s) that they would prefer to receive this information from, and their willingness to receive similar information from a behavioral health clinician. After the study interviews, participants completed a demographic questionnaire and were given a \$25 gift card to thank them for their time. This study was approved via expedited review by the University of Pittsburgh Human Research Protection Office.

### **4.3.2 Data analysis**

Interviews were audiorecorded and transcribed verbatim, and all identifiable information was omitted from the transcripts to maintain confidentiality. Interviews were analyzed using Crabtree and Miller's editing approach. This approach offers an inductive analytic technique to organize and interpret meaningful segments of data.<sup>221</sup> All transcripts were thoroughly reviewed and codes pertaining to unique topic areas were generated to form a codebook. Codebook development involved an iterative process in which a primary and secondary analyst reviewed a subset of transcripts and worked together to give each code a unique name/identifier and definition.

Study transcripts were loaded into Dedoose,<sup>223</sup> a qualitative and mixed methods analysis and organizational software, to support the analytic process. Two analysts independently coded a subset of narratives, met to compare their coding, and discussed inconsistencies. Following this, all remaining narratives were coded independently. Cohen's Kappa scores were calculated at the completion of analysis to determine the degree of inter-coder reliability.<sup>237</sup> Central themes and subthemes were identified during the coding process and provided important insights related to the family planning priorities and preferences of women with SMI.

## **4.4 RESULTS**

A total of 28 interviews, averaging 56 minutes in length, were conducted with women with bipolar disorder (n=10), major depressive disorder (n=12), and schizophrenia/schizoaffective disorder (n=6). The mean participant age was 28.4 years and the majority (70%) was white. Over

half of participants had an annual household income of <\$20,000 and 68% were publicly insured (i.e., Medicaid or dual Medicare/Medicaid). All had a high school diploma/GED and most (65%) had at least some college. Women identified as single (82%), married (14%), or divorced (4%) and nine women were currently cohabitating with a male sexual partner. Seventy-five percent had no children and 54% were never pregnant. Of the 21 women without children, six (28.6%) became pregnant one or more times, but the pregnancies ended in either abortion or miscarriage.

Two primary categories related to family planning counseling priorities were generated by the analysts based on women responses to the questions included in Appendix D: those that were specific to the unique needs and experiences of women with SMI and those that were not specific to living with a serious mental illness. Within each of these categories, several subthemes and corresponding narratives were identified providing nuanced details of women's contraceptive use and family planning concerns. Intercoder reliability was high, with an overall kappa score of 0.95 indicating near perfect agreement prior to adjudication of coding discrepancies.<sup>237</sup> Codes from which kappa scores were generated can be found in Appendix E.

#### **4.4.1 SMI-specific contraceptive and family planning counseling priorities**

The themes below describe contraceptive and family planning counseling topics that are specific to women living with a serious mental illness.

##### ***Impact of contraception on SMI symptoms***

Women expressed interest in obtaining information about the potential impact of contraception and/or its hormonal makeup on mental health symptoms. The majority of participants were diagnosed with a mood disorder (i.e., major depressive disorder or bipolar disorder) so, unsurprisingly, mood changes resulting from contraception was a top concern:

*“If you’re at a clinic that only treats mood disorders – special considerations. You know, like, this may affect your mood. Like, for a copper IUD, this does not affect your mood and it does not act [sic] with any medications. So, someone could be like, ‘Oh wow, that’s the one for me.’”* (ID 105, age 30, bipolar disorder)

Increased depressive symptoms and suicidal thoughts resulting from the chemical properties of contraceptives were both mentioned as potential issues, and one participant reported discontinuing contraception because of her exacerbated depression that she attributed to its use: *“The hormones were something that made me decide not to be on birth control...It took me a really long time to pinpoint that I was having these moments of depression, and that maybe some of them weren’t all me and some of them were the hormones that I was on..”* (ID 113, age 23, major depressive disorder)

### ***Relationship between SMI symptoms and sexual behaviors***

The impact of SMI symptoms on sexual behaviors was the only topic in which several differences existed by SMI diagnosis type. Sex was viewed by some women with major depressive disorder as a coping mechanism during symptom exacerbations. Although sex did not provide long-term relief from depressive symptoms, some women were able to enjoy it in the moment but often regretted it after the fact. One woman with severe depression viewed sex as a punishment, not believing that she was worthy enough to have her own positive sexual experiences. Women with major depressive disorder and bipolar disorder identified impulsivity as an SMI symptom that led to sexual behaviors that they might otherwise avoid. Women with depression stated that a lack of self-worth may lead them to have sex impulsively with men who

they would not typically engage in intercourse, such as an ex-boyfriend or a one-night stand. Women with bipolar disorder revealed that periods of impulsivity were more likely to lead to sex with multiple individuals in a short period of time and that mania could falsely lead a person to believe she is ready to have a child. One women with a diagnosis of schizophrenia reflected on her experiences experience with pregnancy and subsequent abortion, explaining that her illness prevented her from recognizing the potential consequences of having unprotected sexual intercourse. Table 4.1 provides exemplar quotes highlighting the different (and similar in the case of impulsivity and sexual decision making) ways in which SMI symptoms impacted sexual and contraceptive behaviors by diagnostic category.

**Table 4.1. Impact of SMI symptoms and diagnoses on sexual behaviors and contraceptive use**

<b>Bipolar Disorder</b>	<b>Major Depressive Disorder</b>	<b>Schizophrenia</b>
<b><i>Bipolar depression and impact on contraceptive use</i></b>	<b><i>Sex as a coping mechanism</i></b>	<b><i>Inability to recognize potential consequences of sexual activity</i></b>
<i>“Definitely knowing if you’re going to remember to take it. Because I know when I’m depressed, I don’t remember to take my meds without my mom...If you wanna have a very, very, pretty much firm assurance that you’re not going to have a child [you] should decide which form of birth control you want...’Cause, I mean, know you can mess up pretty easily. This is just from my personal experience.” (ID 114, age 19)</i>	<i>“I think it becomes both positive and negative for how you handle your depression. And again, becomes a coping mechanism. I’m sure it [sex] can provide people help, too. But at the same time, I think that it’s really easy for it to become a coping mechanism.” (ID 113, age 23)</i>	<i>“I wasn’t in...what’s the word? In the mode to ask questions – more questions about, ‘What’s going on with my illness?’ How’s this going to affect my relationships in the future?’ Like, ‘How’s this going to affect me getting pregnant or not pregnant if I’m with somebody, you know, sexually?’ Like, I didn’t think about that at all. I think my illness kind of numbed me and I was only thinking certain – one thing at a time kind of thing and it just backfired on me a little bit because I...that means I wasn’t thinking straight. So, I made a mistake, you know.” (ID 116, age 32)</i>
<b><i>Mania and pregnancy decision making</i></b>	<b><i>Sex as a punishment</i></b>	
<i>“Then with bipolar disorder, having those extreme highs where it’s like, ‘I can have a kid right now!’ because I can handle everything in the world...but I’m actually handling everything really poorly. And I need the people outside of myself to be, like, a mirror... ‘This is actually what it looks like, what you’re doing.’” (ID 109, age 38)</i>	<i>“I feel like there’s women out there who are like me. I mean, who feel that sex is a punishment. And maybe to give them counseling to know that sex should be about two people, not one. And that they might purposefully have sex to be abused. And to know that sex is a right, not a punishment. ‘Cause I’ve been through it.” (ID 117, age 43)</i>	
<b><i>Impulsivity and sexual decision making</i></b>	<b><i>Impulsivity and sexual decision making</i></b>	
<i>“There is an impulsiveness to take into account. That a person can go eight weeks without having sex but have one day where they’re impulsive and sleep with four people.” (ID 120, age 20)</i>	<i>“I think that they [health care professionals] should be aware of the potentially impulsive decisions that people with depression make. So they should be, like, extra careful when prescribing contraception ...’Cause like I mentioned, the drunk hookup there. I just felt like, ‘Oh a guy likes me!’, you know, ‘I’m just going to go for it.’” (ID 119, age 22)</i>	

### ***Medication interactions and management***

Contraindications related to concurrent SMI medication and contraceptive use were a topic of concern for some women. One participant reported that her contraceptive ring (NuvaRing) interacted with her Tegretol, a drug used to treat acute mania, leading to breakthrough bleeding. Another questioned whether the antiepileptics she was taking to treat her bipolar disorder would make her birth control less effective. Women with SMI desired more comprehensive information about potential medication interactions during the contraceptive counseling process to avoid potential unintended pregnancy: *“I mean, they should give them all the information that they can give them and let them know if the medication has interactions with other medications.”* (ID 126, age 45, bipolar disorder)

Knowing which SMI medications were safe for a developing fetus and which required discontinuation during the prenatal period was viewed as critical information by participants. Several women provided similar statements regarding understanding the risks and benefits of SMI medication use during pregnancy, including: *“How your medications can affect the baby...what are the risks...what are the benefits – how can you go off?”* (ID 105, age 30, bipolar disorder) Another participant expressed the importance of ensuring that medication decisions take the patient’s best interests into account, despite the potential risks:

*“Let them know there’s no rock-solid evidence, but I think it should be told to them that it’s in their best interest to stay on the medication. I know they’re not supposed to do that because it’s really up to you as the patient, but I really think they should stress that... ‘Cause your health affects your baby’s health’ ... Cause if I’m not ok, he’s not going to be ok.”* (ID 124, age 34, schizoaffective disorder)



Similarly, some women recognized that they may not immediately be able to begin their pre-pregnancy medication regimen after the birth of a child, particularly if a woman is breastfeeding: *“You can’t take certain medications while you’re pregnant, even when you’re breastfeeding you can’t take certain medications, you know? And I think for somebody that’s been on medication for half their life like me – you need to know if that’s really going to fuck things up for a while.”* (ID 123, age 36, major depressive disorder)

### ***SMI symptoms pre-pregnancy, prenatal, and post-partum***

Control of SMI symptoms at any point during the child bearing/rearing process was viewed as important, with some women questioning whether they would have increased vulnerability to post-partum depression given their current SMI diagnosis: *“How likely are you to have post-partum or be depressed [during] your pregnancy, you’ve had depression before and, like, how that impacts your pregnancy and your kid and things like that.”* (ID 110, age 20, major depressive disorder) Others were more concerned about the hormonal fluctuations that are common throughout pregnancy and hoped that health care providers would explain whether hormones were likely to cause serious mood changes. One participant wanted providers to help women recognize the more serious mental health symptoms that may occur during/after pregnancy because of her personal experiences that led to a psychiatric hospitalization:

*“I’d like to know more about the mental illness aspect of pregnancy...It’s not going to happen for everyone, but it could happen. So that way they’re not thinking, ‘Oh my gosh I want to harm my baby – there’s something wrong with me.’ It would be helpful to know hey, if you have thoughts where you don’t want to even get up or...you don’t want to even*

*get out of bed to live, this isn't you being a bad mom. This is, like, mental health issues."*

(ID 102, age 40, major depressive disorder)

Finally, some participants desired information about coping mechanisms that could help them deal with SMI symptoms during and after pregnancy. A woman with bipolar disorder described the necessity to cope with symptoms because, *"When you have a kid...the world won't stop because you feel depressed...or because you're elevated and you've been up for two nights. You have to still get up and take care of your kid."* (ID 114, age 19, bipolar disorder)

### ***Provider sensitivity***

Women with SMI highlighted the need for increased provider sensitivity when delivering family planning counseling to ensure that patient autonomy was maintained and judgement was avoided. One participant felt as though her psychiatrist was placing the onus of contraceptive responsibility on women rather than men:

*"When he asked me if I was on birth control, he said something like, 'I suggest to all my female patients that they be on birth control,' and I was like, just thinking to myself, 'that's a really shitty thing to say...I guess it kind of goes back to why – why all your female patients? Like, talk to your male patients, too, you know?'"* (ID 123, age 36, major depressive disorder)

Others felt as though their doctors were telling them what family planning decisions they should make, rather than engaging in a conversation that allowed women to be a part of these decisions:

*“Jumping into the conversation like, ‘Oh, you need birth control ‘cause you’re too young’ or ‘You have all these mental health issues, it’s not going to be healthy for the baby.’ Instead of assuming, like, ease into the conversation and ask them – ask them their opinion on what they want...I’ve always been told, ‘Oh you can’t do this, you can’t do that.’”* (ID 120, age 20, bipolar disorder)

While participants desired the opportunity to make their own family planning decisions with supportive providers, they did acknowledge that reproductive health-related topics may be uncomfortable for some women, particularly those with a history of abuse: *“I don’t like when they bring it up. It makes me uncomfortable. And I know they’re doing it for a reason, but...it can be tough on certain people...I was never comfortable talking about it and with the shame involved, it’s a sensitive subject.”* (ID 123, age 36, major depressive disorder) Given this, easing into the subject was suggested by some to ensure that the conversation is *“as comfortable as possible.”* (ID 127, age 32, schizoaffective disorder)

#### **4.4.2 Non SMI-specific contraceptive and family planning counseling priorities**

Women with SMI discussed several family planning topics of interest that did not have a direct relationship to an element of living with SMI, but that they believed should be discussed when being counseled about family planning, contraceptive use, and reproductive health.

##### ***Contraceptive options, effectiveness, and logistics***

Many women reflected on the importance of being provided information regarding all methods of contraception with two women stating, *“When I first started using birth control, I would have*

*liked them to have all these other options...When I first started using the birth control pill, all I ever heard of was the pill...and like IUDs – I didn't know there were things in between"* (ID 110, age, 20, major depressive disorder) and *"All the different methods out there. You know, not just the pill, not just the Depo, they have all different kind of birth control now... Just give enough information to know about it so they can at least...make their own choice of what they want to take."* (ID 126, age 45, bipolar disorder) Inadequate information about the array of methods such as long-acting reversible contraception, shorter-term methods, and hormone free methods impacted participants' ability to make fully informed contraceptive decisions.

Similarly, participants discussed the importance of awareness regarding contraceptive method effectiveness: *"Definitely the percentage that is it effective because, like you said, even though these ones might be more aggressive...at least you have the guarantee that it's almost always going to work. Whereas, like, taking birth control [pills] might be like 87%."* (ID 108, age 18, bipolar disorder) A women with schizophrenia also expressed questions about contraceptive effectiveness: *"Does birth control wear off a girl?"* (ID 115, age 29, schizophrenia) Women referred to method effectiveness using percentages or terms like "reliability" and "success rate".

Contraceptive logistics, including information about the chemicals that make up the method, how often it needs to be taken or replaced, and cost were all mentioned by several participants as method-related concerns. Regarding the contraceptive injection Depo Provera, one participant stated, *"I would have liked to receive, like, what is in the Depo? Like, what exactly is in it? The chemicals?"* (ID 124, age 34, schizoaffective disorder). Another woman with bipolar disorder desired method-specific information including:

*“Knowing the length of time each form of birth control lasts is very helpful. And if I need to take it every day or change it once a week or once every three months or whatever, that’s helpful to me because it helps me know, like, will I be able to do that? Will I be able to keep up with this? The amount of pain that the IUD would actually cause?”* (ID 114, age 19, bipolar disorder)

When asked directly, most participants expressed that they were given adequate information about contraception from their providers: *“My gynecologist handed me a packet that explained everything”* (ID 124, age 34, schizoaffective disorder) or they obtained it from other sources: *“I have access to the internet. I can do my own research. And if I had questions, I could always talk to my doctor.”* (ID 121, age 26, bipolar disorder) Despite this, many expressed questions and/or concerns about the methods available to them over the course of the interviews indicating that, perhaps, they truly did not have all the information they desired. For example, the ways in which SMI medications may interact with contraception, how contraception may impact SMI symptoms, and personal lack of knowledge about existing contraceptive options were common concerns among participants. This suggests that, despite the acknowledgement of many women that they have sufficient contraceptive information, gaps in knowledge about these topics remain.

### ***Contraceptive risks and side effects***

Nearly half of participants mentioned that they worried about the potential side effects of birth control and their hormonal ingredients. Women expressed a desire to understand the impact of contraception on fertility: *“How it will affect your ability to have children in the future,*

*depending on how long you take it?” (ID 124, age 34, schizoaffective disorder), the relationship between contraceptive methods and cancer: “With the birth control, mainly I was worried about cancer. Because I have a strong history with cancer in my family” (ID 117, age, 43, major depressive disorder), and signs of an allergic reaction: “If there is a possibility of side effects I would like to know what they are. So, that I know what to look out for or if I am going to have an allergic reaction, stuff like that.” (ID 102, age 40, major depressive disorder)*

One participant expressed that experiencing negative contraceptive side effects may lead to method discontinuation, potentially increasing the risk of method non-use and subsequent unintended pregnancy: *“Your hormones can be affected. I do remember, like, side effects when I first started taking it. I had a horrible migraine for three months straight...But a lot of people give up, you know? Like, ‘Oh, I am not taking this.’” (ID 107, age 36, major depressive disorder)* Bodily damage related to long-term use was also a concern, *“The risks that it can have on your body. Like, if you take these hormones or take this birth control, what is it going to do for your body and is it gonna damage some part of it if you do it too long?” (ID 108, age 18, bipolar disorder)*

### ***Planning and maintaining a healthy pregnancy***

Increasing awareness of pregnancy planning and healthy prenatal behaviors were described by many participants as critical components of family planning counseling. One women inquired about alcohol use during pregnancy: *“Can you drink when you’re pregnant for, like, a couple days? Is that ok? Is a week bad for the baby?” (ID 122, age 24, bipolar disorder)* Maintaining a healthy pregnancy through proper nutrition and exercise was a top family planning priority for many women: *“You gotta eat right and you gotta exercise because, you know, carrying a baby is*

*hard work...You gotta take care of this house that that baby is gonna be living in for them nine months.*" (ID 125, age 37, major depressive disorder)

Despite the expressed importance of this topic, each of the 13 women who became pregnant or had a child prior to the study interview stated that they never discussed planning and/or maintaining a healthy pregnancy with a provider until after conception. As one woman revealed: *"Planning a pregnancy, um, I thought about that...But I didn't think about going for more information because I wasn't at that point in my life yet."* (ID 116, age 32, schizophrenia) Another participant who experienced a teenage pregnancy while also using drugs and alcohol and smoking, did not receive any formal information about pregnancy planning until the second trimester when she finally sought prenatal care. She stated: *"I was scared to tell my mom that I was pregnant, so I waited as long as I could...Like, after four months."* (ID 128, age 19, bipolar disorder) She eventually decreased the number of cigarettes she smoked and the amount of alcohol she consumed after speaking with her obstetrician about the potential health consequences that could result from these behaviors. No participants stated that they received any form of preconception counseling about taking prenatal vitamins, the importance of exercise and healthy eating, or the risks of smoking, alcohol, and drugs on a fetus.

### ***Sexual consent and relationship safety***

Several participants believed that topics related to sexual consent and relationship safety were rarely discussed during patient-provider interactions. Being able to identify an abusive or unsafe relationship was a priority for several participants. One woman stated, *"I wish there was more information on what- it seems like it's getting better- but what an abusive relationship looks like. 'Cause I feel like a lot of people think that fighting is normal. It's not. It's not how it's supposed*

to be.” (ID 109, age 38, bipolar disorder) Another participant felt as though her counseling experience at Planned Parenthood thoroughly covered relationship red flags, but that this was not the norm with most providers:

*“I think at Planned Parenthood they definitely told me about, you know, ‘Watch out for these things in a relationship. If things aren’t going well, call these numbers if you need to.’ That was very nice. And they’ll ask you very directly, ‘Have you ever been in an abusive relationship?’ Are you in an abusive relationship?’ and I think those questions directly, you know, you don’t hear those a lot, so when you’re asked them, you really think about the answer...and what is honest.”* (ID 124, age 34, schizoaffective disorder)

Experiences of abuse and assault were high among the study population with 64% of participants reporting current or past sexual abuse or intimate partner violence.

#### **4.4.3 Healthcare experiences and provider preference**

Participants saw several health care providers including primary care physicians (PCP), gynecologists, psychiatrists, and therapists. Most felt comfortable talking with all their providers about personal health issues and concerns, but three mentioned that they did not experience the same level of comfort if a provider was male. Nineteen participants (68%) confirmed that they were recently screened for or spoke with providers about intimate partner violence and other forms of abuse, with behavioral health providers bringing up the topic most often. Nearly all women (n=25) stated that they spoke with a provider in the past about family planning, contraception, or sexual relationships and most said they would choose to receive this information from a PCP or gynecologist due to their specific training in these topic areas.



However, all but one participant stated that they would feel comfortable and/or appreciate if their therapist or psychiatrist provided them with similar information, with one woman stating the benefit of provider collaboration: “[They could] make sure you get all the information you need...All work together. Make sure that you’re on the right pills, on the right prenatal pills, and make sure everything’s ok with the baby and you.” (ID 122, age 24, bipolar disorder)

## 4.5 DISCUSSION

According to the Centers for Disease Control and Prevention’s family planning recommendations, healthcare providers should help women identify and accomplish their reproductive goals. This can be achieved by providing comprehensive information about contraceptive methods (i.e., effectiveness, correct use, benefits, and side effects) and working in tandem with the patient to determine the most appropriate method given her individual circumstances and needs, providing preconception education to help women maintain a healthy pregnancy, and discussing intimate partner violence.<sup>238</sup> Each of these recommendations aligned with the non-SMI specific priorities and preferences described in the narratives above. Our findings suggest that current guidelines regarding contraceptive counseling that is specific to those with mental health conditions include information about many of the priorities identified by women participating in these qualitative interviews, including consideration of potential medication interactions, the impact of contraception on mood, the ways in which SMI symptoms can influence contraceptive use and adherence, and preserving reproductive autonomy.<sup>86</sup>

Women recognized that their SMI-related symptoms and experiences led to adverse sexual and reproductive experiences and should be considered by clinicians as they provide

contraceptive and family planning services. Some participants with bipolar disorder experienced mania which led to intercourse with multiple partners and impulsive decision making that led to contraceptive nonuse and other risky sexual behaviors. This aligns with existing research showing that impulsivity and other self-destructive behaviors can lead to negative sexual and reproductive health consequences.<sup>53,63,239</sup> Other women with major depressive disorders used sexual intercourse to cope with their symptoms and one viewed sex as a deserved punishment which resulted in engagement in undesired sexual activity. Counseling women about the potential reproductive and behavioral health impacts of these complex and evolving symptoms may provide them with important information to consider when identifying an appropriate contraceptive method and/or foster discussions about relationship safety and sexual consent.

Women mentioned ways in which reproductive health-related topics could be approached in way that is more comfortable to those who may have experienced abuse and/or sexual trauma. In our study sample, over half of women disclosed current or past experiences with intimate partner violence and/or sexual abuse. This research and existing studies show that women want to be asked directly about these experiences in a sensitive and unrushed manner.<sup>240</sup> Given this, providers should screen women to elicit this information in a non-judgmental and safe environment. They should make accommodations during clinical encounters for women who may experience adverse reactions to the receipt of reproductive health care.

Several women described experiences in which their providers did not engage in family planning conversations that promoted shared decision-making. Rather, they felt as though they were being told that contraception was necessary and that their mental health diagnosis precluded them from having a family. Many women with SMI experience unintended pregnancy or become pregnant by choice;<sup>10,13,15,16,19,49,55</sup> given this, making assumptions that women with

SMI should not procreate is counterproductive and potentially dangerous. Arming them with the information they need in a tailored and comprehensive manner is critically important to promote positive contraceptive experiences or aid in the planning of the healthiest pregnancy possible if that is the patient's desired reproductive outcome. However, no participants received information about or had conversations with their providers about pregnancy planning prior to becoming pregnant. The high rates of unintended pregnancy among the SMI population necessitate a more proactive approach to bring awareness to the family planning behaviors a woman may want to consider (e.g. exercising, maintaining proper nutrition, taking folic acid supplementation) in case pregnancy should occur.

Nearly all women stated that their behavioral health care providers were not their first choice for comprehensive family planning information; however, they would be willing to engage in a conversation with them about these topics. Participants interacted with their therapists (both in individual and group therapy) and psychiatrists more often than any other providers. Women frequently spoke to their behavioral health providers, specifically therapists, about relationships, sex, intimate partner and sexual violence, and the impact of these experiences on their mental health symptoms. The interconnection of these topics, contraception, and pregnancy intentions/planning offer the ideal opportunity to find appropriate ways to integrate family planning information into the behavioral health care setting. For example, a therapist or psychiatrist may be the first to know when a woman is having a manic episode and can engage in a conversation to ensure that the woman is practicing safer sex to the extent possible and is keeping her sexual and reproductive intentions in mind while she is symptomatic. Behavioral health care providers often know a patient's sexual abuse history and can be sensitive when bringing up these topics to avoid triggering negative thoughts and emotions. In addition,

behavioral health facilities could have emergency contraception available on-site to provide to women who may be engaging in unprotected sex and/or risky sexual behaviors.

These findings should be considered in the context of several limitations. First, qualitative interviews were not conducted with therapists, psychologists, or psychiatrists to determine the extent of family planning and reproductive health-related information they already provide to women with SMI. More research is needed to determine the feasibility and acceptability of integrating family planning services into behavioral health care settings. However, the receipt, or lack thereof, of these services does not change the perceptions of the women participating in this study or what they remember about the family planning information and care that they have received. Thus, determining ways to increase exposure to and retention of this important information should be a priority. Second, we relied on self-reported diagnosis to identify women with bipolar disorder, major depressive disorder, schizophrenia, or schizoaffective disorder which limited our ability to determine the accuracy of each participant's diagnosis. However, most women were recruited from a setting that provides intensive outpatient services specifically designed to aid in the recovery of individuals with serious mental illness. The study was strategically presented at group therapy sessions in which all individuals in those sessions had a specific diagnosis (e.g., evening bipolar group) increasing the likelihood of recruiting women with the diagnoses of interest. Finally, few women with schizophrenia/schizoaffective disorder were recruited for participation; as a result, understanding the scope of family planning priorities and preferences that are specific to women with these conditions was not possible. However, many of the narratives provided by women with schizophrenia/schizoaffective disorder aligned closely with the thoughts and attitudes of women with bipolar disorder and major depressive disorder, suggesting that large differences across

diagnostic categories may not exist. However, additional research with a larger sample of women with schizophrenia/schizoaffective disorder should be conducted to further identify similarities and differences across diagnostic categories.

#### **4.6 CONCLUSION**

Women with SMI have unique priorities and preferences that must be taken into consideration to provide patient-centered contraceptive and family planning counseling services to a population that is vulnerable to unintended pregnancy, contraceptive misuse/nonuse, IPV/sexual assault, and negative pregnancy outcomes. This study contributes to the growing body of literature about how to tailor reproductive health services for women with SMI by providing narratives of the specific topics and concerns that they believe should be addressed in the clinical setting. Delivering comprehensive family planning care and supporting reproductive health literacy can begin to improve reproductive outcomes for women with SMI. All women deserve the equal opportunity to express their sexuality and realize their family planning goals, however they may be defined. Thus, public health practitioners should work to ensure that women with SMI can safely and effectively prevent or experience pregnancy and achieve optimal reproductive and fertility-related outcomes.

## **5.0 CLOSING REMARKS**

### **5.1 SUMMARY OF MAIN FINDINGS**

Existing published research documents the reproductive disparities that exist among women with serious mental illness (SMI). The three studies discussed in this dissertation explore several important research topics that remain largely absent from existing literature, including: (1) the impact of SMI on contraceptive use and pregnancy intentions, (2) the influence of intimate partners on fertility-related behaviors, (3) contraceptive attitudes, knowledge, and decision making among women with SMI, (4) family planning counseling needs and priorities, and (5) ways in which contraceptive use and family planning experiences differ by SMI diagnosis.

As described in Study 1, no known review of the literature had been conducted to examine commonly used or preferred methods of contraception, knowledge about existing methods, or issues related to contraceptive access among women with SMI. Thus, a comprehensive review was performed to determine the current state of research regarding the contraceptive experiences, knowledge, and attitudes of this population to identify research gaps and potential avenues for intervention.

Outcomes and findings varied greatly across existing literature, but higher quality studies with larger samples sizes and control groups demonstrated that women with SMI have disproportionately poorer contraceptive experiences.<sup>49,127,199,201,204,211</sup> Many studies were

conducted in other countries where cultural norms and beliefs about contraception may differ from those of women residing in the United States and the majority of studies were quantitative in nature underscoring the need for more comprehensive qualitative research to advance the field. Moreover, the high rates of contraceptive misuse or gaps in coverage reported in some studies<sup>199,204,210,216</sup> highlighted the potential benefit of promoting long acting or permanent methods of contraception for use by women with SMI who wished to delay or cease childbearing. However, there exists a dearth of literature regarding method acceptability and knowledge among this population.<sup>127,149</sup> This review laid the groundwork for additional research, specifically using qualitative methods, to obtain a more expansive understanding of the factors that contribute to the contraceptive-related experiences and desires of women with SMI.

Building upon Study 1, Study 2 utilized qualitative interviews to understand the pregnancy intentions, current contraceptive use, and the factors that influence the contraceptive experiences and behaviors of a sample of women with bipolar disorder, schizophrenia/schizoaffective disorder, and major depressive disorder. The majority of women wanted to avoid pregnancy. However, similar to research conducted with women without SMI,<sup>222</sup> participant's pregnancy intentions did not always correspond with the effective use of contraception, putting them at risk for unintended pregnancy.

Several important factors that affected women's contraceptive use and family planning experiences were identified. Depending upon their SMI diagnosis, women's unique symptoms influenced their use of contraception in different ways. For example, mania and the associated increase in sexual risk taking experienced by some women led to condom nonuse. Fear of the potential impact of contraception on depressive symptoms influenced contraceptive choice among some women with major depressive disorder. Participant's attitudes toward long-acting

reversible contraception (LARC) varied; however, many feared these methods, viewed them as invasive, and were uncomfortable with the concept of having an “implant” as a form of contraception – findings supported by research conducted with women without SMI whose views of IUDs and implants were largely negative due to fear of pain, side effects, and long-term risks.<sup>228–231</sup> These results highlight the need for additional strategies to provide women both with and without SMI with comprehensive information about these methods to overcome negative perceptions and, potentially, increase LARC acceptability.

Sexual violence, including reproductive coercion, childhood sexual abuse, and rape, were commonly experienced by study participants, contributing to their increased risk of unintended pregnancy and negative reproductive outcomes. Women with schizophrenia/schizoaffective disorder were more likely to report experiences with reproductive coercion. However, the study’s small sample of women with these diagnoses did not allow conclusions to be made about whether they were more vulnerable to victimization as a result of their SMI diagnosis, or if other known correlates, such as race or experiences with intimate partner violence,<sup>145,232,241</sup> were more likely contributors to this disparity. Thus, more research is needed to explore these associations with greater accuracy.

This is the first known in-depth qualitative exploration of the factors that influence the contraceptive use and family planning experiences of women with SMI. It supports the notion that, while comprehensive counseling is critical, clinicians should assess for factors beyond contraceptive choice, such as intimate partner violence and SMI symptomology, that can influence a woman’s ability to avoid unintended pregnancy. In addition, findings demonstrated the importance of obtaining feedback from women with SMI about what information they believe should be conveyed during contraceptive and family planning counseling sessions.



In Study 3, narratives were collected and analyzed to understand the family planning counseling priorities and preferences of women with SMI. Findings revealed several topics that are of unique importance to this population including: (1) consideration of SMI symptoms when making contraceptive decisions; (2) the impact of SMI symptoms on contraceptive use and sexual behaviors; (3) the potential for interactions between SMI medications and contraception that can decrease medication effectiveness; (4) the teratogenic nature of some SMI medications and their continuation/discontinuation during pregnancy and breastfeeding; (5) potential changes in SMI symptoms during the pregnancy and post-partum periods; and (6) the importance of provider sensitivity when delivering family planning and contraceptive counseling. Women revealed additional topics of interest that were unrelated to SMI experiences, such as contraceptive options, effectiveness, risks, and side effects; how to plan and maintain a healthy pregnancy through diet, exercise, and avoidance of drugs and alcohol; and sexual consent and relationship safety.

These priority topics align closely with existing guidelines that were developed to support the provision of optimal family planning counseling by health care providers.<sup>86,89,90,93,94</sup> However, study participants who were ever pregnant did not recall receiving any form of preconception counseling. The high rate of unintended pregnancy experienced by women with SMI<sup>19,49</sup> necessitates a proactive approach to arming them with information about healthy behaviors they may want to consider in case a pregnancy should occur. This study provided further evidence that, despite the promise of existing guidelines, determining ways to increase exposure to and support retention of this information should be a priority.

Studies focusing on the integration of physical and behavioral health services have demonstrated improvements in outcomes for individuals with serious mental illness including

care satisfaction, chronic disease management, and access to care.<sup>242-246</sup> Participants in Study 3 often spoke to their behavioral health providers about relationships, sexual practices, and intimate partner violence, all experiences that can impact contraceptive use and other fertility-related behaviors. Participants felt comfortable talking with their therapists about these topics and were open to receiving this type of information from behavioral health providers, even if this was outside of the scope of their typical mental health treatment. This study shows that there is opportunity to integrate contraception and family planning counseling into behavioral health treatment settings.

## **5.2 FUTURE RESEARCH**

Findings from Studies 1-3 provide additional evidence that disparities in contraceptive use and family planning exist among women with SMI. Further, this new qualitative data highlights important areas for intervention as well as future research. While these studies deepen our understanding of the contextual factors that contribute to the reproductive experiences of women with SMI, as well as the information women with SMI desire to receive during contraceptive and family planning counseling sessions, important research questions remain.

As described in Chapter 1, it is likely that biological, individual, interpersonal, organizational/system, and societal factors impact the fertility-related experiences of women with SMI. The qualitative interviews conducted to inform Study 2 provide important information about the biological level, including an understanding of how SMI symptoms can influence sexual behaviors and contraceptive use, and the potential contraindications between SMI medication and contraception and/or pregnancy. At the individual level, we now have increased

information about the contraceptive knowledge, or lack thereof, and attitudes of women with SMI. Interpersonally, women's narratives revealed tragic experiences with sexual abuse and reproductive coercion that sometimes led to unintended pregnancy. From an organizational/system's perspective, participant's perceptions of the way that reproductive healthcare is currently delivered remains inadequate, with many stating they received no form of preconception counseling prior to pregnancy.

One element missing from this analysis is the potential ways in which stigma may contribute to the reproductive experiences of women with SMI. The Introduction described several possibilities, such public stigma, which may influence provider's perceptions of women with SMI and, thus, impact the care and medical advice they provide.<sup>102,103</sup> Self-stigma, or the internalization of stigmatizing beliefs, can contribute to decreased self-worth and may impact sexual decision making.<sup>101,104,116</sup> A few participants described concepts related to stigma over the course of the interviews; however, they were not asked specifically about their personal stigma-related experiences; thus, little information was obtained about this topic. More research is needed to understand women's perceptions of both public and self-stigma, its impact on fertility-related behaviors and experiences, and methods to enhance resilience to mental health stigma.

Future research is also needed to explore the ways in which race and/or socio-economic status influence the contraceptive use and family planning experiences of women with SMI. As discussed in Study 3, race may have been a contributing factor to the reproductive coercion experiences of women with schizophrenia/schizoaffective disorder; however, our sample was too small to make conclusions about this relationship. Further, the high rate of unemployment and the lower annual income of many women with SMI can lead to impoverishment,<sup>163-166</sup> which may challenge their ability to obtain contraception and adequate reproductive health care.<sup>126,167</sup>

Additional qualitative research should be conducted with a larger cohort of women with SMI that is stratified by race and poverty level to begin to discern the ways in which these factors contribute to the reproductive experiences of this population. In addition, larger, population-based studies should be conducted to assess the potential mediating and/or moderating role of race, poverty, and other important variables on the fertility-related outcomes of women with SMI. This research will also allow for the continued development of a conceptual framework that describes the complexities of the contraceptive and family planning experiences of this population.

Developing family planning interventions that are sensitive to the unique needs and experiences of women with SMI is an important goal of this research trajectory. Study 1 summarized the extant literature regarding the contraceptive disparities faced by women with SMI. Building upon this work, a systematic review of the literature focusing on contraceptive use and family planning interventions delivered to improve reproductive outcomes for women with SMI is a logical next step. This review could be conducted to lay the groundwork for identifying evidence-based practices to improve reproductive health service delivery and access.

As discussed in Study 3, integrating contraception and family planning counseling into mental health treatment settings was a concept that was well accepted by study participants. Though mental health providers are not specifically trained to deliver reproductive health-related services to the same degree as a primary care physician or gynecologist, they could be trained to reinforce positive fertility-related behaviors when interacting with clients. For example, many women in the study sample received outpatient therapy several times each month. They often disclosed information about sexual relationships to their therapists, but few participants talked with their therapists in detail about their reproductive intentions or contraceptive use. Qualitative

interviews could be conducted with mental health providers to understand the degree to which they already deliver information about contraception and family planning and the acceptability of integrating this into routine practice. This could lead to the development and evaluation of interventions to assess their impact on short-term outcomes, such as contraceptive knowledge and attitudes, as well as intermediate and longer-term outcomes, including contraceptive initiation, gaps in method use, decreases in unintended pregnancy, and improvements in pregnancy outcomes.

The continuation of this important research agenda will fill additional gaps in knowledge about contributors to the reproductive disparities experienced by women with SMI. Information gleaned can inform practice guidelines and intervention development to promote contraceptive use behaviors that align with pregnancy intentions, provide women with risk-reduction strategies to lessen the fertility-related risks associated with being in an abusive relationship, and support patient-centered approaches to informed and shared reproductive decision making. The goal of this research should be to ensure that women with SMI remain in control of their fertility to reduce the disproportionate rates of unintended pregnancy and negative pregnancy-related outcomes experienced by this population.

### **5.3 PUBLIC HEALTH IMPLICATIONS**

Despite the high rates contraceptive nonuse/misuse experienced by women with SMI and their subsequent increased risk for unintended pregnancy, few studies have examined the barriers to contraceptive use experienced by this population. Additionally, no known studies have thoroughly explored where, when, and from whom women with SMI would like to receive

family planning services or the information that would be most pertinent to them. Understanding the preferences and unique experiences of this population is critical to the development of patient-centered interventions that can effectively address their needs. The studies described in this dissertation begin to address these knowledge gaps and generate information that can contribute to increased provider awareness of the reproductive needs and desires of women with SMI, so they can more effectively engage them in productive family planning conversations.

According to the Guttmacher Institute, the public insurance costs associated with unintended pregnancies, including those that resulted in live birth, miscarriage, and abortion, exceeded \$20 billion in 2010.<sup>247</sup> Costs are not solely financial, as mothers, children, and families are also faced with the physical, emotional, and social consequences that can result from a pregnancy that is mistimed or unwanted.<sup>38-43</sup> Healthy People 2020 describes their revised target to achieve a 10% reduction in unintended pregnancy among the U.S. population.<sup>248</sup> The provision of contraception can drastically decrease rates of unintended pregnancy,<sup>190,191,249</sup> however, women with SMI face unique barriers to contraceptive use that must be considered. This dissertation highlights several of these barriers, some that may be addressed with relative ease, such as providing contraception and family planning information in multiple treatment settings, as well as those that are more challenging to overcome, like the sexual violence some women with SMI face across the life span.

Participants provided information about the contraceptive and family planning topics that are important to them. Women discussed ways in which providers can tailor their approach to reproductive counseling to promote a more comfortable experience for women who have been sexually abused. Participants also described how their SMI symptoms can impact fertility-related behaviors and highlighted how these experiences can vary for differing diagnoses. This

information can be used to update existing clinical care delivery guidelines to promote a more patient-centered approach to reproductive counseling.

All women deserve the equal opportunity to express their sexuality and realize their family planning goals, however they may be defined. Thus, it is critically important to ensure that women with SMI can safely and effectively prevent or experience pregnancy and achieve optimal fertility-related outcomes. Public health researchers and practitioners are uniquely positioned to utilize research and intervention development/implementation to reduce the excess burden of contraceptive nonuse/misuse and unintended pregnancy faced by this population. Findings from this dissertation can begin to move the needle beyond describing the problem to enhancing the way in which clinical care is delivered to promote positive reproductive experiences for women with SMI.

## APPENDIX A

### PUBMED CITATION SEARCH STRATEGY (STUDY 1)

Search	Query	# Found
#7	Search (#5 AND #6)	447
#6	Search ("1980/01/01"[Date - Publication]: "3000"[Date - Publication])	21261266
#5	Search (#3 AND #4)	569
#4	Search English[Language]	22303443
#3	Search (#1 AND #2)	689
#2	Search (Contraception[Mesh:noexp] OR Contraception Behavior[Mesh] OR Family Planning Services[Mesh] OR Birth Control[tiab] OR Contraception[tiab] OR Contraceptive[tiab] OR Contraceptives[tiab] OR Family Planning[tiab] OR Fertility Control[tiab] OR Fertilization Inhibition[tiab] OR Inhibition of Fertilization[tiab] OR Planned Pregnancies[tiab] OR Planned Pregnancy[tiab] OR Reproductive Health[tiab] OR Sexual Health[tiab] OR Contraception[ot] OR Contraceptive[ot])	103790
#1	Search (Affective Disorders, Psychotic[Mesh] OR "Bipolar and Related Disorders"[Mesh:noexp] OR "Bipolar Disorder"[Mesh] OR Borderline Personality Disorder[mesh] OR "Depressive Disorder, Major"[Mesh] OR "Depressive Disorder, Treatment-Resistant"[Mesh] OR Mental disorders[Mesh:noexp] OR Mentally Ill Persons[mesh] OR Paranoid Disorders[Mesh] OR Psychotic Disorders[Mesh] OR Schizoid Personality Disorder[mesh] OR Schizophrenia[Mesh:noexp] OR Schizophrenia, Catatonic[Mesh] OR Schizophrenia, Disorganized[Mesh] OR Schizophrenia, Paranoid[Mesh] OR Schizophrenic Psychology[mesh] OR Schizotypal Personality Disorder[Mesh] OR Shared Paranoid Disorder[Mesh] OR Affective Psychoses[tiab] OR Bipolar Affective Psychosis[tiab] OR Bipolar Disorder[tiab] OR Bipolar Disorders[tiab] OR Bipolar Disorders[tiab] OR Borderline Personality Disorder[tiab] OR Borderline Personality Disorders[tiab] OR Brief Reactive Psychoses[tiab] OR Brief Reactive Psychosis[tiab] OR Delusional Disorder[tiab] OR Delusional Disorders[tiab] OR Dementia Praecox[tiab] OR enduring mental illness[tiab] OR Folie a Deux[tiab] OR Folie a Trois[tiab] OR Involutional Depression[tiab] OR Involutional Melancholia[tiab] OR Involutional Paraphrenia[tiab] OR Involutional Paraphrenias[tiab] OR Involutional Psychoses[tiab] OR Involutional Psychosis[tiab] OR Major Depressive Disorder[tiab] OR Major Depressive Disorders[tiab] OR Mania[tiab] OR Manias[tiab] OR Manic Depressive Psychosis[tiab] OR Manic-Depressive Psychoses[tiab] OR Manic State[tiab] OR Mental patient[tiab] OR Mental patients[tiab] OR "mentally ill outpatients"[tiab] OR Mentally ill person[tiab] OR Mentally ill persons[tiab] OR Mentally ill woman[tiab] OR Mentally ill women[tiab] OR Psychosis[tiab] OR Paranoia[tiab] OR Paranoid[tiab] OR Paranoid Disorder[tiab] OR Paranoid Disorders[tiab] OR Paranoid Psychoses[tiab] OR Paranoid Psychosis[tiab] OR Persistent mental illness[tiab] OR Persistent mental illnesses[tiab] OR Persistently mentally ill [tiab] OR Psychoses[tiab] OR Psychosis[tiab] OR Psychotic Affective Disorder[tiab] OR Psychotic Affective Disorders[tiab] OR Psychotic Disorder[tiab] OR Psychotic Disorders[tiab] OR Psychotic Mood Disorder[tiab] OR Psychotic Mood Disorders[tiab] OR Refractory Depression[tiab] OR Refractory Depressions[tiab] OR Schizoaffective Disorder[tiab] OR Schizoaffective Disorders[tiab] OR Schizoid Personalities[tiab] OR Schizoid Personality[ot] OR Schizoid Personality[tiab] OR Schizophrenia[tiab] OR Schizophrenias[tiab] OR Schizophrenic[tiab] OR Schizophreniform Disorder[tiab] OR Schizophreniform Disorders[tiab] OR Schizotypal Personality Disorder[tiab] OR Schizotypal Personality Disorders[tiab] OR Serious Mental disorder*[tiab] OR Serious Mental Illness*[tiab] OR Seriously Mentally Ill[tiab] OR Severe mental disorder*[tiab] OR Severe mental illness*[tiab] OR Shared Paranoid Disorder[tiab] OR Shared Paranoid Disorders[tiab] OR Shared Psychotic Disorder[tiab] OR Shared Psychotic Disorders[tiab] OR Therapy Resistant Depression[tiab] OR Therapy Resistant Depressions[tiab] OR Treatment Resistant Depressive Disorder[tiab] OR Treatment Resistant Depressive Disorders[tiab] OR Affective Psychoses[ot] OR Bipolar Affective Psychosis[ot] OR Bipolar Disorder[ot] OR Bipolar Disorders[ot] OR Borderline Personality Disorder[ot] OR Borderline Personality Disorders[ot] OR Brief Reactive Psychoses[ot] OR Delusional Disorder[ot] OR Delusional Disorders[ot] OR Dementia Praecox[ot] OR enduring mental illness[tiab] OR Folie a Deux[ot] OR Folie a Trois[ot] OR Involutional Depression[ot] OR Involutional Melancholia[ot] OR Involutional Paraphrenia[ot] OR Involutional Psychoses[ot] OR Involutional Psychosis[ot] OR Major Depressive Disorder[ot] OR Major Depressive Disorders[ot] OR Mania[ot] OR Manic Depressive Psychosis[ot] OR Manic State[ot] OR Manic-Depressive Psychoses[ot] OR Manic-Depressive Psychosis[ot] OR Mental patient[ot] OR Mental patients[ot] OR Mentally ill person[ot] OR Mentally ill persons[ot] OR Paranoia[ot] OR Paranoid Disorder[ot] OR Paranoid Disorders[ot] OR Paranoid Psychosis[ot] OR Psychoses[ot] OR Psychosis[ot] OR Psychotic Affective Disorder[ot] OR Psychotic Affective Disorders[ot] OR Psychotic Disorder[ot] OR Psychotic Disorders[ot] OR Psychotic Mood Disorder[ot] OR Psychotic Mood Disorders[ot] OR Refractory Depression[ot] OR Schizoaffective Disorder[ot] OR Schizoaffective Disorders[ot] OR Schizoid Personality[ot] OR Schizophrenia[ot] OR Schizophrenias[ot] OR Schizophreniform Disorder[ot] OR Schizotypal Personality Disorder[ot] OR Seriously mentally ill[ot] OR Shared Paranoid Disorder[ot] OR Shared Psychotic Disorder[ot] OR Therapy Resistant Depression[ot] OR Treatment Resistant Depression[ot] OR Treatment Resistant Depressive Disorder[ot])	361584

\*Note: A similar search strategy was applied to all database searches; however, minor modifications may have been required



## APPENDIX B

### INTERVIEW QUESTIONS PERTAINING TO FACTORS INFLUENCING CONTRACEPTIVE USE AND FAMILY PLANNING (STUDY 2)

- Are you currently using any form of contraception/birth control?
  - *If yes:* What method(s) are you using? Why did you pick this method? Have you had any issues/problems using this method(s)? How did you come to the decision to use contraception?
  - *If no:* Is there a reason that you aren't using any form of contraception or birth control?
  - Have you used any method(s) of birth control in the past?
    - *If yes:* What method have you used? What were your experiences
    - *If no:* Why have you not used a method in the past?
- Have the symptoms of your (SMI) diagnosis affected your use of contraception (*or non-use if they are not currently using a contraceptive method*)? If so, how?
- How many children do you have?
  - Please tell me what it was like when you found out that you were pregnant for the first time. What was that experience like for you?
  - Before you became pregnant, did you want to have children? Why or why not?
  - Did you do anything to plan your pregnancies (*if difficult to remember, ask participant to recall her most recent pregnancy*)? If so, what did you do. [*Probe for changing eating habits, stop drinking/smoking, prenatal vitamins, etc.*]
    - *If yes:* Where did you go for information about pregnancy planning? Who did you talk to? What type of information did you received?
  - Are you thinking about getting pregnant (again)? Tell me more about that.
- What would it be like if you got pregnant right now?
- Has your (SMI) diagnosis affected how you feel about becoming pregnant/having children? If so, how?
- Have you ever had a partner ask you not to use birth control or refuse to use a condom during sex? Can you tell me more about this?
- Have you ever been in a relationship where your partner wanted you to become pregnant when you did not want to become pregnant? Please tell me about your experience.

## APPENDIX C

### EXAMPLE CODES PERTAINING TO CONTRACEPTIVE USE AND FAMILY PLANNING (STUDY 2)

- ***Pregnancy Intentions: This set of codes reflect the current pregnancy intentions of women in the study sample.***
  - **Avoid:** This includes the desire to avoid pregnancy because it is the “wrong time” due to financial, relationship, educational, or other goals that women desire to achieve prior to becoming pregnant. This also includes women who never want to become pregnant/pregnant again.
  - **Want:** This includes the current desire to become pregnant
  - **Ambivalent:** Women in this category may waiver between wanted to become pregnant and acknowledging that this may not be the best time to become pregnant. They usually exhibit some form of hesitance when asked specifically about whether or not they want to have a child at this time.
  - **Lacking Intention:** This differs from ambivalence because it includes women who “aren’t even thinking about pregnancy” (ambivalence involves active thoughts about pregnancy that differ from one another). It may also include women who leave their pregnancy experiences up to an external locus of control (e.g., God). Lacking intention does not imply that that a woman would be happy or unhappy if she were to become pregnant.
  
- ***SMI Symptom/Contraceptive Use Relationship: These codes described women’s concerns regarding the impact that SMI symptoms have on contraceptive use and vice versa.***
  - **Mania:** Any mention of the impact of mania symptoms on contraceptive use (or nonuse) and sexual behaviors (including sexual risk-taking).
  - **Depression:** Descriptions of how depressive symptoms influence contraceptive use and/or choice and sexual behaviors.
  
- ***Contraceptive Knowledge and Attitudes: Codes related to having/not having knowledge of various contraceptive methods as well as their attitudes towards five specific methods of contraception (LARC (IUD, implant), birth control pills, contraceptive injection, condoms, morning after pill).***  
*Note: Only LARC knowledge and attitudes discussed in Study 2.*
  - **No knowledge:** Quotes pertaining to the participants having never heard of the IUD or contraceptive implant.
  - **Fear:** Narratives related to women’s fears of pain or bodily harm associated with the insertion or use of the IUD or contraceptive implant.
  - **Intrusive:** Any mention of the IUD/contraceptive implant being “intrusive”

- **“Implant”**: Any mention of the implant being undesirable, leading women to not consider using this form of LARC.
- ***Substance Use: Codes pertaining to the influence of illicit substances or alcohol on contraceptive behaviors and experiences.***
  - **Substance use**: Any mention of experiences when a participant was less likely to use contraception and/or more likely to engage in risky sexual behaviors as a result of using illicit drugs or drinking alcohol.
- ***Sexual Violence and Abuse: Discussions about the impact that experiences with sexual violence and abuse had/has on contraceptive experiences and/or choice.***
  - **Reproductive coercion**: Quotes from participants about how their current or previous male sexual partner pressured them to become pregnant or sabotaged birth control (this includes flushing pills, overt condom refusal or purposefully ripping or taking off a condom).
  - **Childhood sexual abuse**: Narratives pertaining to participant’s experiences with childhood sexual abuse.
  - **Sexual assault/rape**: Any mention of experiences with previous sexual assault or rape (including rape in the context of marriage).

## APPENDIX D

### INTERVIEW QUESTIONS PERTAINING TO WOMENS FAMILY PLANNING AND CONTRACEPTIVE COUNSELING PRIORITIES AND PREFERENCES (STUDY 3)

- Please tell be about the types of doctors and other healthcare providers that you see regularly.  
*Probe for PCP, psychiatrist, therapist, gynecologist?*
  - How often do you see each provider?
  - How comfortable do you feel talking with each provider?
  - Do you talk to any of these providers about reproductive health, contraception/birth control, family planning, pregnancy, or sex? If so, which ones?
    - If yes: Which of these topics have they talked with you about? Do you feel comfortable talking with them about these topics? Why/why not?
    - Do you feel that these providers are knowledgeable about these topics? Why/why not?
  - Have any of your providers ever asked you about intimate partner violence or abuse within a relationship? Who brought this up? What was that discussion like?
  - Do you think intimate partner violence/abuse is common in sexual relationships? Please explain.
- What information about contraception/birth control do you think is most important? What information has been most helpful to you? What information would you like to have received from a doctor/provider/psychiatrist/therapist but didn't receive?
  - What special considerations should providers make when discussing birth control with women with *[insert SMI diagnosis of participant]*?
  - Do you feel that you have enough information about the contraceptive/birth control methods that are available to you? Please explain.
- What information about sexual relationships do you think is most important? What information has been most helpful to you? What information would you like to have received from a doctor/provider/psychiatrist/therapist but didn't receive?
  - What special considerations should providers make when discussing sexual relationships with women with *[insert SMI diagnosis of participant]*?
- What information about pregnancy and pregnancy planning do you think is most important? What information has been most helpful to you? What information would you like to have received from a doctor/provider/psychiatrist/therapist but didn't receive?
  - What special considerations should providers make when discussing pregnancy and pregnancy planning with women with *[insert SMI diagnosis of participant]*?

## APPENDIX E

### EXAMPLE CODES PERTAINING TO SMI- AND NON SMI-SPECIFIC CONTRACEPTIVE AND FAMILY PLANNING AND COUNSELING PRIORITIES AND PREFERENCES (STUDY 3)

- ***PP-SMI: This set of codes reflects specific contraception and/or family planning-related issues that are specific to women with SMI.***
  - **PP-SMI-1: Impact of hormones and or birth control/contraception on SMI symptoms**
    - This includes information about hormones or birth control affects a person's mood, emotional state, suicidal thoughts, depression, etc.
  - **PP-SMI-2: Relationship between SMI symptoms and birth control/contraceptive use, sexual behaviors, and sexual risk taking**
    - Examples may include manic symptoms leading a woman to have sex with multiple partners due to impulsivity, sex as a coping mechanism for depression, forgetting to take birth control due to SMI symptoms, not thinking about sexual consequences, etc.
  - **PP-SMI-3: SMI symptoms pre-pregnancy, during pregnancy, or post-partum**
    - This includes references to concerns about how emotional stability and/or symptom control is required to have a child or, conversely, how emotional instability makes a person unprepared to have a child, symptom exacerbations and/or management during pregnancy, and post-partum SMI symptoms or increased risk of post-partum depression.
  - **PP-SMI-4: Medication interactions and management**
    - This includes any concerns about or personal experiences with SMI medications causing an adverse reaction with birth control or yielding birth control less effective. This may also include references to birth control methods making SMI medications less effective. Other examples include discussions about staying on or discontinuing medications during pregnant and awareness of the potential impact of SMI medications on a fetus.
  - **PP-SMI-5: Genetic risk and having a child with SMI**
    - Any reference to concerns about passing the risk of SMI down to a child as well the information about raising a child with a mental health disorder.
  - **PP-SMI-6: Provider sensitivity, communication, and patient autonomy**
    - This includes any references to the way that providers should present birth control or family planning information to women with SMI, ineffective or effective doctor/patient communication about family planning, ensuring that providers support reproductive autonomy for women with SMI, and/or provider sensitivity when talking to women with SMI about family planning.
  - **PP-SMI-7: Other**
    - This includes any other narratives that do not fit into one of the above categories.

➤ **PP-Non-SMI: This set of codes reflects contraception and/or family planning-related issues that are NOT specific to women with SMI.**

- **PP-Non-SMI-1: Contraceptive options, effectiveness, and logistics**
  - Any information about the importance of knowing about the various types of contraceptive methods, how well the methods work, what they are made of, and/or how they are used (e.g. how often taken or replaced). This also includes Any references to a woman's ability to access contraception, obtain it from a reputable source, or the cost associated with obtaining contraception.
- **PP-Non-SMI-2: Contraception/hormone risks and side effects**
  - Any narratives describing the importance of knowing the potential side effects of contraception or the hormones they are made of, potential risks of a contraceptive method (can be short-term (e.g. breast enlargement) or long-term (e.g. fear of cancer) risks.
- **PP-Non-SMI-3: Sexual practices and experiences**
  - Any narratives related to the importance of knowing about the risks of various sexual behaviors, number of sexual partners, what sex feels like, etc.
- **PP-Non-SMI-4: Pregnancy planning and healthy pregnancy**
  - Any information related to important information or behaviors related to pregnancy/family planning. This might include narratives about healthy eating and/or exercise, when you are most fertile, being aware of the costs of raising children, stopping drugs or alcohol, receptive of prenatal care, child rearing, or comments related to the inability to truly plan a pregnancy. This also includes comments regarding obtaining or maintaining stability in terms of relationships, housing, financial, emotional, etc. Any references to the importance of having a good relationship before having children, making sure that a person has the resources (home, job, money, social support, etc) necessary to take care of a child, and comments about having a child for the right reasons.
- **PP-Non-SMI-5: Relationship with partner and/or relationship issues**
  - Any narratives related to being open with sexual partners about birth control/family planning, understanding the impact that a sexual relationship can have on a person, and/or the risks of being in sexual relationships (e.g., the partner could leave, etc).
- **PP-Non-SMI-6: Sexual consent, assault/domestic violence, relationship safety, meaning of a healthy relationship**
  - Any discussion about the importance of sexual consent, what it means to be in safe/healthy or unsafe/unhealthy relationship, and what constitutes sexual assault.
- **PP-Non-SMI-7: Abortion information**
  - Any references to the cost of abortion, abortion counseling, abortion methods, etc.
- **PP-Non-SMI-8: STD information**
  - Any narratives related to the importance of STD testing, which methods of contraception do or don't protect against STDs, the importance of safe sex, and/or people not disclosing that they have an STD.
- **PP-Non-SMI-9: Retaining fertility, biological clock, and fertility/pregnancy options**
  - Any discussion about a participant being interested in knowing how to retain fertility if a child is desired in the future, when a woman's biological clock starts ticking, etc.

- **PP-Non-SMI-10: Autonomy & pregnancy decision making**
  - Remarks about women being able to make their own decisions about whether they want to have children and/or the importance of women knowing that women can make decisions about contraception.
- **PP-Non-SMI-11: Other**
  - This includes any other narratives that do not fit into one of the above categories.

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